Person Centered Medicine

Juan E. Mezzich
W. James Appleyard
Paul Glare
Jon Snaedal
C. Ruth Wilson
Editors

Person Centered Medicine International College

Springer

Person Centered Medicine

Juan E. Mezzich • W. James Appleyard •
Paul Glare • Jon Snaedal • C. Ruth Wilson
Editors

Person Centered Medicine

Springer

Editors
Juan E. Mezzich
Icahn School of Medicine at Mount Sinai
New York, NY, USA

W. James Appleyard
International College of Person Centered Medicine
New York, NY, USA

Paul Glare
Northern Clinical School
Faculty of Medicine and Health
University of Sydney
Sydney, NSW, Australia

Jon Snaedal
Landspitali University Hospital
Reykjavík, Iceland

C. Ruth Wilson
Department of Family Medicine
Queen's University
Kingston, ON, Canada

ISBN 978-3-031-17649-4 ISBN 978-3-031-17650-0 (eBook)
https://doi.org/10.1007/978-3-031-17650-0

© Springer Nature Switzerland AG 2023
This work is subject to copyright. All rights are reserved by the Publisher, whether the whole or part of the material is concerned, specifically the rights of translation, reprinting, reuse of illustrations, recitation, broadcasting, reproduction on microfilms or in any other physical way, and transmission or information storage and retrieval, electronic adaptation, computer software, or by similar or dissimilar methodology now known or hereafter developed.
The use of general descriptive names, registered names, trademarks, service marks, etc. in this publication does not imply, even in the absence of a specific statement, that such names are exempt from the relevant protective laws and regulations and therefore free for general use.
The publisher, the authors, and the editors are safe to assume that the advice and information in this book are believed to be true and accurate at the date of publication. Neither the publisher nor the authors or the editors give a warranty, expressed or implied, with respect to the material contained herein or for any errors or omissions that may have been made. The publisher remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

This Springer imprint is published by the registered company Springer Nature Switzerland AG
The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

Contents

Part I Principles of Person Centered Medicine

Part II Methods for Person Centered Clinical Care

Part III Clinical/Health Fields for Person-Centered Care

Part IV Empowerment Perspectives

Contributors

Mohammed T. Abou-Saleh, MPhil, PhD St George's, University of London, London, UK

Department of Psychiatry and Associate Dean for Clinical Affairs, Faculty of Medicine, United Arab Emirates University, Al Ain, United Arab Emirates

Neal Adams, MD, MPH California Institute of Mental Health, Berkeley, CA, USA

Rajiv Agarwal, MD Vanderbilt-Ingram Cancer Center, Nashville, TN, USA

Maria Ammon, Dr Phil, Dipl Psych German Academy for Psychoanalysis (DAP), Berlin, Germany

World Association for Dynamic Psychiatry (WADP), Berlin, Germany

W. James Appleyard, MA, MD, FRCP, FRCPCH Presidency 2013–2017, International College of Person Centered Medicine, New York, NY, USA

Presidency 2003–2004, World Medical Association, Ferney-Voltaire, France

St George's University School of Medicine, Grenada, Grenada

Kent and Canterbury Hospital, Canterbury, UK

Claire Ashton-James, PhD Pain Management Research Institute, Faculty of Medicine and Health, University of Sydney, Sydney, NSW, Australia

Tamires M. Bastos, MD Federal University of Rio Grande do Sul, Porto Alegre, RS, Brazil

Israel Belenkie, MD Cumming School of Medicine, University of Calgary, Calgary, AB, Canada

Saverio Bellizzi, MD, MSc, PhD World Health Organization, Amman, Jordan

Gheorghe Borcean, MD Romanian Medical Association, Victor Babes Medical and Pharmaceutical University, Timisoara, Romania

Michel Botbol, MB, MSc Child and Adolescent Psychiatry, University of Western Brittany, Brest, France

World Association for Dynamic Psychiatry (WADP), Berlin, Germany

International College of Person-Centered Medicine**,** New York, NY, USA

World Psychiatric Association, Geneva, Switzerland

Marijana Braš, MD, MA, MSc, PhD Center for Palliative Medicine, Medical Ethics and Communication Skills, University of Zagreb School of Medicine, Zagreb, Croatia

Marcos Burgos, MD Infectious Diseases, School of Medicine, University of New Mexico, Albuquerque, NM, USA

Infectious Diseases, New Mexico VA Health Care System, Albuquerque, NM, USA

New Mexico Department of Health, Santa Fe, NM, USA

José Luis Calderón-Viacava, MD, DMSc Cayetano Heredia Peruvian University, Lima, Peru

Corpac Medical Center, Lima, Peru

Fredy A. Canchihuaman, MD, MPH, PhD Public Health and Postgraduate Schools, Cayetano Heredia Peruvian University, Lima, Peru

Department of Epidemiology, University of Washington, Seattle, WA, USA

Nathalie Charpak, MD Kangaroo Foundation and Integral KMC Program, San Ignacio Teaching Hospital, Javeriana University, Bogotá, Colombia

George N. Christodoulou, MD, PhD Department of Psychiatry, Society of Preventive Psychiatry, Athens University, Athens, Greece

World Psychiatric Association, Geneva, Switzerland

World Federation for Mental Health, Occoquan, VA, USA

Hellenic Psychiatric Association, Athens, Greece

International College of Psychosomatic Medicine, Florence, Italy

International College of Person Centered Medicine, New York, NY, USA

Christopher Clifford, MD Department of Emergency Medicine, Icahn School of Medicine at Mount Sinai, New York, NY, USA

C. Robert Cloninger, MD, PhD Department of Emergency Medicine, Department of Psychiatry, Washington University School of Medicine, St. Louis, MO, USA

Oscar Cluzet, MD Surgery, Intensive Medicine and Bio Ethics, Latin American Network of Person Centered Medicine, Montevideo, Uruguay

John Cox, BM BCh, MA, DM (Oxon), FRCPsych World Psychiatric Association, Geneva, Switzerland

International College of Person Centered Medicine, New York, NY, USA

Keele University, Keele, UK

Royal College of Psychiatrists, London, UK

International Marce Society, Brentwood, TN, USA

Liliana Laranjo da Silva, MD, PhD Westmead Applied Research Centre, Faculty of Medicine and Health, University of Sydney, Sydney, NSW, Australia

Australian Institute of Health Innovation, Centre for Health Informatics, Macquarie University, Sydney, NSW, Australia

Christopher M. Dennis, MBBS Royal North Shore Hospital, Sydney, NSW, Australia

Northern Clinical School 2014–2021, University of Sydney and the Royal Australasian College of Physicians, Sydney, NSW, Australia

Veljko Đorđević, MD, MSc, PhD Center for Palliative Medicine, Medical Ethics and Communication Skills, University of Zagreb School of Medicine, Zagreb, Croatia

Austen El-Osta, PhD Self-Care Academic Research Unit (SCARU), School of Public Health, Imperial College London, London, UK

Ted Epperly, MD Full Circle Health, Boise, ID, USA

University of Washington School of Medicine, Seattle, WA, USA

Andrew S. Epstein, MD Memorial Sloan Kettering Cancer Center, New York, NY, USA

Marianne Farkas, ScD Rehabilitation Research and Training Center, Center for Psychiatric Rehabilitation, Boston University, Boston, MA, USA

Lucy Gait, PhD Alder Hey Children's Hospital, Liverpool, UK

George Fu Gao, MD, PhD China Center for Disease Control and Prevention, Beijing, China

Eduardo Garrido, MD Center for Primary Medicine, Universidad Tecnologica de los Andes, Abancay, Apurimac, Peru

Tesfamicael Ghebrehiwet, PhD, MPH International College of Person Centred Medicine, New York, NY, USA

Formerly, Consultant, Nursing and Health Policy, International Council of Nurses, Geneva, Switzerland

Al O. Giwa, LLB, MD, MBA, MBE, FACEP, FAAEM Department of Emergency Medicine, Icahn School of Medicine at Mount Sinai, New York, NY, USA

Paul Glare, MBBS, MA, MMed Northern Clinical School, Faculty of Medicine and Health, University of Sydney, Sydney, NSW, Australia

Memorial Sloan-Kettering Cancer Center and Weill Cornell Medical College, New York, NY, USA

Ana Gómez-Carrillo, MD, DrMed Division of Social and Transcultural Psychiatry, McGill University, Montreal, QC, Canada

Rachel Halpin-Evans, MBChB Sydney Children's Hospital, Westmead, NSW, Australia

Simone Hauck, MD, PhD Department of Psychiatry, Medical School, Federal University of Rio Grande do Sul, Porto Alegre, RS, Brazil

Chris Hayes, BMed(Hons), MMed Hunter New England Local Health District, University of Newcastle, Newcastle, NSW, Australia

Thomas Heise, MD, PhD Medical University of Hannover, Hannover, Germany

Institute for Holistic Health Counselling, Feuerthalen, Switzerland

Alison N. Huffstetler, MD Department of Family Medicine and Population Health, Virginia Commonwealth University, Richmond, VA, USA

Manuel Hernán Izaguirre-Sotomayor, MD San Fernando Faculty of Medicine, San Marcos National University, Peruvian Association of Person-Centered Medicine, Lima, Peru

Heena Narotam-Jeena, MBChB Division of Neurology, Department of Medicine, Tygerberg Hospital, Cape Town, South Africa

Jon J. Jonsson, MD, PhD Department of Genetics and Molecular Medicine, Landspitali, National University Hospital, Reykjavík, Iceland

Faculty of Medicine, Department of Biochemistry and Molecular Biology, University of Iceland, Reykjavík, Iceland

Sanjay Kalra, MBBS, MD, DM Department of Endocrinology, Bharti Hospital, Karnal, India

Juerg Kesselring, MD, FRCP Department of Neurology and Neurorehabilitation, Rehabilitation Centre, Valens, Switzerland

Michael Kidd, MD The Australian National University, Canberra, ACT, Australia

Levent Kirisci, PhD Department of Pharmaceutical Sciences, University of Pittsburgh, Pittsburgh, PA, USA

Laurence J. Kirmayer, MD Division of Social and Transcultural Psychiatry, McGill University, Montreal, QC, Canada

Ana Misir Krpan, MD, PhD University of Zagreb, School of Medicine, Zagreb, Croatia

Trinh Le Huy, MD, PhD Department of Oncology, Hanoi Medical University, Hanoi, Vietnam

Francisco J. León-Correa, PhD, MBioEth Universidad Central, Santiago de Chile, Chile

Christine C. Leyns, MD, MFamMed, PhD Department of Public Health and Primary Care, Faculty of Medicine and Health Sciences, Ghent University, Ghent, Belgium

Fundación Vida Plena, Sacaba, Cochabamba, Bolivia

Faculty of Social Sciences, Universidad Mayor de San Simon, Cochabamba, Bolivia

Physician and Community Educator, Cochabamba, Bolivia

Ornella Lincetto, MD, DM Pediatric, DM, MsPH Department of Maternal Newborn Child and Adolescent Health and Ageing, World Health Organization, Geneva, Switzerland

Demis Lipe, MD, MS, FAAEM Department of Emergency Medicine, University of Texas—MD Anderson Cancer Center, Houston, TX, USA

Silke Mader European Foundation for the Care of Newborn Infants, EFCNI, München, Germany

Dante E. Manyari, MD Department of Cardiology, University of British Columbia, Vancouver, BC, Canada

Cardiology Department, Surrey Memorial Hospital, Surrey, BC, Canada

Arti Maria, MD, DM Department of Neonatology, Atal Bihari Vajpayee Institute of Medical Sciences and Dr. Ram Manohar Lohia Hospital, New Delhi, Delhi, India

Clifford Marks, MD Department of Emergency Medicine, Icahn School of Medicine at Mount Sinai, New York, NY, USA

Rebecca Martin, MBBS, FANZCA, FFPM ANZCA Department of Pain Management, Royal North Shore Hospital, St Leonards, NSW, Australia

Julio Mendigure, MPH Ministry of Health, Lima, Peru

Graduate School of the Universidad San Juan Bautista and Universidad Peruana Unión, Lima, Peru

Juan E. Mezzich, MD, MA, MSc, PhD Presidency 2009–2013, International College of Person-Centered Medicine, New York, NY, USA

Presidency 2005–2008, World Psychiatric Association, Geneva, Switzerland

Division of Psychiatric Epidemiology and International Center for Mental Health, Icahn School of Medicine at Mount Sinai, New York, NY, USA

Hipolito Unanue Professor of Person Centered Medicine, San Fernando School of Medicine, San Marcos National University, Lima, Peru

Professor of Epidemiology, Graduate School of Public Health and Professor of Psychiatry, School of Medicine, University of Pittsburgh, Pennsylvania, PA, USA

Department of Psychiatry and Behavioral Sciences, Stanford University School of Medicine, Stanford, CA, USA

Pringl Miller, MD General Surgery, Hospice & Palliative Medicine and Clinical Medical Ethics, Chicago, IL, USA

Roger Ruiz-Moral, MD, PhD School of Medicine, Universidad Francisco de Vitoria, Madrid, Spain

José Pacheco, MD, PhD, MSc, FACOG Universidad Nacional Mayor de San Marcos, Lima, Peru

Christine Patch, PhD, RN, GCRB Queen Mary University of London, London, UK

Wellcome Connecting Science, Wellcome Genome Campus, Hinxton, Cambridge, UK

Alberto Perales, MD, BSc, DScMed, DipEth Institute of Ethics in Health, School of Medicine, San Marcos National University, Lima, Peru

Robert L. Phillips Jr, MD, MSPH The Center for Professionalism & Value in Health Care, American Board of Family Medicine Foundation, Washington, DC, USA

Susan P. Phillips, MSc, MD Department of Family Medicine, Queen's University, Kingston, ON, Canada

Harumi Quezada-Yamamoto, MD, MPH WHO Collaborating Centre, Department of Primary Care and Public Health, Imperial College London, London, UK

Oscar Guillermo Quiroz, MD Universidad Nacional Mayor de San Marcos, Clinica Monterrico, Lima, Peru

Hema Rajappa, MBBS, MD Hunter New England Local Health District, University of Newcastle, Newcastle, NSW, Australia

Zoran Rakusic, MD, PhD University of Zagreb, School of Medicine, Zagreb, Croatia

David Rawaf, MD WHO Collaborating Centre, Department of Primary Care and Public Health, Imperial College London, London, UK

Salman Rawaf, MD, PhD, MPH WHO Collaborating Centre, Department of Primary Care and Public Health, Imperial College London, London, UK

Guy Rutten, MD Diabetology in Primary Care, Julius Center for Health Sciences and Primary Care, University Medical Center, Utrecht University, Utrecht, The Netherlands

Javier Saavedra, MD, DMedSc Psychiatry and Mental Health Section, Academic Department of Clinical Medicine, Universidad Peruana Cayetano Heredia, Lima, Peru

Office for Research Support and Specialized Teaching, National Institute of Mental Health, Lima, Peru

Oswaldo Salaverry, MD, PhD Faculty of Medicine, San Marcos National University, Lima, Peru

Carlos Salcedo, MD General Health Studies, San Marcos National University, Lima, Peru

Ihsan M. Salloum, MD, MPH, DFAPA Institute of Neuroscience, Department of Neuroscience, University of Texas Rio Grande Valley School of Medicine, Harlingen, TX, USA

University of Miami Miller School of Medicine, Miami, FL, USA

Section of Classification, Diagnostic Assessment and Nomenclature, World Psychiatric Association, Geneva, Switzerland

International College of Person Centered Medicine, New York, NY, USA

Luis Salvador-Carulla, MD, PhD Health Research Institute, Faculty of Health, University of Canberra, Canberra, ACT, Australia

Margit Schmolke, PhD Munich Training and Research Institute of the German Academy for Psychoanalysis, Munich, Germany

Ghassan Shahrour, MD Syrian Medical Syndicate, Palestinian Otolaryngological Society, and the Kuwait Medical Association, Hawalli, Kuwait

Cailey Simmons, MD Department of Emergency Medicine, Icahn School of Medicine at Mount Sinai, New York, NY, USA

Ian Sinha, MBBS, FRCPCH, PhD Alder Hey Children's Hospital, Liverpool, UK

Mary D. Slavin, PT, PhD Health Outcomes Unit, Health Law, Policy and Management, Boston University School of Public Health, Boston, MA, USA

Pete Smith, PhD Self-Care Forum, London, UK

Jon Snaedal, MD Presidency 2017–2021, International College of Person Centered Medicine, New York, NY, USA

Landspitali University Hospital, Reykjavík, Iceland

Presidency 2007–2008, World Medical Association, Ferney-Voltaire, France

Odette Spruijt, MBChB, PhD University of Melbourne, Melbourne, VIC, Australia

Otto W. Steenfeldt-Foss, MD, MPH University Health Service of Oslo, Oslo, Norway

Norwegian Medical Association Human Rights Committee, Oslo, Norway

Vigdis Stefansdottir, MSc, PhD Department of Genetics and Molecular Medicine, Landspitali, National University Hospital, Reykjavík, Iceland

Faculty of Medicine, University of Iceland, Reykjavík, Iceland

Drozdstoj Stoyanov, MD, PhD, DSc Division of Translational Neuroscience, Department of Psychiatry and Medical Psychology, Medical University of Plovdiv, Plovdiv, Bulgaria

Kristina K. Stoyanova, PhD Research Institute, Medical University of Plovdiv, Plovdiv, Bulgaria

Kimberly K. Stutzman, MD Family Medicine Residency of Idaho (FMRI), Boise, ID, USA

Ekaterina Sukhanova, PhD University Associate Dean for Academic Affairs, City University of New York, New York, NY, USA

Celine Tabche, MSc, AfN, PhD WHO Collaborating Centre, Department of Primary Care and Public Health, Imperial College London, London, UK

Diogo Telles, MD, PhD Faculty of Medicine, Psychiatry and Psychology Department, University of Lisbon, Lisbon, Portugal

Petra ten Hoope-Bender, RM, MBA Sexual and Reproductive Health and Rights, UNFPA, Geneva, Switzerland

Tim Thornton, MA, MPhil, PhD, DLitt Philosophy and Mental Health, University of Central Lancashire, Preston, UK

Eduardo Ticona, MD, MScBT, PhD "Dos de Mayo" National Hospital, San Marcos University (UNMSM), Lima, Peru

Infectious and Tropical Diseases, San Marcos National University, Lima, Peru

Mark R. Tonelli, MD Department of Medicine and Department of Bioethics and Humanities, University of Washington, Seattle, WA, USA

Mariarí Uzcátegui, MD, DiplPH El Cedral Clinic, Caracas, Venezuela

C. Werdie Van Staden, MBChB, MMed (Psych), MD Faculty of Health Sciences, Centre for Ethics of Philosophy of Health Sciences, University of Pretoria, Pretoria, South Africa

Herman Vildózola, MD, DMSc San Fernando Medical School, San Marcos National University, Lima, Peru

Martha Villar-Lopez, MD Department of Preventive Medicine and Public Health, Faculty of Medicine, San Marcos National University, Lima, Peru

Melissa Villars, MD, MPH Department of Emergency Medicine, Icahn School of Medicine at Mount Sinai, New York, NY, USA

David Webber, PhD International Self-Care Foundation, London, UK

Harvey White, DM (Oxon), MCh St. Bartholomew's Hospital, London, UK

The Royal Marsden Hospital, London, UK

Medical Society of London, Harveian Society, Osler Club and Hunterian Society, London, UK

Royal Society of Medicine of London and British Association of Surgical Oncology, London, UK

Joel S. Willis, DO, PA, MPhil, MA Division of Family Medicine, George Washington University, Washington, DC, USA

C. Ruth Wilson, CM, MD, CCFP, FCFP, LLD Department of Family Medicine, Queen's University, Kingston, ON, Canada

Presidency, North America Region, World Organization of Family Doctors (Wonca), Singapore, Singapore

Michael T.H. Wong, MBBS, MD, MA, MDiv, PhD Department of Psychiatry, LKS Faculty of Medicine, The University of Hong Kong, Pokfulam, Hong Kong, China

Neuropsychiatry Program, Queen Mary Hospital, Pokfulam, Hong Kong, China

Section of Philosophy & Humanities in Psychiatry, World Psychiatric Association, Geneva, Switzerland

Lei Zhou, MD Branch for Emerging Infectious Disease, Public Health Emergency Center, China Center for Disease Control and Prevention, Beijing, China

Chapter 1
Introduction to Person Centered Medicine

Juan E. Mezzich, W. James Appleyard, Paul Glare, Jon Snaedal, and C. Ruth Wilson

---

J. E. Mezzich (✉)
Presidency 2009–2013, International College of Person-Centered Medicine,
New York, NY, USA

Presidency 2005–2008, World Psychiatric Association, Geneva, Switzerland

Division of Psychiatric Epidemiology and International Center for Mental Health, Icahn
School of Medicine at Mount Sinai, New York, NY, USA

Hipolito Unanue Professor of Person Centered Medicine, San Fernando School of Medicine,
San Marcos National University, Lima, Peru

Professor of Epidemiology, Graduate School of Public Health and Professor of Psychiatry,
School of Medicine, University of Pittsburgh, Pennsylvania, PA, USA

Department of Psychiatry and Behavioral Sciences, Stanford University School of
Medicine, Stanford, CA, USA

W. J. Appleyard
Presidency 2013–2017, International College of Person Centered Medicine,
New York, NY, USA

Presidency 2003–2004, World Medical Association, Ferney-Voltaire, France

St George’s University School of Medicine, Grenada, Grenada

Kent and Canterbury Hospital, Canterbury, UK

P. Glare
Northern Clinical School, Faculty of Medicine and Health, University of Sydney,
Sydney, NSW, Australia

Memorial Sloan-Kettering Cancer Center and Weill Cornell Medical College,
New York, NY, USA
e-mail: paul.glare@sydney.edu.au

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_1

J. Snaedal
Presidency 2017–2021, International College of Person Centered Medicine,
New York, NY, USA

Landspitali University Hospital, Reykjavík, Iceland

Presidency 2007–2008, World Medical Association, Ferney-Voltaire, France
e-mail: jsn@mmedia.is

C. R. Wilson
Department of Family Medicine, Queen's University, Kingston, ON, Canada

Presidency, North America Region, World Organization of Family Doctors (Wonca),
Singapore, Singapore
e-mail: ruth.wilson@dfm.queensu.ca

1.1 Introduction

Person Centered Medicine (PCM), as a basic concept, recognizes the whole person as the center of medicine and health and as the objective and protagonist of health actions. This compact notion will be unpacked and explained through complementary delineations, both informal ones and those resulting from systematic conceptualizations studies presented in the course of this introductory chapter.

To understand further PCM as a concept and as a programmatic movement, a number of angles are to be engaged in this chapter. These include historical unfolding, philosophical bases, maturation processes, inter-institutional collaboration, organizational development, and scholarly activities such as research projects, educational programs, and publications.

Then, the present Person Centered Medicine book will be outlined and analyzed in terms of their objectives, authorship, structure and content. Major substantive topics as well as issues for the implementation of person-centered care will be touched on. The chapter will end with concluding words on the book's thrust and horizons.

1.2 Historical Development of Person Centered Medicine

An overview of the historical development of medicine in general reveals the special place of the person throughout such development. The pre-historic Neanderthal era strongly suggests the crucial role of social mutual care for the protection and promotion of life and health among our remote ancestors.

It appears that care for illness and injury became widespread and depended on the close social bonds developed within groups and the concern for each other's well-being [1]. This resonates with the contemporary understanding of universal health as both a right and a responsibility.

An appraisal of Early History documents the personalized concept of health throughout both Eastern and Western ancient civilizations. In the Far East, the first significant records of formal medicine were in China, where the sense of complementarity (the *ying* and *yang*) was a fundamental symbol of health [2]. From 1700 BC, the Vedic and

Sanskrit books in India detailed medical practices some of which, such as Ayurveda holistic medicine and massage, may have been established as early as 3000 BC [3].

Highly relevant to Person Centered Medicine and contemporary ecological concerns is the encompassing concept of health in the Andean cosmovision as harmonic equilibrium among the internal, social and natural worlds, which appear to resonate in several other ancient civilizations [4]. Also interesting and relevant are the discernible coincidences on the concept of life well lived, *eudaimonia* in Aristotelian ethics [5, 6] and *allyn kawsay* in the Andean worldview [7]. The intrinsic value of an encounter between persons highlighted in Ubuntu humanism in Africa [8] resonates with the previously mentioned mutuality of social support for health among Neanderthals.

In the Middle Age, the Golden Era of Islamic Medicine revealed the attentive and considerate attention dispensed to ill persons to promote their well-being, as epitomized by the architecture and landscape of some of the world's earliest hospitals built in that era [9, 10].

During the Modern Age, first, the rediscovered interest on the person in the arts, and then the cultivation of the humanities through the *illustration* and *rationalism*, as eponymized by Spinoza [11], demonstrated high concern for the flourishment of human beings.

The first phase of the Contemporary Age, from the late eighteenth century to the end of the nineteenth century, has as highlights, first, the French Revolution and its Declaration of Human Rights, and second, German Philosophy on ethics, particularly through Immanuel Kant's [12] categorical imperative affirming the person as always a goal, not a means.

A second Contemporary phase, covering the twentieth century, exhibits early person-centered formulations, highlighted by Jose Ortega y Gasset's [13] dictum *I am I and my circumstance, and if I do not save it, I do not save myself*, by the books of Tournier [14], starting with *Médecine de la Personne*, and by Rogers [15] and Rogers and Rosemberg [16] person-centered approaches to education and psychotherapy, especially *Becoming a Person* and *The Person as Center*. There were also proposals for a patient- or person-centered medicine connected with highly relevant medical fields such as dementia [17] and family medicine [18] and within specific countries such as Italy, with proposals related to alternative medicine [19] and medical epistemology [20]. All this took place at the same time as the massive development of scientific medicine, with its hyperbolic interest on organs and diseases, led to striking advances in diagnosis and treatment, but also to neglect of the doctor-patient relationship, dehumanization of medicine and commercialization of health care [21].

1.3 Collaborative and Institutional Development of Person Centered Medicine

Building on twentieth century person-centered care proposals and responding to its noted challenges, a collaborative, institutional and programmatic movement for person centered medicine emerged in the twenty-first century. It involved two phases. The first one from 2005 to 2008 took place in the form of an Institutional Program on Psychiatry for the Person within the World Psychiatric Association (WPA). The second one, since 2008 to date, evolved from the first one by extending its scope from psychiatry to medicine at large and progressing institutionally through collaboration with a large number of top global institutions in medicine and health.

The Institutional Program on Psychiatry for the Person, established by the 2005 General Assembly of the World Psychiatric Association (WPA), involved an organization-wide initiative (engaging its 130 national psychiatric societies and 65 scientific sections) and affirming the whole and contextualized person of the patient as the center and goal of clinical care and health promotion, at both individual and community levels. This was set to involve the articulation of science and humanism to optimize attention to the ill and positive health aspects of the person. As care is basically a partnership experience, the program involved the integration of all relevant health and social services. Furthermore, the program also involved advancing public health policies.

Historians Garrabe and Hoff [22] have noted that the core principles behind psychiatry for the person could be already detected at the very beginning of the WPA in 1950 and appeared to be the critical factors underlying its emergence. As a conceptual and programmatic introduction, two editorials were published in *World Psychiatry*, one on articulating medicine's science and humanism as a basic tenet [23] and another on the dialogic basis of the profession [24]. A monographic set on the conceptual bases of psychiatry for the person was prepared and eventually published [25, 26].

A key area of work was person-centered diagnosis, building on an earlier consultation with a large number of WPA national psychiatric societies and the resulting development of the *International Guidelines for Diagnostic Assessment (IGDA)* combining standardized multiaxial and personalized idiographic formulations [27] as well as on close collaboration with the World Health Organization for the planning of ICD-11 [28, 29]. This eventually led to the construction of the Person-centered Integrative Diagnostic Model [30].

The second phase of the institutional development of Person Centered Medicine started around 2008, through contacts between the leaders of WPA and those of other important global organizations such as the World Medical Association, the World Health Organization, the World Federation of Neurology, the World Organization of Family Doctors (Wonca), the International Council of Nurses, and the international Alliance of Patients' Organizations, among others. These interactions revealed wide interest in a perspective that placed the person at the center of general medicine and health care.

This led to the collaborative organization of the first Geneva Conference on Person Centered Medicine at Geneva University Hospital in April 2008. This started a process of annual Geneva Conferences, from which emerged the International Network, now International College, of Person Centered Medicine [26, 31].

Collaboration has been particularly strong with the World Medical Association (WMA) and the World Health Organization (WHO). Relevant to cooperation with the WMA is its long standing commitment to medical ethics as manifested by its *Geneva Declaration* as an updated *Physician's Oath* [32], and its *Declaration of Helsinki* as Guideline for Ethical Medical Research [33, 34]. In line with this, the WMA, which is headquartered just outside Geneva, has provided logistic support for the ICPCM's annual Geneva Conferences since its first edition in 2008 to date, and has facilitated the prominent participation of WMA presidents at many of these Conferences.

World Health Organization [35] World Health Report identified *People-centered Health Services* as one of its pivots and made this perspective a fundamental element of its Program of Work, which has been the basis for much of its collaboration with the ICPCM along the years. WHO also provided funding for the ICPCM's seminal study on the Systematic Conceptualization of Person Centered Medicine and the Development and Validation of a Measurement Index [36]. WHO also hosted many of the ICPCM Geneva Conferences at its headquarters in Geneva. Furthermore, WHO's Regional Office for the Americas is collaborating closely with the ICPCM's Latin American Network in the exploration and delineation of innovative persons-centered health strategies.

The Geneva Conferences on Person Centered Medicine were conceived since its first edition in 2008 as the stable matrix for the conceptual and procedural maturation of a perspective that could evolve into a programmatic movement for a whole-person medicine. The selection of Geneva for this purpose was predicated in its being known as the *city of encounters* and its hosting within its boundaries and surrounding area the most important global institutions for medicine and health such as the World Medical Association, the World Health Organization, as well as the World Health Alliance that encompasses the International Council of Nurses, International Pharmaceutical Federation, the World Dental Association, and the Council of International Organizations of Medical Science, among others.

As the chronological list of Geneva Conferences show on Table 1.1, there have been 14 such events between 2008 and 2022, one every year except in 2020 due to the Covid19 pandemic. The Conferences in 2021 and 2022 were held on line only.

Table 1.1 ICPCM Geneva conferences on person centered medicine

No.	Year	Main theme
1	2008	Conceptual explorations on person-centered medicine
2	2009	From concepts to practice
3	2010	Collaboration across disciplines, specialties and programs
4	2011	Articulating person-centered clinical medicine and people-centered public health
5	2012	Chronic diseases: person- and people-centered perspectives
6	2013	Person-centered health research
7	2014	Person- and people-centered care for all
8	2015	Person-centered primary health care
9	2016	Person-centered integrated care through the life course
10	2017	Celebrating 10 years of promoting healthy lives and well-being for all
11	2018	Person centered women's health 40 years after alma ata
12	2019	Promoting well-being and overcoming burn-out
13	2021	Self-care and well-being in the times of Covid-19
14	2022	Optimizing clinical care through person centered medicine

Their main themes, as a group, covered general conceptual and strategic issues, examined core principles of PCM, and dealt with major challenges such as the burnout of health professionals and the Covid19 pandemic. Since the 5th Geneva Conference, their impact was extended through a Declaration that was disseminated widely.

The International Congresses of Person Centered Medicine were organized by the ICPCM and a host institution annually since 2013 as attempts to extend the PCM perspective world-wide and to learn how PCM may be practiced in different latitudes and meridians. The first one in Zagreb recognized the pioneer PCM achievements of our colleagues in Croatia, and honored Andrija Stampar, the founder of the Zagreb University School of Public Health and early person-centered care proponent who chaired the First World Health Assembly and coined the still currently official definition of health focused on the promotion of well-being. As shown in the list of these nine Congresses on Table 1.2, they have been held annually in four different world regions. Their main themes decided jointly by the ICPCM Board and the host organization have covered topics that are of both broad international significance and pointed interest locally. Every International Congress has been generating a Declaration to extend its impact, accompanied by an academic paper to support it.

The Paul Tournier Prize constitutes an annual event to promote Person Centered Medicine by honoring the legacy of Paul Tournier, the Geneva family doctor regarded as one of the fathers of Person Centered Medicine. It is awarded annually since 2017 by the International College of Person Centered Medicine in cooperation with the Paul Tournier Association and the Paul Tournier Family, to scholars who have made highly distinguished international contributions to this programmatic perspective. The Prize winners, who are listed on Table 1.3, have come so far from North America, Latin America and Europe, which are the world regions, along with Oceania, currently most active in the cultivation of Person Centered Medicine.

Table 1.2 ICPCM International Congresses of Person Centered Medicine

No.	Year	City	Main Theme
1	2013	Zagreb	Whole person in health education and training
2	2014	Buenos Aires	Advancing humanistic and interdisciplinary health care
3	2015	Londres	Celebrating primary care achievements: seeing the person behind the patient and a life course approach
4	2016	Madrid	Person centered medical education and the goals of health care
5	2017	Zagreb	Person-centered cancer care
6	2018	Nueva Delhi	Person-centered care for non-communicable diseases
7	2019	Tokyo	Work-life balance: challenges and solutions
8	2020	Montevideo	Responding to the pandemic with persons-centered comprehensive care, human rights and sustainable development goals
9	2021	Kuwait	Culture and person centered clinical care and public health in the eastern Mediterranean region

Table 1.3 Winners of the Paul Tournier Prize

Prize year	Winner's name	City and country
2017	Wim Van Lerberghe	Geneva, Switzerland
2018	C Robert Cloninger	St. Louis, USA
2019	Alberto Perales	Lima, Perú
2020	George Christodoulou	Athens, Greece
	John Cox	Cheltenham, United Kingdom
2021	W James Appleyard	Canterbury, United Kingdom
2022	Sandra Van Dulmen	Nijmegen, The Netherlands

1.4 Conceptual Development of Person Centered Medicine

In its most basic form, it may be said that Person Centered Medicine (PCM) is a perspective that places the whole person as the center of an encompassing concept of health and as the target and protagonist of health actions. Analyzing this formulation, the term *perspective* could be seen just as a generic concept or, taking into account various important considerations discussed throughout this book, it could be said that it is a historically- and philosophically-grounded collaborative programmatic movement. For a further ontological interpretation, it could be said in the words of the eminent Latin American internists Calderon and Vildózola [37], that this perspective constitutes both a fundamental *principle* and a crucial *strategy* in medicine.

A key term in the definition of PCM is the *person*, which appears more valuable than alternatives such as "individual" or "self" on two important grounds. One is its strong connection to ethics, a concern of the highest order in medicine as evidenced by the commitment of the World Medical Association [34] to its Helsinki Declaration, and by the close relationship between person and ethics, i.e., WHO ethics specialist Bouësseau [38] asserted at a Geneva Conference on Person Centered Medicine that if a research project is ethical it has to be person-centered and if it is person-centered, it would be ethical. Furthermore, Ierodiakonou [6] has argued that Aristotle's ethics work is based on person-centered considerations, and Kant's [12] categorical imperative states that the person is always a goal not a means. Consideration of ethics, ensures respect for the dignity of persons and for their autonomy (which is essential for coupling promotion of human rights with promotion of human responsibilities).

A second ground for preferring the term person to various alternatives is the richness of its descriptive and scientific meaning, as follows, (1) *Person* is quite proteic and comprehensive with biological, psychological, social, ecological and spiritual dimensions, (2) It promotes a concept of whole health, encompassing ill health (diseases, disabilities, health problems) and positive health (functioning, resilience, well-being), (3) It represents an organizing pivot for understanding the increasingly prevalent multimorbidity and the corresponding need for the coordination of health services, (4) It highlights the persons that are behind the roles of patients, health professionals, and family members. The last point also explains why person-centered is preferable to patient-centered, i.e., "patient" is just a role, while "person" stimulates broadness and creativity in care.

Further substantiating and delineating the conceptual value of the *person*, is that this is ontologically a central, basic, irreducible element; and epistemologically, it can be stated that person-level knowledge is both important and possible [39]. Concerning the centrality of the person for understanding health, this has been pointedly argued by Cassell [40] and Cassell and Stoyanov [41] ("the person as center of health") and by Tempier [42] ("what is good for the person, is good for his/her health"). In regard to the view of the person as target and protagonist of health actions, this is widely acknowledged as Cassell [43] does in his *Nature of Healing*.

To complement the presentation and analyses above of a central formulation of PCM, some other helpful formulations are presented next. Well received in the clinical arena is the assertion that PCM involves a medicine *of the person* (of the totality of the person's health, including its ill and positive aspects), *for the person* (promoting the fulfillment of the person's life project), *by the person* (with clinicians extending themselves as full human beings with high ethical aspirations, and *with the person* (working respectfully, in collaboration and in an empowering manner with the person presenting for care) [31].

Also important, as proposed by then WHO Assistant Director General and now PAHO Director General Carissa Etienne, is the articulation of person-centered clinical medicine and people-centered public health and to involve a wide range of professional and patient organizations to implement and promote such perspectives [44]. As *person* and *people* are seen as the two sides of the same coin, the term *persons* is often used.

Furthermore, as a theory of medicine, PCM is seen as *informed* by evidence, experience, and values, and aimed at restoring and promoting the health and well-being of whole persons. Finally, the following two research models on conceptualization and measurement and on a person-centered integrative diagnosis are denotative of the conceptual development of Person Centered Medicine.

1.4.1 Systematic Conceptualization and Measurement of Person-centered Medicine and Care

In response to the growing interest and variable understanding of person-centered medicine and care, the need for efforts on their systematic conceptualization and measurement became apparent. With financial support from the World Health Organization, the International College of Person Centered Medicine undertook this task [36]. The objectives included the elucidation of the core concepts of person centered medicine and healthcare, the design of a prototype measuring instrument, and the study of its metric structure, further development, acceptability, reliability and validity. The methods employed were the following: A systematic review of the literature, consultation exercises with broad international panels composed of health professionals and representatives of patient and family organizations, and quantitative and qualitative data analyses.

The following key concepts underlying person centered medicine were elucidated: (1) Ethical Commitment, (2) Cultural Awareness and Responsiveness, (3) Holistic scope, (4) Relational Focus, (5) Individualized Care, (6) Common Ground for Collaborative Diagnosis and Care, (7) People-centered Systems of Care, and (8) Person-centered Health Education and Research. On this basis, a Person-centered Care Index was developed composed of 8 broad items and 33 sub-items, each measured on a 4-point scale. The PCI is displayed in Table 1.4.

Table 1.4 The person-centered care index (PCI)

No.	Indicators	Never	Occasionally	Frequently	Always
1.	Ethical commitment				
1.1	The dignity of every person involved is honored	1	2	3	4
1.2	The patient's rights are respected	1	2	3	4
1.3	The patient's autonomy is supported	1	2	3	4
1.4	The patient's empowerment is advanced	1	2	3	4
1.5	The patient's personal values and needs are understood and respected	1	2	3	4
1.6	The fulfillment of the patient's life project is enabled and encouraged	1	2	3	4
2.	Cultural sensitivity				
2.1	The patient's ethnic identity and cultural values are recognized	1	2	3	4
2.2	The patient's language and communication preferences are considered	1	2	3	4
2.3	The patient's gender and sexual preferences are respected	1	2	3	4
2.4	The patient's spiritual needs are pointedly considered	1	2	3	4
3.	Holistic scope				
3.1	The biological, psychological, social, cultural and spiritual factors of health inform understanding and care	1	2	3	4
3.2	Both health problems/disabilities and positive health are attended	1	2	3	4
4.	Relational focus				
4.1	Clinicians, patients and families work in partnership	1	2	3	4
4.2	Empathy in clinical communication is emphasized	1	2	3	4
4.3	Inter-personal trust is fostered throughout the care process	1	2	3	4
5.	Individualized care				
5.1	The patient's individuality and unique qualities inform care	1	2	3	4

(continued)

Table 1.4 (continued)

No.	Indicators	Never	Occasionally	Frequently	Always
5.2	The patient's historical and social context are factored in process of care	1	2	3	4
5.3	The patient's personal growth and development are promoted	1	2	3	4
6.	Common ground for diagnosis and care				
6.1	Diagnosis of health status involve patient/clinician joint understanding	1	2	3	4
6.2	Diagnosis is cooperatively worked out for whole person and whole health	1	2	3	4
6.3	Care plan decisions are made collaboratively	1	2	3	4
7.	People-centered systems of care				
7.1	The health and rights of all people in the community are attended	1	2	3	4
7.2	The community participates in the planning of health services	1	2	3	4
7.3	Collaboration across disciplines and service programs is promoted	1	2	3	4
7.4	Personalized services are aimed at attaining high quality and excellence	1	2	3	4
7.5	Health services are responsive to specific community needs	1	2	3	4
7.6	Health services are integrated and coordinated around patients' needs	1	2	3	4
7.7	Services emphasize people-centered primary care	1	2	3	4
7.8	Services ensure continuity of care	1	2	3	4
7.9	Services are informed by wide person-centered perspectives	1	2	3	4
8.	Person-centered education, training and research				
8.1	The health system promotes person-centered public health education	1	2	3	4
8.2	The health system promotes person-centered health professional training	1	2	3	4
8.3	The health system promotes person-centered health research	1	2	3	4
Global average score					
Additional evaluative comments					

Copyright: Mezzich JE, Kirisci L, Salloum IM et al. for the International College of Person Centered Medicine

Please rate the following person-centered care indicators in terms of their level of presence in a given health service. The term "patient" here refers to a person who experiences health problems and/or uses health services. To obtain a global average PCI score, please add the partial scores and divide this by the number of items actually rated.

The study of its metric structure revealed high Cronbach internal consistency (0.95), scale unidimensionality through factor analysis (69% of the variance accounted for by the first factor), and interesting inter-correlations such as the subitem attaining the highest correlation with the global average score being "fulfillment of the person's life project" (0.88). Validation studies in California, London and Lucknow (India) showed quite high levels of inter-rater reliability (above 0.80 intra-class correlations for most items) and substantial content validity.

The elucidated core concepts of person centered medicine appear to be consistent with those of international studies on the bases of person- and people-centeredness in primary care and on research and implementation of person centered care. The concepts are also consistent with the key domains of person-centered diagnostic approaches. Further validation studies with larger samples in diverse settings and cultures seem to be warranted. In conclusion, the emerging core concepts of person centered medicine appear to be robust. The Person-centered Care Index based on such concepts appears to have suitable metrics and promising acceptability, reliability and content validity.

1.4.2 The Person-Centered Integrative Diagnosis Model

Also of substantial conceptual value for Person Centered Medicine is the Person-centered Integrative Diagnostic (PID) model aimed at evaluating the person's whole health through key informational domains, upon establishing a common ground among involved professionals, patient and family, and employing categories, dimensions and narratives as descriptive tools [30]. The specific objectives of the pertinent research program were to review the conceptual bases of person-centered integrative diagnosis as a component and contributor to person-centered psychiatry and medicine and to outline its design and development. To this effect, an analysis was conducted of the historical roots of person-centered psychiatry and medicine and of emerging efforts to reprioritize medicine from disease to patient to person in collaboration with global health professional associations and with the coordinating support of the International Network and the subsequent International College of Person Centered Medicine.

The emerging Person-centered Integrative Diagnosis (PID) model articulates science and humanism to obtain a diagnosis *of the person* (of the totality of the person's health, both ill and positive aspects), *by the person* (with clinicians extending themselves as full human beings), *for the person* (assisting the fulfillment of the person's health aspirations and life project), and *with the person* (in respectful and empowering relationship with the evaluated person). This broader and deeper notion of diagnosis goes beyond the more restricted concepts of nosological and differential diagnoses [45]. More specifically, the proposed Person-centered Integrative

Diagnostic model, is defined by three keys: (a) broad informational domains, covering both ill health and positive health along three levels: health status, experience of health, and contributors to health, (b) pluralistic descriptive procedures (categories, dimensions and narratives), and (c) evaluative partnerships among clinicians, patients and families.

An unfolding research program is focused on the construction of practical guides and their evaluation, followed by efforts to facilitate clinical implementation and training. In summary, Person-centered Integrative Diagnosis is aimed at appraising the total health of the total person through plural descriptions and evaluative partnerships in order to establish the bases for integrative and effective care of the total person.

1.5 Scholarly Development of Person Centered Medicine

Research, educational and publication activities are milestones of PCM scholarly development. They are outlined below.

1.5.1 Research on Person-Centered Diagnosis

The diagnostic instrument investigated involved the practical application of the Person-centered Integrative Diagnosis (PID) model in terms of the (Latin American Guide for Psychiatric Diagnosis) (GLADP-VR) published by the Asociación Psiquiátrica de América Latina, Sección de Diagnóstico y Clasificación [46]. This guide represents an adaptation of the ICD-10 that seeks through a biopsychosocial approach to better reflect the holistic framework and culture of Latin American countries. This revision of the original GLADP included updated Latin American annotations and the new integrated diagnostic model centered on the person.

The aim of this study was to evaluate among Latin American psychiatrists the levels of applicability and usefulness of the GLADP-VR in comparison with major international diagnostic classification systems [47]. The survey evaluation instrument included questions about fundamental characteristics of a useful diagnostic guide and comparative questions about the acceptability and usefulness of the GLADP-VR, the original ICD-10, DSM-IV and DSM-5, and suggestions to improve the guide. The sample included 127 Latin American psychiatrists with an interest on diagnosis and classification and membership in one of the 17 national psychiatric societies affiliated with Latin American Psychiatric Association (APAL). They were sent the evaluation instrument by e-mail. Thirty-seven (29.1%) responses were obtained. There were no indications of demographic bias between respondents and no-respondents. The vast majority of respondents answered the questionnaire completely. Ninety-two percent reported knowing the GLADP-VR before the survey and 65.6% had actually used it before.

Concerning results, the most commonly used diagnostic system was the original ICD-10 (86.5%), followed by the GLADP-VR (56.8%). Regarding applicability, the diagnostic system recognized as the most user-friendly was the ICD-10 followed by the GLADP-VR, with the most difficult being the DSM-5. Concerning diagnostic accuracy, the GLADP-VR was found most useful; and the DSM-5 was least useful. Regarding usefulness for clinical care and professional practice, the ICD-10 was rated highest, followed by the GLADP-VR, and lowest was DSM-5. Regarding usefulness for yielding a complete view of the clinical situation, the GLADP-VR was best (83.3%), and DSM-5 was the lowest. Concerning cultural and psychosocial contextualization, the GLADP-VR was considered most useful, well above the original ICD-10 and the DSMs. Furthermore, the GLADP-VR was considered more useful for teaching and research by about 80% of psychiatrists, superior to the other diagnostic systems.

The findings of this study on the most prevalent use of ICD-10 are consistent with the results of a survey conducted earlier by the World Psychiatric Association across the world [48]. In addition, in the present study less than half of the respondents used regularly the DSMs. The findings of the present study concerning the GLADP-VR were quite consistent with the corresponding findings of an earlier preliminary evaluation of the GLADP-VR. This seems to be related to the GLADP-VR comprehensive personalized diagnostic formulation with various components, including narratives. In conclusion, there were indications that the GLADP-VR is seen in Latin America as having higher diagnostic accuracy, yielding a comprehensive view of the clinical situation and its context, and more suitable for teaching, research, and work in community mental health.

1.5.2 Research on Person-Centered Care

This research line is illustrated by a Comparative Study of Prototype Hospitals in Lima with the Person-centered Care Index Rated by Health Professionals conducted by Perales et al. [49]. The development of generic instruments with substantial metric features to appraise progress towards person-centered care is quite encouraging. The aim of the present study was to initiate a person-centered care research program in Latin America through the comparative evaluation of prototype hospitals in Lima, Peru with the use of the generic Person-centered Care Index rated by health professionals.

The study design involved the comparative appraisal of person-centered care in four prototype hospitals through the engagement of health professionals using the generic Person-centered Care Index (PCI) [36]. A Spanish version of the PCI was prepared for the present study in Lima, Peru. For this, groups of physicians and nurses working in clinical medicine and surgery services were engaged from four prototype hospitals, i.e., a public general hospital, a public specialized hospital, a social security hospital, and a private hospital.

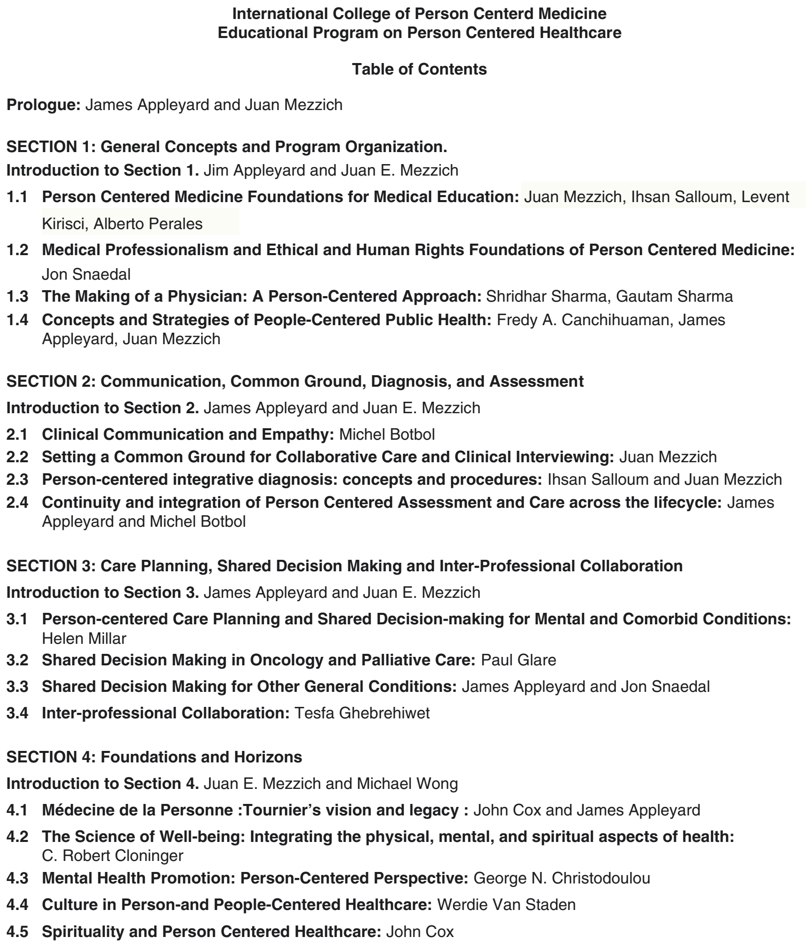
Analyses of the Person-centered Care Index (PCI) global scores that resulted from health professionals rating with the PCI four prototype hospitals revealed significant differences among these hospitals. They were placed in the following decreasing order of person-centered care: private hospital, public specialized hospital, public general hospital, and social security hospital. There were no significant overall differences between the ratings for clinical medicine services and those for surgical services, nor between the ratings made by physicians and those made by nurses. Professionals with less experience tended to make higher PCI ratings than those with more experience. Overall ratings of the ease of use and person-centered care suitability of the PCI were between moderate and substantial levels. The findings suggested the value of the PCI for clinical and health service evaluations and continued research on person centered care in Latin America and beyond.

1.5.3 Educational Programs on Person-Centered Healthcare

Health professional education was from the beginning at the core of the programmatic movement on Person Centered Medicine [50]. Initial discussions to outline concepts and procedures took place during the annual Geneva Conferences and International Congresses on Person Centered Medicine outside their public sessions, under various heads and moderators. Its leadership eventually was assumed by Professor Jim Appleyard who had extensive academic educational experience in the United Kingdom, the Caribbean Grenada and in Uganda, and had led the World Medical Association and some of its ethical programs as well as the International Association of Medical Colleges [51].

The ICPCM Educational Program on Person-centered Healthcare started getting formally organized during the International Congress in New Delhi, hosted by the Indian Medical Association. Chapter authorship was assumed by members of the ICPCM Board who are as well experts on various aspects of the educational program and lecturers at the above mentioned events. The three initial sections of the Educational Program were, (1) General Concepts and Program Organization, (2) Communication, Common Ground, Diagnosis and Assessment, and (3) Care Planning, Share Decision Making and Inter-Professional Collaboration. They were published in three Issues of the *International Journal of Person Centered Medicine* (IJPCM).

A year later these papers plus some other materials were assembled into a monographic volume titled *Seeking the Person at the Center of Medicine*, published by the University of Buckingham Press under the sponsorship of the Kuwait Medical Association. A fourth section of the Educational Program, titled Foundations and Horizons was added shortly afterwards and is being published in a Special Issue of the IJPCM. The four sections are the current components of the ICPCM Educational Program on Person Centered Healthcare, a ‘live program” intended to be so by its director Jim Appleyard. Its table of contents is presented in Fig. 1.1.



International College of Person Centerd Medicine
Educational Program on Person Centered Healthcare

Table of Contents

Prologue: James Appleyard and Juan Mezzich

SECTION 1: General Concepts and Program Organization.

Introduction to Section 1. Jim Appleyard and Juan E. Mezzich

1.1 Person Centered Medicine Foundations for Medical Education: Juan Mezzich, Ihsan Salloum, Levent Kirisci, Alberto Perales

1.2 Medical Professionalism and Ethical and Human Rights Foundations of Person Centered Medicine: Jon Snaedal

1.3 The Making of a Physician: A Person-Centered Approach: Shridhar Sharma, Gautam Sharma

1.4 Concepts and Strategies of People-Centered Public Health: Fredy A. Canchihuaman, James Appleyard, Juan Mezzich

SECTION 2: Communication, Common Ground, Diagnosis, and Assessment

Introduction to Section 2. James Appleyard and Juan E. Mezzich

2.1 Clinical Communication and Empathy: Michel Botbol

2.2 Setting a Common Ground for Collaborative Care and Clinical Interviewing: Juan Mezzich

2.3 Person-centered integrative diagnosis: concepts and procedures: Ihsan Salloum and Juan Mezzich

2.4 Continuity and integration of Person Centered Assessment and Care across the lifecycle: James Appleyard and Michel Botbol

SECTION 3: Care Planning, Shared Decision Making and Inter-Professional Collaboration

Introduction to Section 3. James Appleyard and Juan E. Mezzich

3.1 Person-centered Care Planning and Shared Decision-making for Mental and Comorbid Conditions: Helen Millar

3.2 Shared Decision Making in Oncology and Palliative Care: Paul Glare

3.3 Shared Decision Making for Other General Conditions: James Appleyard and Jon Snaedal

3.4 Inter-professional Collaboration: Tesfa Ghebrehiwet

SECTION 4: Foundations and Horizons

Introduction to Section 4. Juan E. Mezzich and Michael Wong

4.1 Médecine de la Personne :Tournier's vision and legacy : John Cox and James Appleyard

4.2 The Science of Well-being: Integrating the physical, mental, and spiritual aspects of health: C. Robert Cloninger

4.3 Mental Health Promotion: Person-Centered Perspective: George N. Christodoulou

4.4 Culture in Person-and People-Centered Healthcare: Werdie Van Staden

4.5 Spirituality and Person Centered Healthcare: John Cox

Fig. 1.1 Table of contents of the ICPCM Educational Program on Person Centered Healthcare

1.5.4 The International Journal of Person Centered Medicine

The importance of having a dedicated academic periodical for the cultivation of the emerging programmatic movement on person centered medicine was identified early in the course of the annual Geneva Conferences. An opportunity then appeared to achieve this objective in a collaborative manner, namely as a joint venture between, on one hand, the emerging International Network of Person Centered Medicine registered in the State of New York, which would be responsible for scientific content and editorial leadership and, on the other, the University of Buckingham Press, established in London, which would be responsible for the finances, logistics and the production process of the Journal.

Publically starting with the mission of advancing the global communication of scholarship and research for personalized healthcare, the *International Journal of Person Centered Medicine* was set to provide an effective forum for the rapid communication of advances in PCM and a major vehicle for the stimulation of thinking, scholarly interchange and basic and applied research as they pertain to the personalization of care for the patient and the development of humanistic models of care for groups of individual patients within the context of their social settings. As the conceptual and procedural development of PCM has evolved over the years, correspondingly the focus and scope of the journal have evolved as well. The cover of a recent issue of the Journal is displayed in Fig. 1.2.

Since the beginning of the Journal, a number of highly distinguished individuals with impressive and well established international reputations in their fields agreed to assume leadership responsibilities and to join the Editorial Board, some of them

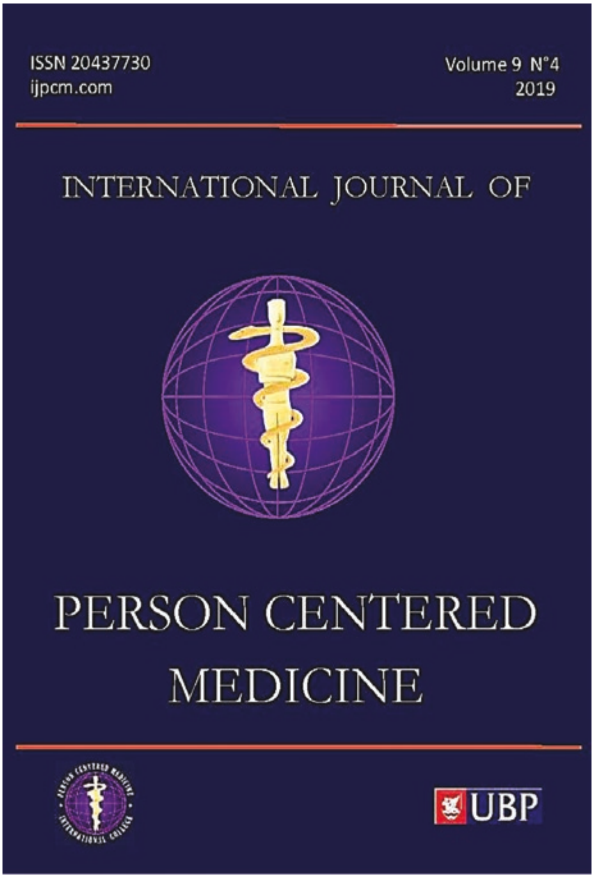


Fig. 1.2 Cover of the International Journal of Person Centered Medicine, Vol 9 N° 4

accepting the onerous task of a regional editor. Over the years, this group has evolved, some members rotating out and others joining the effort. As of 2022, the Journal editorial leadership includes Chief Editor Juan E. Mezzich (USA and Peru), and Co-Editors C. Robert Cloninger (USA) (North America), Christine Leyns (Bolivia & Belgium) (Latin America), Sandra Van Dulmen (The Netherlands) (Europe), Werdie Van Staden (South Africa) (Africa), Michael TH Wong (Hong Kong, China) (Asia), Paul Glare (Australia) (South Pacific), and Levent Kirisci (USA) (Statistical Editor).

Since its inception, the Journal has published eleven annual volumes. It is indexed by various agencies, most recently by the China Knowledge Information Network, reportedly the world's largest indexing and repository service.

1.5.5 The Person-Centered Books Program

Another major publication ICPCM activity refers to textbooks. First it was the *Person Centered Psychiatry* book, then the recently published educational monograph on *Seeking the Person at the Center of Medicine*, and now the present *Person Centered Medicine* volume.

Perhaps the ***Person Centered Psychiatry book*** appeared first in this series because the Person Centered Medicine programmatic movement started among the 130 national member societies and 65 scientific sections of the World Psychiatric Association and therefore as a person-centered field it had more time to mature. Also true is that its core concern on mental health is not privative of psychiatry but has a panoramic cross-sectional place in the whole of medicine. Its publisher was Springer, Switzerland and its cover is shown in Fig. 1.3.

The experience of its five editors, Mezzich et al. [52] ranges from genetics to behavioral sciences to clinical care to public health. They are among the earlier and more consistent contributors to person centered psychiatry.

The 40 chapters of the book encompass an introduction and 39 chapters clustered into the following five sections: (1) Principles (nine chapters), (2) Diagnosis and Assessment (five chapters), (3) Person-centered Care Approaches (seven chapters), (4) Person-centered Care for People with Specific Mental Conditions (11 chapters), and (5) Special Topics (seven chapters). The 83 chapter authors, all prominent scholars and clinicians come from 30 different countries from across the world.

The second volume in the ICPCM book series, titled ***Seeking the Person at the Center of Medicine***, was edited by Appleyard and Mezzich [53] and published by the University of Buckingham Press. It contains the core of the "live" ICPCM Educational Program on Person-centered Healthcare. It is predicated on the pressing need, articulated increasingly by patients themselves, to move

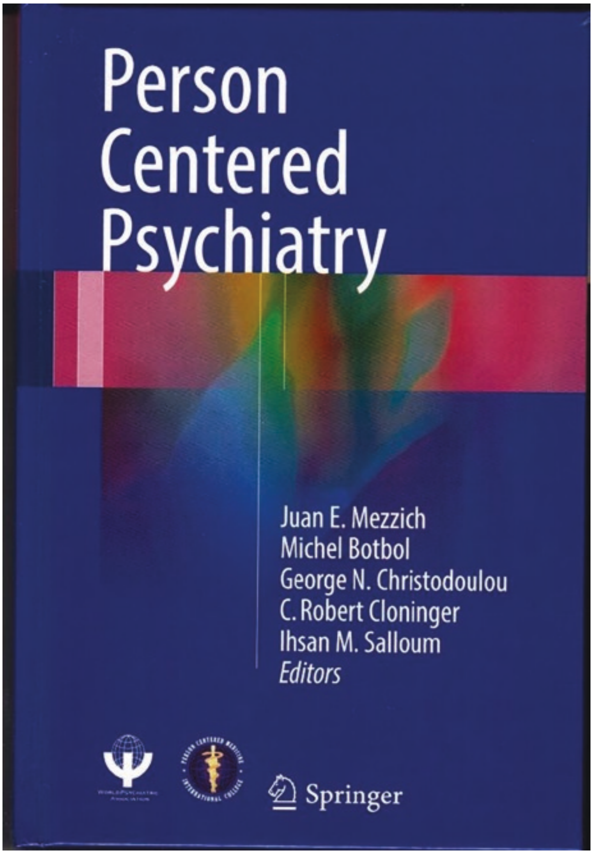


Fig. 1.3 Cover of the person centered psychiatry book

towards personalized, integrated and contextualized models of clinical practice within a humanistic framework of care that recognizes the importance of applying science in a manner which respects the patient as a whole person and takes full account of his values, preferences, and aspirations. This monograph is divided into three discrete but interrelated sections. The first section of four papers includes the conceptualization and measurement in person centered medicine and embraces the relevance of the social determinants of health and people centered public health. The second group of articles moves on to the practical aspects of patient-physician communication and the importance of a comprehensive diagnosis. The third section emphasizes the importance of shared decision making with key examples and inter-professional collaboration. The program is a living document and it is intended to be revised with the help of those who study and apply a person-centered approach to their own practice. Its cover is presented in Fig. 1.4.

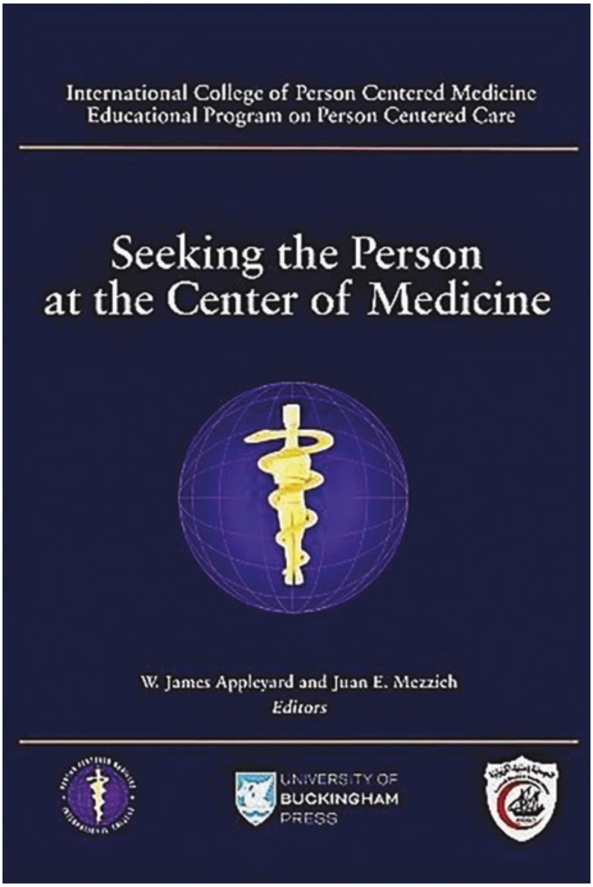


Fig. 1.4 Cover of the book on seeking the person at the Center of Medicine

International College of Person Centered Medicine
Educational Program on Person Centered Care

Seeking the Person
at the Center of Medicine

W. James Appleyard and Juan E. Mezzich
Editors

UNIVERSITY OF
BUCKINGHAM
PRESS

1.6 Presentation of the Person Centered Medicine Book

The textbook on Person Centered Medicine presents in an authoritative manner the PCM international collaborative programmatic movement, as it has evolved to date, and its growing knowledge base. It is officially sponsored by the International College of Person Centered Medicine and published by Springer Nature Switzerland. This section outlines the purpose, authorship, structure, and content of the book.

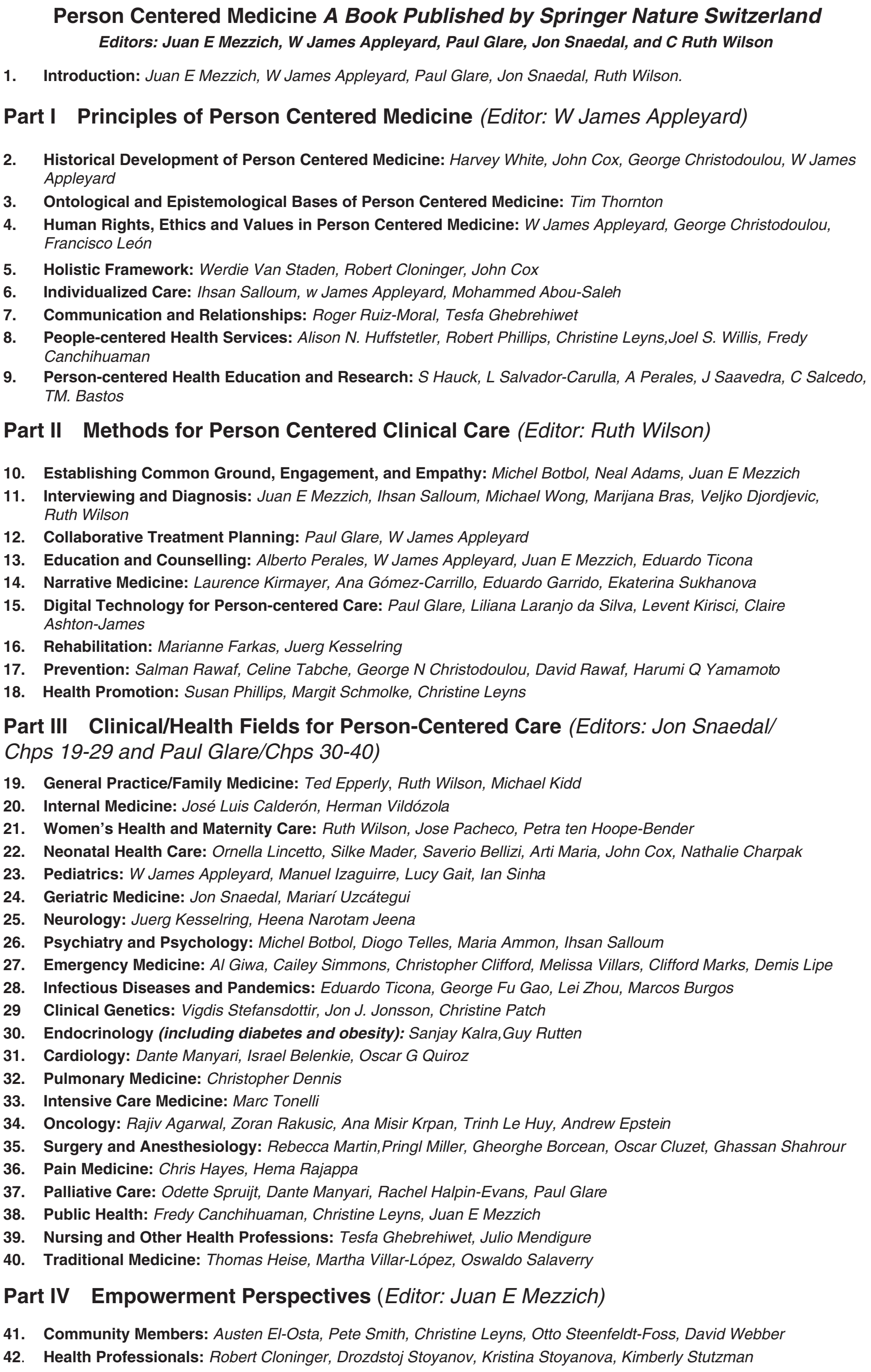
The book is edited by five professorial clinician-scholars in Family Medicine, Pediatrics, Geriatric Medicine, Palliative Medicine and Psychiatry. Most chapters are written by two or more authors from diverse parts of the world. This arrangement intends to promote authoritative consensus, convergence validity, and broad international perspectives and coverage. In total, 105 clinician-scholars authored the book chapters. As a group they come from 25 different countries, covering all continents and world regions, i.e., North America, Latin America, Europe, Africa, the Middle East, Asia and Oceania.

The book structure encompasses an Introduction to the field and the book, and four sections on Principles of Person Centered Medicine (8 chapters), Methods for Person Centered Clinical Care (9 chapters), Clinical/Health Fields for Person Centered Care (22 chapters), and Empowerment Perspectives for Community Members and Health Professionals (2 chapters). Figure 1.5 displays the table of contents of the book, including its editorship and publisher, and the book sections within which chapters are nested along with the authors of each.

1.6.1 Section Highlights

The Section on **Principles of Person Centered Medicine** (PCM), starts with a chronological review of the history of medicine in general and of person centered medicine in particular, both in narrative and tabular forms. It denotes that persons' health and life have represented fundamental social caring concerns throughout human history. The critical review of the ontology and epistemology of PCM reveal its strengths as well as its exploratory aspects as a theory of medicine and a practical strategy. Its axiological and ethical bases are the foremost principles of PCM. Other principles that articulate science and humanism are also reviewed, including a holistic framework for understanding and action, the value of communication and relationships, the need to individualize care, and the consequential establishment of a common ground among health professionals, patient and family for collaborative diagnosis as joint understanding, and shared decision-making for collaborative care. PCM principles at the systems level involve the persons-centered integrated organization of health services and enriching professional education and health research as person-centered crucial support activities.

The Section on **Methods for Person Centered Clinical Care** reviews the procedural aspects of various components of person-centered clinical care. The review starts with how to establish common ground among physicians, patients, and families for collaborative diagnosis and shared decision making, a common ground which is recognized as the crucial first step for the whole person-centered medical practice. The ensuing chapters deal in fact with a collaborative approach to the two most basic components of clinical care, i.e., diagnosis and treatment. Diagnosis, however, is not just the conventional identification of disorders (*nosological diagnosis* for [45]) but a diagnosis of disorders and positive health (*full diagnosis* for Lain Entralgo), i.e., total health diagnosis, which also encompasses diagnosis of risks and protective factors, and consideration of the experience and values of the protagonists in the collaborative process, all to be presented in a comprehensive schema and in a narrative summary. Treatment decisions are also to be made collaboratively. As care involves more than conventional treatment, a chapter on education and counselling provides such complement. Powerful descriptive and processing



Person Centered Medicine ***A Book Published by Springer Nature Switzerland***

Editors: Juan E Mezzich, W James Appleyard, Paul Glare, Jon Snaedal, and C Ruth Wilson

1. **Introduction:** *Juan E Mezzich, W James Appleyard, Paul Glare, Jon Snaedal, Ruth Wilson.*

Part I Principles of Person Centered Medicine *(Editor: W James Appleyard)*

2. **Historical Development of Person Centered Medicine:** *Harvey White, John Cox, George Christodoulou, W James Appleyard*
3. **Ontological and Epistemological Bases of Person Centered Medicine:** *Tim Thornton*
4. **Human Rights, Ethics and Values in Person Centered Medicine:** *W James Appleyard, George Christodoulou, Francisco León*
5. **Holistic Framework:** *Werdie Van Staden, Robert Cloninger, John Cox*
6. **Individualized Care:** *Ihsan Salloum, w James Appleyard, Mohammed Abou-Saleh*
7. **Communication and Relationships:** *Roger Ruiz-Moral, Tesfa Ghebrehiwet*
8. **People-centered Health Services:** *Alison N. Huffstetler, Robert Phillips, Christine Leyns,Joel S. Willis, Fredy Canchihuaman*
9. **Person-centered Health Education and Research:** *S Hauck, L Salvador-Carulla, A Perales, J Saavedra, C Salcedo, TM. Bastos*

Part II Methods for Person Centered Clinical Care *(Editor: Ruth Wilson)*

10. **Establishing Common Ground, Engagement, and Empathy:** *Michel Botbol, Neal Adams, Juan E Mezzich*
11. **Interviewing and Diagnosis:** *Juan E Mezzich, Ihsan Salloum, Michael Wong, Marijana Bras, Veljko Djordjevic, Ruth Wilson*
12. **Collaborative Treatment Planning:** *Paul Glare, W James Appleyard*
13. **Education and Counselling:** *Alberto Perales, W James Appleyard, Juan E Mezzich, Eduardo Ticona*
14. **Narrative Medicine:** *Laurence Kirmayer, Ana Gómez-Carrillo, Eduardo Garrido, Ekaterina Sukhanova*
15. **Digital Technology for Person-centered Care:** *Paul Glare, Liliana Laranjo da Silva, Levent Kirisci, Claire Ashton-James*
16. **Rehabilitation:** *Marianne Farkas, Juerg Kesselring*
17. **Prevention:** *Salman Rawaf, Celine Tabche, George N Christodoulou, David Rawaf, Harumi Q Yamamoto*
18. **Health Promotion:** *Susan Phillips, Margit Schmolke, Christine Leyns*

Part III Clinical/Health Fields for Person-Centered Care *(Editors: Jon Snaedal/ Chps 19-29 and Paul Glare/Chps 30-40)*

19. **General Practice/Family Medicine:** *Ted Epperly*, *Ruth Wilson, Michael Kidd*
20. **Internal Medicine:** *José Luis Calderón, Herman Vildózola*
21. **Women's Health and Maternity Care:** *Ruth Wilson, Jose Pacheco, Petra ten Hoope-Bender*
22. **Neonatal Health Care:** *Ornella Lincetto, Silke Mader, Saverio Bellizi, Arti Maria, John Cox, Nathalie Charpak*
23. **Pediatrics:** *W James Appleyard, Manuel Izaguirre, Lucy Gait, Ian Sinha*
24. **Geriatric Medicine:** *Jon Snaedal, Mariarí Uzcátegui*
25. **Neurology:** *Juerg Kesselring, Heena Narotam Jeena*
26. **Psychiatry and Psychology:** *Michel Botbol, Diogo Telles, Maria Ammon, Ihsan Salloum*
27. **Emergency Medicine:** *Al Giwa, Cailey Simmons, Christopher Clifford, Melissa Villars, Clifford Marks, Demis Lipe*
28. **Infectious Diseases and Pandemics:** *Eduardo Ticona, George Fu Gao, Lei Zhou, Marcos Burgos*

29 **Clinical Genetics:** *Vigdis Stefansdottir, Jon J. Jonsson, Christine Patch*

30. **Endocrinology** ***(including diabetes and obesity):*** *Sanjay Kalra,Guy Rutten*
31. **Cardiology:** *Dante Manyari, Israel Belenkie, Oscar G Quiroz*
32. **Pulmonary Medicine:** *Christopher Dennis*
33. **Intensive Care Medicine:** *Marc Tonelli*
34. **Oncology:** *Rajiv Agarwal, Zoran Rakusic, Ana Misir Krpan, Trinh Le Huy, Andrew Epstein*
35. **Surgery and Anesthesiology:** *Rebecca Martin,Pringl Miller, Gheorghe Borcean, Oscar Cluzet, Ghassan Shahrour*
36. **Pain Medicine:** *Chris Hayes, Hema Rajappa*
37. **Palliative Care:** *Odette Spruijt, Dante Manyari, Rachel Halpin-Evans, Paul Glare*
38. **Public Health:** *Fredy Canchihuaman, Christine Leyns, Juan E Mezzich*
39. **Nursing and Other Health Professions:** *Tesfa Ghebrehiwet, Julio Mendigure*
40. **Traditional Medicine:** *Thomas Heise, Martha Villar-López, Oswaldo Salaverry*

Part IV Empowerment Perspectives (*Editor: Juan E Mezzich)*

41. **Community Members:** *Austen El-Osta, Pete Smith, Christine Leyns, Otto Steenfeldt-Foss, David Webber*
42. **Health Professionals:** *Robert Cloninger, Drozdstoj Stoyanov, Kristina Stoyanova, Kimberly Stutzman*

Fig. 1.5 Table of contents of the person centered medicine book tools are presented as narrative medicine and digital medicine. Separate chapters review additional components of care, i.e., prevention and rehabilitation. And the final one caps it all as health promotion or salutogenesis, in line with persons-centered medicine being aimed at the fulfillment of all.

The **Section on Health Fields for Person-centered Care** is the largest in the Book as it contains 22 quite diverse chapters. It starts with two pivoting fields. The first on Family Medicine or General Practice is aimed at addressing prominently the fundamentals of health care, the articulation of levels of care, contextualization with family and community, and coordination with public health, and thus has a major role in persons-centered medicine. The second, internal medicine, also has a pivot role representing and coordinating the highest levels of specialized care and perhaps of this its contributors in this book recognize PCM as a fundamental principle and a crucial strategy, beyond differences in procedures and tactics. The ensuing chapters on Women's Health, Neonatal Care, Pediatrics, and Geriatric Medicine are closer to the first two in the sense that focus on broad groups of the general population more than on specific diseases or procedures. Chapters 25 (Neurology) to 37 (Palliative Care) correspond to the more conventional medical and surgical specialties largely focused on clinical conditions and specific treatments. Even so, person centered medicine, as these chapters' authors recognize, is still highly pertinent in order to fulfill the fundamental responsibilities of physicians beyond differences in diagnostic and therapeutic techniques these practitioners are expected to use competently. In this group of specialty chapters, that on Psychiatry and Psychology has a particular place given that it deals not only with mental disorders but also prominently with mental health, which as a crucial aspect of positive health is a major goal of person centered medicine. The last three chapters have special features and roles. Public Health is of course a major broad area of health services and policies, complementing here the clinical fields. The chapter on Nursing and Other Health Professions emphasizes the crucial importance of inter-professional training in order to ensure effective collaborative care, a key goal of person centered medicine. Traditional Medicine is grounded on history and anthropology and as such provides depth and contextualization to medical practice.

Practical Issues for the Implementation of Person-centered Care were dealt with particularly in this Section on Health Fields. Concerning Key Factors for such implementation, a preliminary review of some of the chapters revealed that all the eight principles of PCM [36] were identified by this small group of chapters as key factors. Most frequently identified were the historically deepest principle, *Ethical Commitment*, and the most recently developed, *Common Ground for Collaborative Diagnostic Understanding and Shared Decision Making.* Next in frequency of identification were *Holistic Framework, Relationship and Communication Focus,* and *Individualized Care.* In addition to the three other principles less frequently identified, there were two other Key Factors suggested in terms of "focus on outcomes" and "hope for recovery". Concerning the Extent To Which the Field is Person-centered, one chapter suggested that the field was already quite person-centered in practice and in terms of formal authoritative statements; while others suggested there was still much to be done although there is a growing perception of the value of this approach. Concerning the Obstacles for the Implementation of Person-centered Care a large number of barriers were identified, including a mind-body dualism that militates against a holistic approach, financial incentives that privilege attention to organs and techniques, and unawareness and unpreparedness of practitioners to look for and carry-out person-centered medicine. Concerning Field Changes Needed for Person-centeredness, the many suggestions offered included adding self-care, mutual care and community engagement to medical science evidence, implementation of inter-professional collaboration, introduction of regulatory provisions and financial incentives to promote person-centeredness, and upgrading clinicians' personal attitudes towards the fundamental role of healthcare. Book readers and researchers may enrich the responses to these Person-centered Implementation Issues.

The final **Section on Empowerment Perspectives** addresses the importance of social engagement for care at the center of medicine and health since Neanderthals times [1] to person-centeredness in the twenty-first century. Such empowerment is first applied to community members where new health strategies such as self-care and mutual care are being developed and where active social participation in caring for each other's health and well-being, since primary school years, is essential. These perspectives are also applied to health professionals, on one hand, to optimize their work through the establishment of common ground with patients and families for collaborative broad diagnostic understanding and shared decision-making, and on the other, to overcome burn-out and promote well-being leading to healthy professional corps that are socially effective and personally fulfilled.

1.7 Colophon

The prevalent outlook of medicine in the twentieth century marked by reductionist and dehumanized care is slowly changing towards the twenty-first which is being recognized as the century of the Person, not only in Medicine and Health, but also in Education and other social activities. Emerging within this promising context is Person Centered Medicine as a broad, conceptual, international and collaborative programmatic movement. Springer published in 2016 a textbook on Person Centered Psychiatry under the sponsorship of the International College of Person Centered Medicine and the World Psychiatric Association, having a core concern on mental health, which is not a private domain of psychiatry but has a panoramic cross-sectional place in the whole of medicine.

Now, the textbook on Person Centered Medicine presents in an authoritative manner the PCM international collaborative programmatic movement, as it has evolved to date, and its growing knowledge base. It is officially sponsored by the International College of Person Centered Medicine and published by Springer Nature Switzerland. Its authorship and structure reflects the features of a programmatic movement that is historically- and science-informed, ethically-committed, and socially responsible. Its vision and goals involve total health for a total person.

Ongoing work and upcoming publications would focus on redesigning health systems fit to purpose, training health professionals who are ready for collaborative practice, and people engaged in their own and mutual care, and integrating ancestral and community knowledge and wisdom with the contributions of all health-relevant social sectors.

Acknowledgements and Disclosures The book editors and chapter authors do not report conflicts of interest.

Professor Jim Appleyard passed away after fulfilling his authorship and editing responsibilities. He personified what is best of person centered medicine and thus his legacy is inspiration and encouragement for colleagues and friends across the world.

References

1. Spikins P, Needham A, Tilly L, Hichens G. Calculated or caring: Neanderthal healthcare in social context. World Archeol. 2018;50(3):384–403.
2. Heise T. Chinas Medizin bei uns. Einführendes Lehrbuch zur traditionellen chinesischen Medizin. Berlin: VWB; 1996.
3. Flood G. Introduction to Hinduism. Cambridge: Cambridge University Press; 1996.
4. Alvarado D. Una comprensión andina del cuerpo. Lima: Ediciones Multigrafik; 2019. p. 31–49.
5. Bartlett RC, Collins SD. Nicomachean ethics. Chicago: University of Chicago Press; 2012.
6. Ierodiakonou C. Medicine as a model of Aristotle's ethics and his person-centered approach. Int J Person Cent Med. 2014;4:31–4.
7. Stefano V (2019) Los fundamentos éticos de las cosmologías indígenas. Amérique Latine Histoire et Mémoire. Les Cahiers ALHIM
8. Ramose MB. The philosophy of the Ubuntu and Ubuntu as a philosophy. In: Coetzee PH, Roux APJ, editors. The African philosophy reader. 2nd ed. New York: Routledge; 2003.
9. Abou-Saleh MT, Salloum IM. Bimaristan Arghun Al-Kamili in Aleppo, Syria: a mental hospital with unique architecture designed to meet patient needs in Medieval Islam (1354 AD). Arab J Psychiatry. 2020;31(2):191–5.
10. Haddad SI. History of Arab medicine. Beirut: Bouheiry Brothers; 1975.
11. Spinoza B. Éthique. Trad de B Pautrat. Paris: Seuil; 2003.
12. Kant I. Critique of practical reason. Transl Werner Pluhar. Indianapolis: Hacket Publishing Company; 2002.
13. Ortega y Gasset J. Meditaciones del Quijote. In: Obras Completas de José Ortega y Gasset, vol. 1. Madrid: Editorial Santillana; 1914. p. 745–825.
14. Tournier P. Médecine de la Personne. Neuchatel: Delachaux et Niestle; 1940.
15. Rogers CR. On becoming a person: a therapist's view of psychotherapy. Boston: Houghton Mifflin; 1961.
16. Rogers CR, Rosemberg RL. La Persona como Centro. Traducido del portugués, vol. 1981. Barcelona: Herder; 1981. p. 253.
17. Kitwood T. Dementia reconsidered: the person comes first. Buckingham: Open University Press; 1997.
18. Stewart M. Patient-centered medicine: transforming the clinical method. Thousand Oaks: Sage; 1995.
19. Sarsina PR. The social demand for a medicine focused on the person: the contribution of complementary and alternative medicine to healthcare and health genesis. Evid Based Complement Alternat Med. 2007;4:45–51.

20. Brera GR. The manifesto of person centered medicine. Med Mind Adolesc. 1999;14:1–2.
21. Heath I. Promotion of disease and corrosion of medicine. Can Fam Physician. 2005;51:1320–2.
22. Garrabe J, Hoff P. Historical views on psychiatry for the person. Int J Person Cent Med. 2011;1:125–7.
23. Mezzich JE. Psychiatry for the person: articulating medicine's science and humanism. World Psychiatry. 2007;6:1–3.
24. Mezzich JE. The dialogal basis of our profession: psychiatry with the person. World Psychiatry. 2007;6:129–30.
25. Mezzich JE, Christodoulou G, Fulford KWM. Introduction to the conceptual bases of psychiatry for the person. Int J Person Cent Med. 2011;1:121–4.
26. Mezzich JE, Snaedal J, van Weel C, Botbol M, Salloum IM. Introduction to person-centered medicine: from concepts to practice. J Eval Clin Pract. 2011;17:330–2.
27. World Psychiatric Association (WPA). Essentials of the World Psychiatric Association's International guidelines for diagnostic assessment (IGDA). Br J Psychiatry. 2003;182(45):37–66.
28. Banzato CEM, Mezzich JE, Berganza CE. Philosophical and methodological foundations of psychiatric diagnosis. Psychopathology. 2005;38(4):155–230.
29. Mezzich JE, Ustun TB. International classification and diagnosis: critical experience and future directions. Psychopathology. 2002;35(2–3):59–201.
30. Mezzich JE, Salloum IM, Cloninger CR, Salvador-Carulla L, Kirmayer L, Banzato CE, Wallcraft J, Botbol M. Person-centered integrative diagnosis: conceptual bases and structural model. Can J Psychiatr. 2010;55:701–8.
31. Mezzich JE, Snaedal J, van Weel C, Heath I. The International Network for Person-centered Medicine: background and first steps. World Med J. 2009;55:104–7.
32. World Medical Association. Geneva declaration: physician's oath. Geneva: Author; 1948.
33. Wiesing U, Parsa-Parsi RW, Kloiber O. The World Medical Association Declaration of Helsinki 1964-2014: 50 years of evolution of medical research ethics. Koln: Deutscher Arzte-Verlag; 2014.
34. World Medical Association. Helsinki declaration: recommendations guiding doctors in clinical research. Helsinki: Author; 1964.
35. World Health Organization. The world health report 2008: primary care: now more than ever. Geneva: World Health Organization; 2008.
36. Mezzich JE, Kirisci L, Salloum IM, Trivedi JK, Kar SK, Adams N, Wallcraft J. Systematic conceptualization of person centered medicine and development and validation of a person-centered care index. Int J Person Cent Med. 2016;6:219–47.
37. Calderon JL, Vildózola H (in press). Person-centered internal medicine. In: Mezzich JE, Appleyard WJ, Glare P, Snaedal J, Wilson CR (eds) Person centered medicine. Cham: Springer
38. Bouësseau M-C. Strengthening research ethics review systems. Int J Person Cent Med. 2013;3:263–5.
39. Thornton T. Ontological and epistemological bases of Person Centered Medicine. In: Mezzich JE, Appleyard WJ, Glare P, Snaedal J, Wilson CR (eds) Person centered medicine. Cham: Springer; in press.
40. Cassell E. The person in medicine. Int J Integr Care. 2010;10:50–1.
41. Cassell E, Stoyanov D. The person as center of health. In: Mezzich JE, Botbol M, Christodoulou G, Cloninger CR, Salloum IM, editors. Person centered psychiatry. Cham: Springer; 2016.
42. Tempier R. Treatment and care of psychosis: the person first. In: Paper presented at Symposium on Person Centered Care, WPA Regional Meeting, Beijing; 2010.
43. Cassell E. The nature of healing: the modern practice of medicine. Oxford: Oxford University Press; 2012.
44. Mezzich JE, Miles A, Snaedal J, van Weel C, Botbol M, Salloum IM, Van Lerberghe W. The Fourth Geneva Conference on Person-centered Medicine: articulating person-centered medicine and people-centered public health. Int J Person Cent Med. 2012;2:1–5.
45. Laín-Entralgo P. El Diagnóstico Médico: Historia y Teoría. Barcelona: Salvat; 1982.

46. Asociación Psiquiátrica de América Latina, Sección de Diagnóstico y Clasificación. Guía Latinoamericana de Diagnóstico Psiquiátrico, Versión revisada (GLADP-VR). Lima: Asociación Psiquiátrica de América Latina; 2012.
47. Saavedra JE, Otero A, Brítez J, Velásquez E, Salloum IM, Zevallos S, Luna Y, Paz V, Mezzich JE. Evaluation of the applicability and usefulness of the Latin American guide for psychiatric diagnosis, revised version, in comparison with other international systems among Latin American Psychiatrists. Int J Person Cent Med. 2017;7:216–24.
48. Mezzich JE. International surveys on the use of ICD-10 and related diagnostic systems. Psychopathology. 2002;35:72–5.
49. Perales A, Kirisci L, Mezzich JE, Sánchez E, Barahona L, Zavala S, Amorín E. Comparative study of prototype hospitals in Lima with the Person-Centered Care index rated by health professionals. Int J Person Cent Med. 2018;8:47–65.
50. Mezzich JE, Salloum IM, Kirisci L, Perales A. Person centered medicine foundations for medical education. Int J Person Cent Med. 2018;8:90–103.
51. Appleyard WJ. Narratives in clinical practice: the essence of person centered care? Int J Person Cent Med. 2013;3:123–6.
52. Mezzich JE, Botbol M, Christodoulou GN, Cloninger CR, Salloum IM. Person centered psychiatry. Cham: Springer; 2016.
53. Appleyard WJ, Mezzich JE. Seeking the person at the center of medicine. London: Buckingham University Press; 2021.

Part I
Principles of Person Centered Medicine

Chapter 2
Historical Overview of Person Centered Medicine

Harvey White, George N. Christodoulou, John Cox, and W. James Appleyard

---

H. White (✉)
St. Bartholomew's Hospital, London, UK

The Royal Marsden Hospital, London, UK

Medical Society of London, Harveian Society, Osler Club and Hunterian Society, London, UK

Royal Society of Medicine of London and British Association of Surgical Oncology, London, UK

G. N. Christodoulou
Department of Psychiatry, Society of Preventive Psychiatry, Athens University, Athens, Greece

World Psychiatric Association, Geneva, Switzerland

World Federation for Mental Health, Occoquan, VA, USA

Hellenic Psychiatric Association, Athens, Greece

International College of Psychosomatic Medicine, Florence, Italy

International College of Person Centered Medicine, New York, NY, USA

J. Cox
World Psychiatric Association, Geneva, Switzerland

International College of Person Centered Medicine, New York, NY, USA

Keele University, Keele, UK

Royal College of Psychiatrists, London, UK

International Marce Society, Brentwood, TN, USA

W. J. Appleyard
Presidency 2013–2017, International College of Person Centered Medicine, New York, NY, USA

Presidency 2003-2004, World Medical Association, Ferney-Voltaire, France

St George's University School of Medicine, Grenada, Grenada

Kent and Canterbury Hospital, Canterbury, UK

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_2

2.1 Introduction

Medicine is nothing without the person. The historical overview of person centered medicine to be conducted in this chapter will be organized in sections corresponding to relatively standard history eras or ages. In each them, a more basic medical historiography will be presented followed by more specific person-centered concerns and developments.

2.2 Pre-history (Up to 4000 BC)

As *homo sapiens* metamorphosed into a person with an individual character—and moreover became a member of a stable group—relationships and interactions inevitably changed, leading to growing interdependence. Initially communities were relatively simple and static; skills and knowledge were most likely incipient. Persons not feeling well and those around them may have waited and watched for a resolution of illness, accompanied and comforted by each other. As communities became more differentiated and sophisticated, core tasks such as food gathering and then hunting were undertaken by some on behalf of the others. Neanderthal care for illness and injury was widespread and depended on close social bonds, at least as in later times. Fundamentally, they seem to have lived in groups with substantial concern for each other's wellbeing [1].

Neanderthal healthcare is significant not in its distinctiveness compared with that of more modern humans in later periods but in its similarity. Neanderthals appear to share a common human emotional and practical response to vulnerability and suffering in those to whom they were close. Attitudes also reflected in the care of children and to the body at death through mortuary practice. The very similarity of Neanderthal healthcare to that of later periods has important suggested implications—that basic organized care is not unique to our species but is also seen in animal groups [2]. Despite the skills and acquired knowledge meeting many caring needs within the communal group, there must have been frustrations in certain areas including the understanding of death and infirmity. Inevitably, some believed they had special powers in communicating with the dead as well as good and evil spirits. With few therapeutic measures available, magical healing often became part of their repertoire. The 'medicine man'—initially a male but eventually also a role undertaken by women—became a feature of many very early communities [3].

Of major relevance to person centered medicine, the above observations about Neanderthals bring into clear focus how important were accompanying, concern, and commitment by the primary support group for the protection and restoration of health.

2.3 Early History (4000 BC to 476 AC)

The mutation into a physician was far distant but the course of travel had been set and would depend on observation, the accumulation of knowledge, records and eventually the development of a higher structure within society. This led to apprenticeship, centers of learning and places where treatment could be delivered by specialists. These, ultimately, became subjected to certain controls imposed upon them by Trade Guilds which also oversaw the way in which they were able to practice. [4] Although religions have usually championed the needs and wishes of the individual, this was often subservient to the analysis and treatment of a case in a trial. Less thought was given to considering the wishes, sensitivities and anxieties of those receiving universally accepted and prescribed treatment. Patients were consequently becoming a statistic in the delivery of scientific medicine. During five millennia of evolution of the medical profession, the importance of the person as a patient has become secondary to the ever-increasing complexity of the delivery of care [5]. This results in a loss of dignity, compassion and respect.

Archaeological excavations across Europe right to the Atlantic seaboard—including, also, the **Middle East Egypt, and Andean cultures**—confirm that many people survived serious injury and even surgical intervention [6]. This is proved by the deposition of new bone around the sites of injury or intervention. We know, therefore, that incipient but effective treatments have been attempted since very early times.

In the Far East, the first significant records of formal medicine were in **China**, where the sense of complementarity (the *ying* and *yang*) was a fundamental symbol of health. Some of the earliest records correspond to Huangdi Neiging—the so called 'first' but actually mythical Emperor who seemed to have reigned from 2500 BC. Often referred to as the 'Yellow Emperor', the book associated with him was a series of questions and answers on medical topics [7]. It became a popular text during the reign of Emperor Shi Huang, founder of the Qin dynasty in 247 BC. Although traditional **Japanese** medicine—kampo which taught that mind and body were inseparable for health—was introduced via **Korea** in the fifth century CE, the first written records of Japanese medicine, do not appear until the seventh century AC in documents known as the 'Daido Ruijuho' commissioned by Emperor Kanmu [8]. Clearly, therefore, oceans at that time formed an almost impenetrable barrier to communication and the exchange of culture.

There was, however, a relatively seamless exchange, across land masses accompanying trade. Cuneiform tablets discovered in **Babylon** and dated to 266 BCE in the reign of King **Hammurabi** recorded legal aspects of regulating malpractice within society generally [9]. Within this were some medical examples. Certain errors and malpractices were associated with a monetary fine. These were less severe if it was a slave rather than a freeman who had been wronged. The general thrust of the code of practice was the protection of the individual person and that the physician should 'do no harm'.

Later, in **India**, the Vaidya Oath warned Hindu physicians not to undertake unlawful acts during the course of their medical duties. From 1700 BC the Vedic and Sanskrit books in India detailed medical practices some of which such as Ayurvedic holistic medicine and massage may well have been established as early as 3000 BC [10]. In Assyria cuneiform tablets from the reign of King Ashurbanipal (668–627 BCE) further codified the laws which had been developed over centuries [11].

The formal development of the medical ethical code and person-centered care in the West can be traced most directly to **Ancient Greece**, specially to Plato, Socrates, Aristotle and Hippocrates.

The collection of writings known as the **Hippocratic** (450–370 BC) ‘Corpus’ has contributed immensely to the development of medical practice. They emphasized the need for confidentiality and non-maleficence as well as the role of a psychosomatic element in some conditions. Emotions such as anxiety, sadness and fear may be responsible for physical symptoms. Mental conditions were attributed to an imbalance of the ‘humours’—water, air, fire and earth leading to phlegmatic, sanguine, choleric and melancholic moods. Not dissimilar attempts were made by ancient Chinese philosophers with their ‘yin and yang’ concept of dualism to explain the balance of opposites in both nature and medicine. The pre-Socratic philosophers of nature (*physikoi*) in the sixth century B supported a biological perception of illness as distinct from a theocratic one. A major contributions of Hippocratic teaching was to develop these ideas and teach that the “holy disease” (epilepsy) was no more holy than the rest of the diseases and that, contrary to the beliefs of the time, it resulted from physical causes. The exact date of the Hippocratic code or ‘oath’ and indeed the likelihood that one individual was responsible for the code is questionable.

The two important centers of medicine with Asclepions (healing sanctuaries) and Asclepiads (priests of Asclepion) were Cnidos which had close connections with Egypt, and Kos. The Hippocratic Oath is probably a combination of the ‘Cnidian sentences’ and the ‘Hippocratic corpus’ [12]. As training was undertaken at both places, there is speculation that part of the ‘oath’ was an address to students at the end of their training. (Lane Fox) Hippocrates also highlighted the importance of respect for one’s teachers and expressed opposition to euthanasia and abortions. His emphasis on confidentiality referred to both ‘free’ citizens and slaves alike. This is important as it is an early example of a person-centered approach. The principle that physicians should not treat illnesses but persons who suffer from illness was accepted and confirms the importance of the person.

Plato and Socrates also made a significant contribution to person-centered medicine, holistic medicine and psychosomatic medicine. In the dialogue “Charmides” the two basic principles of Psychosomatics, namely psychogenesis and ‘holism’—a term not actually used until 1926 by Jan Smuts—were communicated. Plato further contributed to person centered medicine by stating in the dialogue “Phaedros” that Medicine is not just giving medication but it is an Art and concludes that in the same way that medicine treats the body, words cure the soul [13].

The basic concepts and provisions of the Hippocratic teachings have been developed into contemporary ethical codes. An example is the incorporation of beneficence and non-maleficence within the ethical concept of ‘’Principlism’ [13]. Philosophers of ancient Greece, like **Plato and Aristotle compiler of the Nicomachean Ethical Treatises** have greatly influenced our present-day and constantly developing perception of ethics [14, 15]. Aristotle also made major contributions to person-centered care by highlighting *well-being* in terms of life lived well (“eudaimonia”), i.e., the fulfillment of health and personhood.

Other ethical oaths such as the **‘Oath of Sun Simiao’ (581–681 CE) in China** show how widely attention was being paid to ethical aspects of medical practice.

Also important for medicine and health among early civilizations is the **Andean** world view [16, 17], with its emphases on ethical solidaristic living (living well in a dignified manner, *allyn kawsay*, not leaving anybody behind), and a profound (and surprisingly modern) concept of health as harmonious equilibrium among the internal, social and natural worlds). Also pertinent is to mention here **South African** ancestral cultures, emblematized by **Ubuntu** humanism (encounter of persons as a goal in itself; becoming a person through other persons) [18].

2.4 Middle Age (476–1493 AC)

2.4.1 Pre-islamic Period

The culture and medical practices of the ancient Eastern civilizations, reached the Seleucid Empire—a Hellenistic State in Western Asia—through trade and Westward migration from the third century BCE onwards. Then from the second century BCE the Sassanid Empire—the last Persian dynasty before Islam—came to benefit from this influx of culture from the East [19]. As trade, migration and both Byzantine and Islamic conquests pushed to the West, there was the opportunity also to absorb the culture and medical practices of Greece, the Roman Empire and Egypt from around the Mediterranean littoral. All these ancient civilizations had been developing and recording medical traditions of their own. Excavations at Mycenae in Greece (1400 BCE) yielded a hoard of surgical instruments.

There are records of medical and surgical patients and medical books in Rome in the first century CE including when Galen, a native of Pergamum in Asia Minor, came to practice in Rome. Galen maintained that there was no distinction between mental and physical aspects of disease. He described various physical conditions expressed through mental symptoms and concluded that in view of the fact that the soul is affected by physical influences it must be an integral part of the body.

He carried this conclusion further by stating that body and soul may share the same composition [20].

The torch of medical learning was not passed on smoothly like a relay baton. Sometimes conflicts and established prejudices—both temporal and spiritual—held up dissemination of medical learning—when, for example, religious doctrine inhibited anatomical dissection. On other occasions the converse was true. An example of this was the unintended consequence when Nestorius, the Patriarch of Constantinople, was declared a heretic at the Council of Ephesus in 431 AC.

His followers fled East with the Greek and Roman medical texts which were housed in the libraries of Constantinople. Nestorians set up various centers of medical learning and teaching in the Sassanid Empire. Prominent amongst these were those at Nisibis, Jundishapur and Edessa.

2.4.2 Islamic Medicine Golden Age

With the emergence of Islam in seventh century CE, their close proximity to the Nestorian diaspora provided an opportunity for the Greek and Roman texts to be translated into Arabic. The resulting texts incorporated the wisdom and practices from many centuries and from many civilizations stretching Westward from China.

The apogee of Islamic Medicine is epitomized by the physicians Haroon Al Rashid, Rhazes and Avicenna, centered in Baghdad and prominent in the Eastern Arab Caliphate between 766 and 1037 AC during what is referred to as the 'Golden Age'. Avicenna was influenced by Aristotelian philosophy. The works he is believed to have compiled include *The Canon of Medicine*, a encyclopedia, which became a standard medical text at many medieval universities and remained in use as late as 1650 AC [21].

When the territorial conquests of Islam moved to the West along the coast of North Africa, they were able to encapsulate the Egyptian medical traditions and those of the Western Byzantine Empire and finally the ancient Berber traditions from the Atlas Mountains. The Islamic invasion of the Iberian Peninsula in 711 CE made this wealth of knowledge accessible to Northern Europe. Physicians who emerged here and flourished in the Western Caliphate between 936 and 1204 AC were Albucasis, Avenzoar, Averroes and Maimonides. The centre most significantly engaged in the translation of the medical texts, into the European *lingua franca* of Latin and also French was Toledo. Gerard of Cremona (1114–87 CE) was prominent amongst the translators who were encouraged by King Alfonso X. Indeed, Toledo became part of the interface between two cultures who had not previously met significantly [22].

European medicine was therefore led out of the Dark Ages as a result of communication with the Arab world. However, when the 'reconquist' started—from as early as 790 AC—a gradual expulsion of Arabs began from Spain. Some of the medical scholars, rather than returning to North Africa, journeyed overland towards the East, populating universities such as Padua which developed a fine medical tradition. Graduates were attracted to these Universities from Northern Europe and even England. Europe continued to benefit enormously from the wealth of medical knowledge brought by Islam via Spain. Therapies not previously practiced in Europe and especially a knowledge of herbal medicine was part of this legacy. In addition, the Arab influence left behind important **principles of care** by developing the **earliest health care institutions or hospitals** such as the Maristan in Granada (courtyards with medical facilities as well as places of commerce and refuge) within communities [23]. The principles in their delivery of care were holistic treatment, gentle care, pleasant areas, specialist units and outreach home visits. Accreditation of physicians, multi-denominational care and minimal religious control were either adopted or 'reinvented' in Europe.

Maimonides, 1135–1204 AC although Jewish and living in Spain under Arab rule, enjoyed the intellectual freedom afforded to them by their oppressors. His 'prayer' or code of practice aimed to remove all evil people who might 'frustrate the wisest purposes of our art'. He also 'willed himself to be open to improvement and instruction to benefit mankind' [24]. It is unlikely that all these historic codes would have developed without any communication with or understanding of the needs of neighboring communities and civilizations. In recent years, the World Medical Association and Board of Internal Medicine have developed codes in response to current needs.

2.4.3 Other Salient and Late Middle Age Events

The Crusades reflect the articulation of religion and war. The First Crusade was ordered by Pope Urban II in 1095 CE to retake Jerusalem after it had fallen first to the Sassanid Empire and then the Arabs under Umar. The Knights of St. John (Hospitallers) was founded in 1023 CE to tend to sick pilgrims and subsequently they came to be involved in the care of those injured during the Crusades [25]. The polarization of the Arab and Western world has never really recovered and the West has to a large extent forgotten the intellectual and medical debt which historically is owed to the Arab invasion of the Iberian Peninsula—the final common path of the passage and development of medical knowledge which started its long journey from origins in the East.

Travel and trade have often led to the introduction of disease and epidemics between communities which had previously not been in contact. Occasionally this was overwhelming and in the form of a pandemic when no related cross-immunity existed. Plagues inflicted on Egypt by the God of Israel are recorded all through the book of Exodus. More recently and well documented historically is the First Plague in Europe (541 AC). This was caused by fleas with rats as the intermediate 'host'. With ever increasing contact between countries through trade and travel, plagues became a feature of the Middle Ages. The next pandemic was in 1300 CE and known in Europe as the 'Black Death' [26]. Its path can be traced along the Silk Road from the East. The last major outbreak was in London was 1665 AC, a year before the Great Fire which may indirectly have helped eradicate the final traces of the plague by reducing the rat population. Interestingly, the pandemic caused by the corona virus which started in 2019 CE also seems to have started in the East and worked its way westward across the Globe—aided by international air travel and trade.

Following the First Crusade, leprosy was introduced into England by the returning Crusaders. Leper colonies had been developed in England after the disease was initially brought in by the Norman invaders. These colonies probably formed some of the first medical communities. After the Crusades, leprosy, again, became a problem and further colony to house and contain the sick in isolation were constructed. Examples of these are St John's Hospital in Oxford and St Nicholas Hospital near Canterbury Kent UK.

What is regarded as the **first general hospital in England** to look after patients with broad and various medical problems is St Bartholomew's Hospital founded in 1123 AC and attached to an Augustinian Priory in Smithfield, London. The Founder of the Hospital and first Prior of the associated Monastery was Rahere. He had become ill in Rome when on a pilgrimage. He must have been impressed with the provision of care for the sick which he had seen on his travels. This had undoubtedly benefitted from Arab influence. After a 'vision' Rahere vowed to found a hospital on his return to London if he was restored to health [27]. The resulting foundation is now about to celebrate the 900th anniversary of continuous clinical care.

The **invention of printing** by Johannes Guttenberg in 1440 was a development of enormous importance for the dissemination of general, professional and scientific information.

2.5 Modern Age (1493–1789)

The rediscovery of the person in the arts and the cultivation of the humanities denote the profile of the Modern Age. Its later phases involved the development of illustration and rationalism, which contributed to the bases of the French Revolution and the emergence of the Contemporary Age.

2.5.1 Impact of Travel and Publications

Without travel to and communication with countries and cultures leading to the sharing of ideas and knowledge, the delivery of care would inevitably stagnate. International travel by doctors has, for Centuries, been enormously beneficial in this respect. There are documented examples of academic pilgrimages made to Padua by Andreas Vesalius from Leuven as early as 1537 and William Harvey from Cambridge in 1599. It was there that they both sat at the feet of Hieronymus Fabricius who, in 1562, had revolutionized the teaching of anatomy with public dissection. This focused attention on the individual—muscles, nerves, bones and internal organs—rather than disease involving communities. It was not, however, until many years later following experiments with animals when back in England that Harvey developed his theory of the circulation of blood. By observation, he proved that blood flowed along veins which have one-way valves and 1628 his treatise *De Motu Cordis* on the circulation of blood was published. From such early examples, medical travel now embraces individual visiting fellowships and also conferences which allow a vital exchange of ideas and skills. Co-operative international initiatives encouraging travel to other countries including travelling fellowships and organizations such as *Medicine sans Frontiers* have been founded. This has led to an exchange of knowledge on the one hand and aid, instruction and community care to stricken communities on the other.

2.5.2 Influence of Religion and Churches

During the fifteenth century, the influence of the Churches on learning in general and medicine, in particular started to wane. A leader in this separation was Theophrastus Bombastus von Hohenheim—otherwise known as Paracelsus (1493–1541). He was the son of a Swiss Physician and considered to be almost a prophet by the German Rosicrucians. His ideas were defined as Paracelcianism. Although many of his prophesies were not fulfilled, he is often regarded as the father of modern medicine as, like Hippocrates, he rejected sacred magic and questioned religious orthodoxy.

By the sixteenth century, the impact of learning, observation and apprenticeship unfettered by the Church allowed medical practitioners to find an important place in society all over Europe. They formed Trade Guilds which oversaw training and standards. These often grew into professional bodies—as happened when the Barbers and Surgeons became united in London in 1540 under the guidance of Thomas Vicary. In 1800 it metamorphosed into a Royal College with a Royal Charter. An important example of a Barber-Surgeon practicing in France is that of Ambroise Paré (1510–1590) who had been apprenticed to his brother. His skills, as with many Islamic practitioners in earlier times, ranged widely from cataracts, bladder dysfunction and stones to arterial ligation—and, importantly, record keeping which now included illustrations.

Thomas Percival 1740–1804 was an English physician and health reformer who in 1803 wrote *Medical Ethics; or, a Code of Institutes and Precepts, Adapted to the Professional Conduct of Physicians and Surgeons*. He is said to have coined the term ‘medical ethics’ to describe moral correctness. He was also a pioneering campaigner in Manchester for public health measures, factory regulation and occupational health. He led a group of doctors who supervised textile mills. Their report influenced Robert Peel to introduce the *Health and Morals of Apprentices Act 1802*. This legislation stipulated that children could work for only 12 h a day. The workplace had to be clean and light, and inspectors admitted so that they could make suggestions about health and wellbeing. This underlined the importance of the person in any group whether that was a factory workforce then or a cohort in an evidenced based trial today. [28]

2.5.3 Further Advances in Medicine

A period of great advancement and discovery in medicine was ushered in from the seventeenth century onwards. This was a consequence of careful observation, measurement and classification made possible by many technical advances in unrelated fields such as optics. The development of the microscope was made possible as a result of the ability to make lenses and a knowledge of the physics of light waves. The first ‘compound’ microscopes—having an objective and an eyepiece lens appeared in Europe about 1620. These allowed Malpighi to observe and describe capillary vessels in 1661.

Herman Boerhaave (1668–1738 CE) was a Dutch physician who pioneered a quantitative approach to medicine by using a thermometer to measure the temperature of patients [29]. The recording of physical and chemical aspects of disease in patients by physicians has, since then, been and remains the cornerstone of diagnosis of disease in individual patients despite the growing importance of any circumstantial evidence from public health and epidemiology.

2.6 Contemporary Age (1789–Present)

The intellectual ferment leading to the French Revolution and its affirmation of Human Rights, which marks the beginning of the Contemporary Age, continued in an intensified and systematic manner in the ensuing centuries.

Of considerable impact for new developments was the severe outbreak of cholera near Broad Street in London from 1846 to 1860. John Snow (1813–1858) an English physician linked the outbreak to contaminated water [30]. This gave great impulse to the science of **epidemiology and public health**.

By 1719 Antonie van Leeuwenhoek in the Netherlands had refined the microscope sufficiently to see bacteria which led to great advances in **microbiology**. Edward Jenner developed the technique of **vaccination** for smallpox and introduced vaccination for Smallpox in 1796. The **French microbiologist Louis Pasteur** (1822–1895) made great advances in our understanding of **infection and fermentation** and is universally remembered for his work on the heat treatment of milk and wine below their boiling temperature to prevent fermentation.

Robert Koch (1843–1910) working in Germany identified the bacteria which caused tuberculosis, cholera, and anthrax. In so doing, he identified the **scientific criteria required to identify a particular micro-organism** with a specific infection—known as Koch’s postulates.

Joseph Lister (1827–1912) a British surgeon working in Glasgow translated the developing knowledge of bacteria and infection to his surgical practice and used a dilute carbolic spray to make the field of operation sterile which did not damage the tissues. The success of this led to surgeons introducing measures leading to **aseptic surgery** [31].

An expansion of surgical horizons followed the first public demonstration of the **anesthetic properties of ether** by William Morton in 1846 at the Massachusetts General Hospital in Boston. Anesthesia and pain control have been among the important developments in many branches of medicine—and it is tailored not only to the procedure but also to the person. The **discovery of blood groups** by Karl Landsteiner in 1901 **led to the practice of blood transfusion** and new horizons in surgery including extra-corporeal circulation and oxygenation.

The medical profession has always been quick to harness developments in scientific disciplines for its own purposes. Following **Wilhelm Roentgen's discovery of X-rays** in 1895 and **Marie Sklodowska Curie's demonstration of the therapeutic properties of radium**, a whole new field of therapy started with radiotherapy leading on to computerized tomography and body imaging. For developing the technique of axial tomography, Alan Cormack and Godfrey Hounsfield shared the Nobel Prize in 1979.

From the end of the nineteenth century, **Austrian neuro-psychiatrist Sigmund Freud pioneered the exploration of the unconscious**, with an enormous impact on psychology and many other fields. This revealed the importance of subjectivity, crucial in diagnostic assessment, and empathy of fundamental value for collaborative and person-centered care.

For the last 50 years **antibiotics** have been singularly effective in controlling many infections—most famously the first being penicillin originally found incidentally by Alexander Fleming in 1928. Developing resistance of organisms since then has provided challenges which the ingenuity of scientists have so far been largely able to meet. However, the effectiveness of antibiotics is becoming less certain as organisms mutate and adapt. Moreover, **virus infections** are now a real threat as global trade and travel allow mutant forms to cause serious epidemics and even pandemics across the globe as experienced in the **Coronavirus Covid 19 pandemic** from 2020 which strained the capacity of all the world's health systems.

Opening a crucial genomic era, if any proof were needed that individuals are unique and an expression of their ancestors, this was confirmed by the discovery in 1953 of the **double helix 'building blocks' of DNA by Francis Crick and James Watson**. Ultimately, the human gene project (HGP) was completed with the cooperation of several international laboratories in 2003. This offered greater insight and understanding not only of molecular medicine but also evolution. The genetic code of an individual as expressed in their DNA is a unique template which has been programmed by their ancestry. Any modification during the life of an individual will not only affect their own life but also serve as a blueprint for future progeny.

The introduction of scientific and experimental methodology into clinical medicine in the nineteenth century brought with it an increased demand for **experimentation on human subjects**, particularly in bacteriology, immunology, and physiology. This research was done mainly on patients in hospital, often without their consent, striving for the advancement of science and medicine. As a result of injury to some patients subjected to non-therapeutic research, however, controversy and public debate ensued about the ethics of human experimentation. The first regulations about non-therapeutic research in Western medicine came from the Prussian minister for religious, educational, and medical affairs in 1900. This led to the requirement for **informed consent** from the patient which confirmed not only the rights of an individual but also the unassailable dignity and importance of each person requiring medical attention [32].

The **World Medical Association**, in 1948 incorporated the **principles of Hippocratic Medicine into its *Declaration of Geneva***, and set **ethical bases for research on human subjects in its Declaration of Helsinki** in 1964, which is regularly updated and has emerged as the most respected ethics reference for medical research [33].

Health Systems are attracting considerable interest advances in medicine have caused escalating costs of health care which many governments have not felt able to afford for all their populations and new management systems have been introduced. These are changing the traditional relationship between the patient as a person and the physician by introducing differing 'priorities'. Some rationing of primary care has been rather myopically seen as an affordable way forward. Also of importance, burn-out phenomena are being seen not only as indications that individual health professionals need to take better care of their own health, but also the responsibility of health systems in neglecting and abusing their employees [34].

The principles of **Primary Health Care** were first outlined in the ***Declaration of Alma-Ata*** by the World health Organization in 1978, which was a seminal milestone in global health [35]. Forty years later, global leaders reaffirmed those principles at the *Global Conference on Primary Health Care in Astana*, Kazakhstan in October 2018.

Health Care in the view of some health planners aims to provide an agreed level of services to those in the state or country within their jurisdiction. This was judged to be the most efficient and effective way to achieve a certain standard of uniform care in a community when there was a limited budget. In some countries, this has not been able to keep pace with the new and expensive investigations and treatments continually being introduced. Any limitations in the overall funding and delivery of Primary Health Care mean that the resources available must be targeted to individual patients with greater efficiency. Considerations must include a person's health needs throughout life, the benefits of multidisciplinary treatment, and the empowering of individuals, families and communities to take charge of their own health.

Care should be provided *in* the community as well as *through* the community. The concept of Primary Health Care addresses not only the needs of the individual and family health, but also the broader issue of Public Health in defined communities or populations. Tejada de Rivero [36] a Peruvian physician and one of the architects of the Alma Ata Declaration has recently cogently argued that the **real meaning of "primary care" is *integral care of all for all***.

Prologuing paradigm **changes in the twentieth century,** conflicts have often been a catalyst for developments in medical treatment. John Hunter addressed the problems of gunshot wounds in 1761. In the First World War 1914–1918, the importance of triage in field hospitals and the introduction of portable blood transfusion kits by Geoffrey Keynes helped to reduce the massive loss of life on the battlefield. Afterwards great and overdue social changes took place. The effects were aggravated by the Influenza pandemic of 1919. Amongst intellectual social philosophers, eugenics and renewed nationalism became dominant themes.

Reacting to considerable personal and professional turmoil, **Paul Tournier** (1898–1986) a family physician in Geneva elevated his way of practicing medicine by engaging creatively his patients and exploring the context of their underlying difficulties and the prospects for enhancing their health holistically and spiritually. Tournier [37] first book *Médecine de la Personne* outlined his vision of an integrated body/mind/spirit framework for understanding and healing. This embraced psychodynamic and developmental aspects as well as broad theological concepts. The approach can be applied to all healthcare situations and is limited only by a lack of empathy and communication with the patient. Tournier's thinking was widely disseminated through his writings and at international conferences. In order to encourage wide discussion, he formed in 1947 an International Study Group on Medicine of the Person. This group met annually and is still active today in Switzerland, United Kingdom, United States, Germany and France. Tournier's ideas have continued to influence the present day work of the International College of Person Centered Medicine.

During the period following the Second World War, involving efforts at social and ethical introspection, an influential American psychologist and educator, **Carl Rogers** (1902–1987) independently developed his own unique person-centered approach to understanding personality and human relationships. He was, therefore, an early promoter of a humanistic approach to psychology, psychotherapy, person-centered counselling and student-centered education. An individually targeted relationship between patient and professional carer is critical in helping people make changes in their lives. It is not the therapist that changes the person, nor the person that changes by one self; it is the relationship *between* the two individuals that allows change to occur. Rogers believed that an ideal relationship between therapist and patient was built on three elements, the first being a mutual empathetic understanding. He also believed that the inability to communicate is a result of a failure to listen effectively. Secondly, that their thoughts, feelings and actions should be in close alignment and thirdly, that there should be an unconditional and positive mutual regard [38, 39].

As a reaction to reductionistic Flexner [40] scientific medical education model and "evidence-based-medicine" [41] clinical model, and the often dehumanized and commercialized organization of health services, more encompassing models that articulate science and humanism have emerged under the general term of person centered medicine.

More broadly and historically, the **emergent paradigm on person-centered medicine**, may be traced back to how medicine was conceived and practiced in ancient civilizations and through the present time, including efforts to redress contemporary reductionist distortions in clinical medicine and public health. With a sense of paramount ethical commitment, many leaders in medicine have recognized the interdependency of science and humanism and reaffirmed a medicine of the person, for the person, by the person, and with the person. Recent systematic explorations of person centered care have identified as key concepts in addition to its ethical imperative: a holistic framework to understand health and illness, cultural awareness and responsiveness, a communicational and relationship focus at all levels, individualization of care, establishment of common ground among clinicians, patient and family to arrive at and formulate a joint diagnosis and shared care decisions, people-centered organization of integrated care, and person-centered health education and research.

The collaborative construction of person centered medicine has been unfolding over the past two decades. In 2005 the World Psychiatric Association (WPA) established a broad institutional program on Psychiatry for the Person, building on the articulation of science and humanism as the essential joint motivation for the organization and work of WPA since its foundation in 1950 [42]. This initiative was later extended to medicine at large in close collaboration with the World Health Organization, the World Medical Association, the International Council of Nurses, and the International Alliance of Patients' Organizations, among a number of other international health institutions [43]. From a process of annual Geneva Conferences on Person Centered Medicine since 2008 emerged an International Network and then an International College of Person Centered Medicine. Step-wise maturation of this process has led to the establishment of an International Journal of Person Centered Medicine, the organization of International Congresses in different corners of the world complementing the Geneva Conferences, and the publication of Declarations extending the work and impact of Conferences and Congresses [34, 44, 45].

2.7 Articulating Person Centered Medicine Concepts and Historical Eras

The narrative historical overview of Person Centered Medicine presented in the previous sections within the intricacies and complexity of the general framework of the history of medicine, is now complemented in Table 2.1 by a schematic display attempting to present a more specific unfolding of Person Centered Medicine and some of its key features along historical eras.

Table 2.1 reveal very early antecedents of PCM in the form of the crucial nature of care by social support groups for the maintenance and restoration of a person's health, documented since Neanderthal's Pre-historical times [1]. During the ensuing Early History era, virtually all ancient Eastern and Western civilizations exhibited personalized or person-centered concepts of health and healthcare [46].

In the Middle Age, the Golden Era of Islamic Medicine revealed the attentive and considerate attention dispensed to ill persons to promote their well-being, as

Table 2.1 Historical unfolding of Person Centered Medicine and Health

		Principles of person-centered medicine and health							
Historical periods	Broad person-related life and health concepts	Ethical commitment	Holistic framework	Cultural awareness and responsiveness	Relationships and communication	Collaborative diagnosis and care	Individualized care	People-centered health systems	Person-centered education and research
Pre history (up to 4000 years BC) *Neanderthals*	Social care as essential for life and health [1]	Social responsibility for care [1]			Social relations crucial for care [1]	Care based on social collaboration [1]		Articulation of social support and healthcare [1]	
Early history (Since 4000 BC) *Chinese, Ayurvedic, Hellenic, Andean, African Ubuntu Civilizations*	Ethical, personalized, integrative and collaborative approach to healing and care [18, 46]	Ethical concerns in all ancient civilizations, living well by caring for each other [18, 46]	Holistic understanding and care [18, 46]	Community-based personal identity [18, 46]	Common ground for living, becoming persons through other persons [18, 46]		Individualized healing [18, 46]		
Middle age (since 476 AC, fall of Western Roman Empire) *Islamic World, Europe*	Benevolence and equity in Islam counselling and hospitals. Avizenna and Razzes represented the medical golden age [47, 48]	Concern for well-being, equity and humane care [48]						Emergence of world's first hospitals, which emphasized gentle humane care [47, 48]	

(continued)

Table 2.1 (continued)

Historical periods	Broad person-related life and health concepts	Principles of person-centered medicine and health							
		Ethical commitment	Holistic framework	Cultural awareness and responsiveness	Relationships and communication	Collaborative diagnosis and care	Individualized care	People-centered health systems	Person-centered education and research
Modern age (since 1493 AC: fall of Eastern Roman Empire) *Renaissance* *Illustration*	Rediscovery of the person in the arts, and cultivation of the humanities, illustration and rationalism, eponymized by Spinoza [49]								Systematization of knowledge of life and health [50]
Contemporary age (since 1789 AC) *A. Late XVIII C Through XIX C* *French Revolution* German Philosophy	Affirmation of human rights by the French Revolution, and foundations of human nature and dignity through German philosophers [51–53]	French Revolution's Universal Declaration on Human Rights Kant [51] the person is always an end not a means Percival's Medical Ethics [28]							

Table 2.1 (continued)

Historical periods	Broad person-related life and health concepts	Principles of person-centered medicine and health							
		Ethical commitment	Holistic framework	Cultural awareness and responsiveness	Relationships and communication	Collaborative diagnosis and care	Individualized care	People-centered health systems	Person-centered education and research
B. XX century	Early person-centered formulations on contextualization [54], personal healing and spirituality [37] and broad person-centeredness [38, 39]. World Medical Association [55, 56] ethical codes	Paul Tournier's service to others and spirituality; humanistic and ethics response to Flexner [40] scientific medical education, World Medical Association's [55, 56] Geneva Declaration on Ethical Oath and Helsinki Declaration on Medical Research ethics	Holistic broadness and integration [37, 38, 54]		*I am I and my circumstance;* Ortega y Gasset' [54]; engaging persons Tournier [37]				Rogers [38] and Rogers and Rosemberg [39] (becoming a person, and the person as center)

(continued)

Table 2.1 (continued)

Historical periods	Broad person-related life and health concepts	Principles of person-centered medicine and health							
		Ethical commitment	Holistic framework	Cultural awareness and responsiveness	Relationships and communication	Collaborative diagnosis and care	Individualized care	People-centered health systems	Person-centered education and research
C. XXI Century	Central concepts of Person-Centered Medicine (PCM) involves the recognition of the person as the center of health and the goal and protagonist of health actions Reaction to Flexnerian [40] and EBM [41] reductionist models, through a balanced articulation of science and humanism	Ethical commitment as foremost PCM principle [57, 58]	Holistic and dynamic concept of well-being [59]	Kirmayer et al. [60] cultural awareness and responsiveness	Van Dulmen and van Bijnen [61] communication in healthcare	Crucial role of common ground [62, 63]	Individualized care [64]	PCM and [35] people-centered and integrated health systems; health goal in terms of healthy lives and well-being for all, connected to the other 16 goals [65], sustainable development goals	Centering on the person crucial support activities on health education, training and research [66]

epitomized by the architecture and landscape of some of the world's earliest hospitals built in that era [47].

During the Modern Age, first, the revelation of the person in the arts, and then the cultivation of the humanities through *illustration and rationalism*, as eponymized by Spinoza [49] demonstrated high concern for the flourishment of human beings. At the same time, major explorations were made of the systematic understanding of the natural world, as illustrated by the detailed taxonomies primarily of plants and animals, but also of human diseases in Linnaeus [50] systematization work.

The Contemporary Age is divided in Table 2.1 into three phases. The first one from late eighteenth century to the end of the nineteenth century has as highlights, first, the French Revolution and its Declaration of Human Rights, and second, German Philosophy on ethics, particularly through Emmanuel Kant's [51] categorical imperative affirming the person as always a goal, not a means.

The second Contemporary phase, covering the twentieth century, exhibits early person-centered formulations, highlighted by Jose Ortega y Gasset's [54] dictum I am I and my circumstance, and if I do not save it, I do not save myself, by the books of Tournier [37], starting with *Medicine of the Person*, and by Rogers [38] and Rogers and Rosemberg [39] person-centered approaches to education and psychotherapy, especially *Becoming a Person* and *The Person as Center*. All this took place at the same time as the massive development of scientific medicine, with its hyperbolic interest on organs and diseases, which led to striking advances in diagnosis and treatment.

The third Contemporary phase involving the present twenty-first century, has seen a fuller development of Person Centered Medicine both as a concept and as a programmatic collaborative movement, including the elucidation of eight principles (ethical commitment, holistic framework, cultural awareness and responsiveness, relationship and communication focus, individualized care, common ground for collaborative diagnosis and care, people-centered and integrated health services, and person-centered health education and research) from which measuring procedures have evolved [58]. This paradigmatic perspective also represents a theoretical articulation of science and humanism as a balanced contrast to reductionist evidence-based medicine Sackett et al. [41] and Flexner's [40] medical education models as well as to dehumanized and commercialized health systems.

2.8 Conclusions

This overview of the historical development of medicine in general and person centered medicine in particular have shown the special place of the *person* throughout such development. The historical analysis has travelled from pre-historical times, to early history involving ancient Eastern and Western civilizations, to the Middle Age, the Modern Age, and discernible phases of the Contemporary Age. The analysis has intended to illustrate in the main body of this manuscript the complexity and intricacies of the longitudinal unfolding of medicine in relation to recognized historical eras and the multiplicity of influential national, regional, political and migratory factors as well as the emergence and inter-play of concepts, experimental discoveries, and organization of services in medicine and health.

A more focused and tabular analysis of the unfolding of the broad concepts and what could be considered as eight principles of *person centered medicine* across the tenets of the historical eras listed above was quite revealing of the fundamental place of the person at the center of medicine and how much we can learn from such historical analysis. At the outset, the pre-historic Neanderthal era strongly suggests the crucial role of social mutual care for the protection and promotion of life and health among our remote antecessors. An appraisal of Early History documents the personalized concept of health throughout both Eastern and Western ancient civilizations. A highlight here may be the encompassing concept of health in the Andean cosmovision as harmonic equilibrium among the internal, social and natural worlds, which appear to resonate in several other ancient civilizations. Of particularly illuminating value for person centered medicine are the discernible coincidences in that Era on the concepts of life well lived, *eudiamonia* in Aristotelian ethics and *allyn kawsay* in the Andean worldview. Inter-connecting eras, the fundamental intrinsic value of the *encounter between persons* in African *Ubuntu* humanism may remind us of the mutuality of social support for health among Neanderthals.

Also emerging from the above analyses is the presence of broad person centered medicine concepts in all historical eras. Among the specific eight principles of person centered medicine, ethical commitment was the most frequently present across eras, attesting to its wide historical scope and conceptual depth. Next in presence were relationship focus, holistic framework, and people-centered organization of services, all individually and groupally highly distinctive of person centered medicine.

Elucidated furthermore in these analyses are historical pearls of enormous significance for present and future concerns. One is the crucial value of mutual social support for healthcare noted among Neanderthals which argues that the contemporary drive for universal health must be both a right and a responsibility. Another is that the wide holistic framework needed for understanding health and projecting health actions should include an ecological dimension (as in the traditional Andean concept of health as harmonic equilibrium among our internal, social and natural worlds). These considerations and the historically anchored broad concepts and specific principles of person centered medicine emerge as highly relevant and promising for responding effectively to the major global challenges such as pandemics and climate change that we confront as human species.

Acknowledgements and Disclosures The authors do not report conflicts of interest in the preparation of this manuscript.

References

1. Spikins P, Needham A, Tilly L, Hichens G. Calculated or caring: Neanderthal healthcare in social context. World Archeol. 2018;50(3):384–403.
2. Chase PG. The emergence of culture. New York: Springer; 2006.
3. Graf F. Magic in the ancient world. Cambridge: Harvard University Press; 1997.
4. Singman JL. The middle ages. New York: Sterling; 2013.
5. Christodoulou GN. Psychosomatic medicine, past and future. New York: Plenum Press; 1987.
6. Gross CG. The neuroscientist. Thousand Oaks: Sage; 1999.
7. Lu GD, Needham J. Celestial lancets. London: Routledge; 2002.
8. Motoo Y, Seki T, Tsutani K. Traditional Japanese medicine. Chin J Integr Med. 2011;17:85–7.
9. Edwards C. The Hammurabi code. London: Watts; 1921.
10. Flood G. Introduction to Hinduism. Cambridge: Cambridge University Press; 1996.
11. Bertman S. Life in ancient Mesopotamia. Oxford: Oxford University Press; 2005.
12. Lane Fox R. The invention of medicine: from Homer to Hippocrates. London: Allen Lane Penguin Radom House; 2020.
13. Beauchamp TL, De Grazia D. Principles and principlism. In: Khushf G, editor. Handbook of bioethics. Heidelberg: Springer; 1978.
14. Bartlett RC, Collins SD. Nicomachean ethics. Chicago: University of Chicago Press; 2012.
15. Ierodiakonou C. Medicine as a model of Aristotle's ethics and his person-centered approach. Int J Person Cent Med. 2014;4:31–4.
16. Alvarado D. Una comprensión andina del cuerpo. Lima: Ediciones Multigrafik; 2019. p. 31–49.
17. Varese S (2018) Los fundamentos éticos de las cosmologías indígenas, Amérique Latine Histoire et Mémoire. Les Cahiers ALHIM 36
18. Gade CB. The historical development of the written discourses on Ubuntu. S Afr J Philos. 2011;30(3):303–29.
19. Frye RN. The Cambridge ancient history. Cambridge: Cambridge University Press; 2005.
20. MacDonald G. Bulletin of Institute of Classical Studies, vol. 114. Oxford: Oxford University Press; 2014.
21. Bennison AK. The great caliphs: the golden age of the Abbasid Empire. Yale: Yale University Press; 2009.
22. Rahman SA. Islamic Spain. Noida: Goodwood Books; 2001.
23. Al-Ghazal SK (2021) Bimaristans in Islamic medical history. Aboutislam.net Newsletter
24. Rosner F. The Physicians' prayer. Bull Hist Med. 1967;41:51.
25. Boas AJ. Jerusalem in the time of the Crusades. London: Routledge; 2001.
26. Ziegler P. The black death. New York: Penguin Google Books; 1998.
27. Medvei VC, Thornton JL. The Royal Hospital of St Bartholomew, London, 1974
28. Haakonssen L. Medicine and morals in the enlightenment. Amsterdam: Editions Rodopi; 1997.
29. Underwood EA. Boerhaave after three hundred years. Br Med J. 1968;4:820.
30. Snow J. On the mode of communication of Cholera. London: Churchill; 1849.
31. Metchnikoff E. The founders of modern medicine: Pasteur, Koch, Lister. New York: Freeport; 1939.
32. Lederer SE. Subjected to science. Human experimentation in America before the second world war. Baltimore: Johns Hopkins University Press; 1995.
33. Vollmann O, Winau R. Informed consent in human experimentation before the Nuremberg code. BMJ. 1996;313(7070):1445–9.
34. Cloninger CR, Salvador-Carulla L, Kirmayer LJ, Schwartz MA, Appleyard J, Goodwin N, Groves J, Hermans MHM, Mezzich JE, van Staden CW, Rawaf S. A time for action on health inequities: foundations of the 2014 Geneva declaration on person- and people-centered integrated health care for all. Int J Person Cent Med. 2014;4:69–89.
35. WHO. Primary health care. Report of the International Conference on Primary Health Care Alma-Ata USSR. Geneva: WHO; 1978.

36. Tejada de Rivero DA. What is primary health care: some considerations almost thirty-five years after Alma-Ata. Rev Peru Med Exp Publ Health. 2013;30:283–7.
37. Tournier P. Médicine de la Personne. Neuchatel: Delachaux et Niestle; 1940.
38. Rogers CR. On becoming a person: a therapist's view of psychotherapy. Boston: Houghton Mifflin; 1961.
39. Rogers CR, Rosemberg RL. La Persona como Centro. Traducido del portugués. Barcelona: Herder; 1981. p. 253.
40. Flexner A. Medical education in the United States and Canada. A report to the Carnegie foundation for the advancement of teaching. New York: Carnegie Foundation; 1910.
41. Sackett DL, et al. Evidence-based medicine: what it is and what it isn't. BMJ. 1996;312:71.
42. Mezzich JE. Psychiatry for the person: articulating medicine's science and humanism. World Psychiatry. 2007;6:65–7.
43. Mezzich JE, Snaedal J, Van Weel C, Botbol M, Salloum IM. Person centered medicine: from concepts to practice. J Eval Clin Pract. 2011;17:2.
44. Christodoulou GN, Mezzich JE, Cloninger CR, Christodoulou N, Villar E, Appleyard J, Botbol M. Promoting healthy lives and well-being for all: the contribution of the International College of Person Centered Medicine (ICPCM). Psychiatriki. 2018;29(1):52–7.
45. Mezzich JE. Ten years of construction of person- and people-centered medicine and health. Int J Person Cent Med. 2017;7(4):200–4.
46. Heise T, Villar-Lopez M, Salaverry O. Person-centered traditional medicine. In: Mezzich JE, Appleyard J, Glare P, Snaedal J, Wilson R (eds) Person centered medicine. Springer, Cham, in press.
47. Abou-Saleh MT, Salloum IM. Bimaristan Arghun Al-Kamili in Aleppo, Syria: a mental hospital with unique architecture designed to meet patient need in Medieval Islam (1354 AD). Arab J Psychiatry. 2020;31(2):191–5.
48. Haddad SI. History of Arab medicine. Beirut: Bouheiry Brothers; 1975.
49. Spinoza B. Éthique. Trad de B Pautrat. Paris: Seuil; 2003.
50. Linnaeus C. Genera plantarum. Sweden: Upsala; 1737.
51. Kant I. Critique of practical reason. Transl. Werner Pluhar. Indianapolis: Hacket Publishing Company; 2002.
52. Heidegger M. Being and time. New York: Harper Collins; 2008.
53. Scheler M. El puesto del hombre en el cosmos. Buenos Aires: Losada; 2003.
54. Ortega y Gasset J. Meditaciones del Quijote. Obras Completas de José Ortega y Gasset, vol. 1. Madrid: Editorial Santillana; 1914. p. 745–825.
55. World Medical Association. Geneva declaration: physician's oath. Geneva: Author; 1948.
56. World Medical Association. Helsinki declaration: recommendations guiding doctors in clinical research. Helsinki: Author; 1964.
57. Mezzich JE, Appleyard WJ, Botbol M, Ghebrehiwet T, Groves J, Salloum I, Van Dulmen S. Ethics in person centered medicine: conceptual place and ongoing developments. Int J Person Cent Med. 2013;3:255–7.
58. Mezzich JE, Kirisci L, Salloum IM, Trivedi JK, Kar SK, Adams N, Wallcraft J. Systematic conceptualization of person centered medicine and development and validation of a person-centered care index. Int J Person Cent Med. 2016;6:219–47.
59. Cloninger CR, Salloum IM, Mezzich JE. The dynamic origins of positive health and wellbeing. Int J Person Cent Med. 2012;2:179–87.
60. Kirmayer LJ, Bennegadi R, Kastrup MC. Cultural awareness and responsiveness. In: Mezzich JE, Botbol M, Christodoulou GN, Cloninger CR, Salloum IM, editors. Person centered psychiatry. Heidelberg: Springer; 2016.
61. Van Dulmen A, van Bijnen A. What makes them (not) talk about proper medication use with their patients? An analysis of the determinants of GP communication using reflective practice. Int J Person Cent Med. 2011;1(1):27–34.

62. Mezzich JE, Salloum IM, Cloninger CR, Salvador-Carulla L, Kirmayer L, Banzato CE, et al. Person-centered integrative diagnosis: conceptual bases and structural model. Can J Psychiatr. 2010;55:701–8.
63. Botbol M, Adams N, Mezzich JE. Establishing common ground, engagement, and empathy in person centered care. In: Mezzich JE, Appleyard J, Glare P, Snaedal J, Wilson R (eds) Person centered medicine. Springer, Cham, in press.
64. Salloum IM, Appleyard J, Abou-Saleh MT. Individualized care in person centered medicine. In: Mezzich JE, Appleyard J, Glare P, Snaedal J, Wilson R (eds) Person centered medicine. Springer, Cham, in press.
65. United Nations. Sustainable development goals. New York: Author; 2015.
66. Hauck S, Salvador-Carulla L, Perales A, Saavedra J, Salcedo C, Martins Bastos T. Person-centered health education and research. In: Mezzich JE, Appleyard J, Glare P, Snaedal J, Wilson R (eds) Person centered medicine. Springer, Cham, in press.

Chapter 3
Ontological and Epistemological Bases of Person Centered Medicine

Tim Thornton

3.1 Introduction

The precise nature of Person Centered Medicine (PCM) is contested. What are its implicit contrasts? Person versus patient or person versus sub-personal body part, for example? What are its essential features? Does it presuppose a specific set of person-level *values*? Such potential choices and conflicting claims, addressed in other chapters of this book, have consequences for articulating the bases of PCM.

'Base' itself suggests two meanings. It may mean the explicit justification or rationale for advancing PCM. Here, a more minimal reading is offered and the main work of justification is left for other chapters. The 'bases' of PCM are taken to be its presuppositions: specifically, the kinds of ontological and epistemological claims it *presupposes* to be true. As will become clearer, however, this does offer some partial account of its rationale, too.

However its precise nature is articulated, PCM assumes the following broad claims. Ontologically, the level of the person is an irreducible and significant feature of ontology and a proper focus for healthcare. Epistemologically, not only is knowledge of the human person (human beings, people) possible and significant in healthcare, there are also irreducible forms of person-level knowledge which are important to healthcare. A commitment to PCM is thus a substantive commitment to ontological and epistemological claims. These commitments will be examined in turn. At the end, other possible necessary elements will be considered.

T. Thornton (✉)
Philosophy and Mental Health, University of Central Lancashire, Preston, UK
e-mail: TThornton1@uclan.ac.uk

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_3

3.2 Objectives

The aim is to clarify the implicit conceptual or philosophical commitments (in ontology and epistemology) of subscribing to PCM. One key premiss is that to subscribe to PCM is to assume the genuine existence of persons, for example. A fully worked out account of that commitment might require a completely satisfactory philosophical analysis of 'person' and refutation of all rival accounts. But that is an unrealistic account of what is required to support PCM. This short chapter will restrict itself to the sort of claims presupposed for PCM. A full philosophical defence of PCM might be possible but would also require narrowing down a precise specification of what PCM is. The aim here is more modest but therefore of broader application to a range of views of what PCM involves.

3.3 Approaches to Fulfil the Objectives and Knowledge Base #1: The *Ontological* Presuppositions of PCM

At the very least, PCM presupposes the existence of persons. Further, it assumes that the 'level' of the person is important and irreducible in healthcare. That is, truths about persons are not reducible without loss to truths at a more basic level, such as the biochemical functioning of the body and its parts. If such truths were reducible, there would be no need to complement or contrast conventional biomedical approaches with something distinct. PCM would be subsumed by a biomedical view of healthcare.

PCM need not reject the importance of bio-medical medicine so much as complement it. A proper knowledge of the functioning of bodily systems seems to be an essential feature of anything recognisable as general *medicine* by contrast, for example, with healthcare disciplines that focus solely on specific forms of mental pathology or distress, such as psychotherapy. On the other hand, to count as *person* centred, PCM must resist the claim that the concept of the person reduces without loss into a set of component bodily systems.

Given the success of modern science in explaining larger systems by decomposing them into the behaviour of smaller scale, simpler systems, what would rationalise the presupposition that the person is a basic feature of ontology and irreducible to smaller scale biology?

One once influential answer—and a helpful illustration here—is provided by Cartesian substance dualism. Descartes' own account of the bulk of the natural world was that of a mechanical 'plenum': a packed world of direct causal pushes and pulls. Responding to the rise of mechanical natural philosophy—corresponding with the rise of modern science—Descartes assumed that mechanical models would apply very generally. At the same time, however, he exempted the mind from this domain. His dualism divides the world into two realms of different sorts of substance: res extensa—the domain of direct causal interaction within a spatial realm—and res cogitans, the non-spatial mental realm. Despite this distinction, the mental realm appears to be modelled on the mechanical philosophy in one sense: mental states are free-standing states, acting as though akin to causal factors [1, pp. 237–243]. This is one of the features that makes accounting for everyday mental phenomena difficult: for example, the capacity for thoughts to be relational rather than free-standing, *about* things, to possess 'intentionality [ibid: 242–243]. If thoughts are free standing items in an inner realm, how can they be about anything, in the outer realm? Another is the problem Descartes himself recognised of accounting for the apparent interaction of the mental and extended realms.

If those objections are put to one side for the moment, however, Cartesian substance dualism would provide a rationale for PCM by explaining one of its presuppositions. Substance dualism implies that persons—possessors of both mental and physical attributes—cannot be entirely made of extended matter. The mental belongs to a distinct non-bodily realm. But subscription to what now seems an outmoded approach to the mind would be a high price to pay for subscribing to PCM. So if not that, why else might one take the concept of the person to be irreducible?

One lesson of academic philosophy of mind since the 1970s is that there are many (apparently or epistemically) possible models of the relation of mind and body [2, p. 653]. At one end of a spectrum is substance dualism. At the other is eliminativism: the view that there are no mental states because the mental is a failed theory of the physical and should be eliminated. Between are varieties of forms of property dualism, more or less closely tethered by supervenience (an asymmetric relation of dependence), and reductionist physicalism (the view that the mental can be reduced without loss to physical descriptions). Thus, a commitment to PCM requires a rejection of eliminativism and reductionist physicalism but leaves open a variety of other ontological positions. But what might motivate that choice however precisely it might be realised?

Within analytic philosophy of mind, two main lines of argument have been stressed. One concerns the irreducibility of the qualitative aspects of mental states and experiences: their qualia. One such argument is Frank Jackson's thought experiment concerning Mary the neuroscientist, locked in a black and white room but knowing the full physics and neurophysiology of colour vision [3]. Surely, runs the line of thought, she learns something new when presented for the first time with a red object? But if so, there is at least one fact to be learnt—what red looks like to the conscious mind—that cannot be captured within physical and neurophysiological theory. So reductionism of the mental to the physical is false.

A second line of argument, associated with Donald Davidson, concerns the irreducibility of the structure of rationality to mere lawlike relations between natural events [4, pp. 229–244]. On the twin assumptions that the mental is essentially tied to rationality, and that rationality cannot be codified into any structure of laws and hence captured in physical theory, then the mental is irreducible to physical properties.

Such arguments—or the premises of such arguments however precisely formalised: the appeal to qualia or to rationality—supply plausible motivations for subscribing to a view of the irreducibility of the mental to something physical of bodily. But that is not yet to say that the notion of a person is specifically of importance. What of the centrality of the person?

There is a line of thought in philosophy dating back to David Hume which would motivate scepticism about its importance, even while conceding the importance of the mental. Hume presents an argument that focuses on the nature of the *self* as something mental able to unify (mental) experiences as the experiences of a particular subject. Hume suggests that an introspective search for such a self, as the subject of thoughts and experiences, yields nothing.

> For my part, when I enter most intimately into what I call myself, I always stumble on some particular perception or other, of heat or cold, light or shade, love or hatred, pain or pleasure. I never can catch myself at any time without a perception, and never can observe anything but the perception…. If anyone, upon serious and unprejudiced reflection, thinks he has a different notion of himself, I must confess I can reason no longer with him. All I can allow him is, that he may be in the right as well as I, and that we are essentially different in this particular. He may, perhaps, perceive something simple and continued, which he calls himself; though I am certain there is no such principle in me [5, p. 252].

Hume's final comment is clearly meant to be ironic. Introspection, Hume suggests, reveals nothing that could stand in the sort of relation to one's mental states that a self is supposed to do. This leads him to advocate a minimalist 'bundle theory' of mind. The self is identified simply with the mental states encountered in introspection and not with an ego which stands in some ownership relation to them. Philosophers since Hume have adopted a variety of responses that concede the basic point. Daniel Dennett argues that the self is an abstraction: a narrative structure of mental states. 'A self is also an abstract object, a theorist's fiction' [6]. Others have denied the existence of self in favour of underlying neurological structures [7–9].

There is, however, a conflicting line of thought dating back to Kant that grants an important basic status to the person. The philosopher Peter Strawson offers an explicitly Kantian account [10, 11]. To earn the right to the idea that experiences are unified as the experiences of a particular subject (a person), there has to be some way to specify or identify that subject. Without some such criteria, the idea of a single subject is vacuous. But as Hume's description of introspection reveals, conscious experience does not yield any criteria to identify a subject (or owner) for one's experiences. It reveals only the experiences themselves. From this, Hume concludes that there is no substantial self. But there are criteria for the identification of a subject available elsewhere: third-person criteria for the ascription of experiences to fellow human beings on the basis of what they say and do.

Strawson suggests that these can provide substance to the idea of a self even though they are not appealed to in self-ascriptions of experiences. This is because, while self-ascription of experiences is made without any appeal to these (or any other) criteria to identify a subject, it is still made in accord with them. As Strawson puts it, 'The links between criterionless self-ascription and empirical criteria of subject-identity are not in practice severed' [11, p. 165]. Thus, it is because we are identifiable from a third person perspective as embodied subjects located within the world that we can also self-ascribe experiences without appeal to, but still in accord with, those criteria. The third-person criteria substantiate the idea of a subject.

Strawson goes on to argue that the person is a basic feature of ontology. Persons have, essentially, both physical and mental predicates. It is this combination that underpins the kind of subjective perspective to which Hume appeals but which cannot, by itself, constitute a self. As the contemporary philosopher John McDowell puts it:

> The alternative [to a purely mental construal of the self as subject of experience] is to leave in place the idea that continuity of "consciousness" constitutes awareness of an identity through time, but reject the assumption that that fact needs to be provided for within a self-contained conception of the continuity of "consciousness". On the contrary, we can say: continuous "consciousness" is intelligible (even "from within") only as a subjective angle on something that has more to it than the subjective angle reveals, namely the career of an objective continuant with which the subject of the continuous "consciousness" identifies itself. The subjective angle does not contain within itself any analogue of keeping track of something, but its content can nevertheless intelligibly involve a stable continuing reference, of a first person kind; this is thanks to its being situated in a wider context, which provides for an understanding that the persisting referent is also a third person, something whose career is a substantially traceable continuity in the objective world [12, p. 363].

This is not to suggest or justify the claim that a Kantian account of the nature of the person and a Strawsonian justification of its ontologically basic status is a necessary presupposition of PCM. But it provides a worked example of the kind of account to which PCM is committed: to the existence and importance of persons as a basic feature in ontology.

3.4 Approaches to Fulfil the Objectives and Knowledge Base #2: The *Epistemological* Presuppositions of PCM

Just as PCM presupposes that the person is a proper part of ontology—an irreducible level of description of the natural world—so it also carries epistemic presuppositions. Centrally, it is possible to have *knowledge* of persons. To clarify this point, think of the more normal English plural. It is possible to have knowledge of *people*. Well of course it is! But a biomedical perspective that explicitly rejected the principles of PCM would still claim knowledge of the bodies, of their functions and dysfunctions, of people. Thus, to arrive at a presupposition that marks PCM out as a distinct substantive and potentially contentious approach, it is necessary to say something more. It is not just that knowledge of persons is possible, for example, of their bodies, but that knowledge of persons or people *as persons* is possible. What might be the characteristic content of such person-specific knowledge?

The previous section, however, mentioned one way to substantiate just such a claim. Descriptions of mental phenomena answer to a distinct constitutive principle that 'finds no echo in physical theory': the Constitutive Ideal of Rationality [4, p. 223]. To adopt a different metaphor: even without subscribing to a dualism of *substances* (mental and physical), one might still recognise a distinction between two *conceptual* spaces or modes of intelligibility: the space of reasons and the realm of law [13]. The former has application at the level of the person and captures a normative or evaluative character in the assessment of reasons for belief or action. One of the features that mark out persons or people from other objects of scientific scrutiny is that people, unlike planets or atoms, act for reasons or motives or to further goals or interests and they can be successful or fail in the attempt. This introduces a normative dimension—a dimension of correctness or incorrectness, good or bad—that is missing from basic physical sciences. Thus, part of the way in which PCM earns the right to claim a *sui generis* level of knowledge of persons *as persons* is to commit to the importance and irreducibility of placing subjects in the 'logical space of reasons'.

This link opens up connections to other areas often taken to be part of PCM when less minimally approached. (Recall that this chapter has adopted a minimal approach to what PCM requires in order to explore the central ontological and epistemological presuppositions of *any* plausible view of PCM.) The space of reasons is also the space of values. Thus, any version of PCM that argues for the moral and ethical consequences or presuppositions of treating patients as persons will have to trade in this space: the space of evaluating the Good and the True.

But while sketching the logical space of knowledge of persons *as persons* helps show the nature of the ambition for PCM it does not address one specific worry that, while philosophically-influenced, can occur in reflective moments inspired by everyday life. It is the worry that, desirable that knowledge of other people—as persons—is, it is strictly impossible. One can never achieve good enough evidence to justify claims about another's mental life. Such is the worry. Here is a way to seem—misleadingly!—to ground it. Consider again the Cartesian substance dualist picture of the relation of mind and body. If mind and body occupy different dimensions—the physically extended and the thinking—then it seems that no form of perception based on causal receptivity in the physical realm can yield awareness of other minds because minds are simply not in that realm. How therefore is knowledge of others *as persons* so much as possible? Surely one can never bridge the gap between one's own experience of another person and their actual thoughts and feelings? This worry then seems to float free of the specifically Cartesian dualist background. Even if the mind is software running on the hardware of brains—as philosophical functionalism claims—how is it possible to infer from someone's behaviour to their underlying software state?

During the last 30 years, there have been two dominant philosophical answers to this question. One approach argues that such knowledge is akin to scientific theoretically mediated knowledge of unobservable entities: 'theory theory' [14]. Its main rival starts from the idea of empathic projection: one imaginatively places oneself in the position of the other and imagines one's thoughts and experiences: 'simulation theory' [15]. It is worth noting in practice how unsatisfactory either is to ground the idea that one can ever have genuine *knowledge* of how another person—a patient or service user or even a loved one, perhaps—is feeling. We do not seem to know the theory presupposed by the former approach while the act of imagination outlined by the second seems inadequate for *knowledge*.

PCM need presuppose no particular account of how person-level knowledge of persons as persons is possible. Its commitment is not to any specific explanation of *how* but to the more generic claim *that* it is possible. However, it is worth noting that the very idea that there is a problem to be solved may be more philosophical—albeit longstanding—artefact than common sense.

A helpful alternative view stems from the same account of the basic role of persons highlighted in the previous section which is both essentially mental and physical. If one starts from that perspective, rather than the dualistic separation of mind and body, then there is no need to deny the common-sense idea that human minds can *express* themselves in human behaviour and hence be known by others through that expressive behaviour. This contrasts with the 'alienated' conception of our relation to others that underpins a Cartesian view of human bodies where bodies are brute machines at best merely controlled by minds that inhabit a different dimension. On the non-Cartesian picture, one can have a form of *almost* direct knowledge of another's mental states. It is direct knowledge of the expression of the mental state. As John McDowell argues, experience of other people is not limited to their bare behaviour, with mentality hidden behind it. The idea of almost direct knowledge can be applied:

> in at least some cases of knowledge that someone else is in an "inner" state, on the basis of experience of what he says and does. Here we might think of what is directly available to experience in some such terms as "his giving expression to his being in that 'inner' state"; this is something that, while not itself actually being the "inner" state of affairs in question, nevertheless does not fall short of it in the sense I explained [1, p. 387].

Although one person's inner states do not themselves fall within the direct perceptual experience of another person (hence 'almost'), the fact that they express them can. This idea of expression is *not* one that is consistent with the *absence* of the inner state. So McDowell replaces an account in which all that is visible to an observer is another person's intrinsically brute or meaningless behaviour, standing in need of further interpretation and hypothesis, with one in which that behaviour is charged with meaning and expression.

One way to think about this alternative to the Cartesian picture is to think about how one might describe another person's smile. We naturally reach for apparently epistemically risky and mind-presupposing words over the supposedly more basic purely physical descriptions. A smile is relaxed, ecstatic, forced, brave etc. Such descriptions are easier to offer than the purely geometric and non-mental descriptions that the Cartesian picture of the relation of others' bodies and minds would suggest.

This particular philosophical 'diagnosis' of the implicit error behind the thought that it can seem that direct person-level knowledge is impossible provides one rationale for thinking that the epistemological strand of PCM is fully justifiable. But it is not necessary to accept this diagnosis to subscribe to PCM. The epistemological mark of PCM is merely that there is an available form of knowledge, couched at the level of the person, that is a key component of healthcare alongside more basic knowledge of bodily functions and dysfunctions.

3.5 Other Necessary Conditions for PCM?

The two conditions considered above concern the most abstract ontological and epistemological commitments of PCM. Nothing, surely, could count as a form of PCM unless it accepted them? But additional claims have been made about other potentially necessary features of PCM. For example, Juan Mezzich, writing with a number of co-authors, has developed a much richer account over the last decade (e.g. [16, 17]). He summarises his view in five key claims of which the first, third and fifth are the ‘three main definitional ones’ (Mezzich personal communication 12 August 2021 and 20 August 2021).

- The whole person is at the center of the concept of health and is the proper objective of health actions.
- The concept of health to which the person is related encompasses both ill health (diseases) and positive health, particularly well-being and quality of life, as they are intrinsic or essential to the fulfilment of the person.
- In the clinical field, PCM is often seen as a medicine of the person (of the totality of the person’s health, including both ill and positive aspects), for the person (to assist in the fulfilment of each person’s health aspirations and life project, and not merely disease management), by the person (with clinicians extending themselves as total human beings with high ethical aspirations), and with the person (in respectful collaboration and in an empowering manner).
- PCM fundamentally articulates science (as essential) and humanism (as the essence of medicine).
- In contrast to Evidence Based Medicine, PCM involves a Medicine that is informed by evidence, experience and values and is aimed at the restoration and promotion of health of the whole person.

Adding more necessity claims makes the view of PCM more specific and hence invites the challenge of rival specifications which deny (some of) these elements and perhaps add others. But given the picture summarized thus by Mezzich, what would be its underpinning philosophical grounding or justification? What further ontological and epistemological commitments are introduced by this greater specificity, beyond the two abstract claims considered so far in this chapter?

Space precludes a detailed answer to these questions but a preliminary sketch is given below starting with the first claim that the whole person is at the center of the concept of health and is the proper objective of health actions.

To claim that health—positive or negative, in accord with the second commitment—is an essentially person-level concept rules out the idea that sub-personal notions of disease or disorder or dysfunction, for example, are anything other than parasitic on a logically prior notion of the health of the individual. That suggests—if it does not strictly imply—a rejection of a primarily evolutionary or biological notion of health and illness set out at the sub-personal level. In other words, it presents at least some difficulty for a view of disorder as dysfunction since, by contrast with the commitment above, dysfunction does seem to be a notion that applies at the sub-personal level, at the level of mere biological traits. In other words, the first claim is a substantial ontological claim about the nature of health and ill-health. What could *justify* this commitment?

One suggestion is made in the second commitment listed above: the idea that health and illness are concepts that relate to well-being, quality of life and the fulfilment of the person. This is an Aristotelian view. It suggests that the goal of healthcare is human flourishing not, say, some biological mean. But further, on an Aristotelian view, flourishing is an essentially *value-laden* notion and this is picked up in the third, and the fourth and the fifth commitments listed above.

Mezzich's third commitment specifies some of the values involved. Again according with a broadly Aristotelian view, this includes both a connection to human flourishing rather than mere disease management and making demands on the virtue(s) of clinicians, not least to work in respectful collaboration with patients and clients.

The fourth and fifth commitments are broadly epistemological but fit with the view so far set out. Given the person-level view of health and illness and the idea that the aim of healthcare is a value-laden notion of human flourishing, medicine has to draw on resources outside the narrowly scientific (or at least outside a narrow picture of what is scientific) to achieve this.

Mezzich's picture helps to illustrate the fact that while it is possible to articulate a minimalist interpretation of PCM as merely a commitment merely (ontologically) to the existence of the person and (epistemologically) to the idea that person-level knowledge of other people is possible, further richer—though thus riskier—views with more specific ontological and epistemological commitments exist. Mezzich's account briefly sketched connects flourishing and values in a particular Aristotelian view of healthcare. A full philosophical justification of this thus calls for a self-conscious articulation and defence of the connections presupposed. For example, it may require a defence against a rival view that health and illness can be viewed as biological properties realised at a sub-personal level. That said, it may be that a view of PCM is proposed not because it is a *true* account of the nature of health and disease but because it would be a *virtuous* or better approach to healthcare, tracking the good rather than the true [18].

Such self-conscious philosophical work may, however, suggest yet further connections. For example, a natural way to chart human flourishing is via a narrative conception of a life [19]. And hence one possible partnership—suggested by philosophical and conceptual work—is between PCM and *narrative* medicine. Another is to the Recovery Model in mental healthcare [20].

3.6 Practical Implications

The practical implications of adopting a PCM approach will be explored more directly in other chapters of this book. The purpose of this conceptual and theoretical chapter is to clarify the presuppositions and suggest the logical space for such a distinctive view. Only if some things are ruled out by it does PCM have any content. The argument above is that what is ruled out is the idea that person-level claims can be reduced without loss to lower level bio-medical claims and that there is no distinctive person-level knowledge. A brief route map has been sketched to escape the pessimistic thought that it is simply impossible to have knowledge of other people's mental states.

But some practical implications are immediately apparent. If person level knowledge exists and is irreducible and assuming that it is important to healthcare (a claim for which no argument has been offered here for reasons of space but is apparent elsewhere in this book) then the pursuit of person level knowledge requires the right kind of inquiring stance. Since the most obvious way to find out how things stand with another person is to ask them, to listen to what they say, and to watch what they do, then these forms of inquiry must be available in doctor-patient, or specialist-client, or practitioner-service user relations.

3.7 Discussion and Conclusions

Person Centred Medicine is a substantial and contentious view within the philosophy and practice of healthcare. The mark of its substance is that it rules some things out. It is incompatible with some other views of nature and hence healthcare. This chapter has explored two of its main broad presuppositions concerning ontology and epistemology. Its commitment to the existence of the person as a basic and irreducible element within ontology stands in opposition to views that deny that by, for example, promising to reduce the concept of the person to more basic phenomena. Thus, it stands opposed to various reductionist views. Its commitment to there being a form of person level knowledge and it being achievable stands in opposition both to claims that there is no such irreducible level and sceptical claims that it is impossible to attain. Although advocates for PCM need not have a fully worked out philosophy of the person or person-level knowledge, this chapter has sketched the nature of this sort of commitment and made some suggestions for how they might be supported.

Acknowledgements and Disclosures The author reports no conflicts of interest in the preparation of this manuscript.

References

1. McDowell J. Meaning knowledge and reality. Cambridge: Harvard University Press; 1998.
2. Fulford KWM, Thornton T, Graham G. Oxford textbook of philosophy and psychiatry. Oxford: Oxford University Press; 2006.
3. Jackson F. What Mary didn't know. J Philos. 1986;83:291–5.

4. Davidson D. Essays on actions and events. Oxford: Oxford University Press; 1980.
5. Hume D. A treatise of human nature. Oxford: Oxford University Press; 1978.
6. Dennett D. The self as a center of narrative gravity. In: Kessel F, Cole P, Johnson D, editors. Self and consciousness: multiple perspectives. Hillsdale: Erlbaum; 1992.
7. Hofstadter D. I am a strange loop. New York: Basic Books; 2007.
8. Metzinger T. Being no one – the self-model theory of subjectivity. Cambridge: The MIT Press; 2003.
9. Taylor JG. The race for consciousness. Cambridge: The MIT Press; 1999.
10. Strawson PF. Individuals. London: Methuen; 1959.
11. Strawson PF. The bounds of sense. London: Methuen; 1966.
12. McDowell J. Mind value and reality. Cambridge: Harvard University Press; 1998.
13. Sellars W. Empiricism and the philosophy of mind. Cambridge: Harvard University Press; 1997.
14. Davies M, Stone T, editors. Folk psychology: a guide to the theory of mind debate. Oxford: Blackwell; 1995.
15. Davies M, Stone T, editors. Mental simulation: evaluations and applications. Oxford: Blackwell; 1995.
16. Mezzich, J. E., Botbol, M., Christodoulou, G. N., Cloninger, C. R., and Sallaum (2016) 'Introduction to person centered psychiatry' in Mezzich, J. E., Botbol, M., Christodoulou, G. N., Cloninger, C. R., and Sallaum (eds) Person centered psychiatry. Springer, Cham.
17. Mezzich J, Snaedal J, van Weel C, Heath I. Toward person-centered medicine: from disease to patient to person. Mount Sinai J Med. 2010;77:304–6.
18. Thornton T. Is recovery a model? In: Rudnick A, editor. The recovery of people with mental illness. Oxford: Oxford University Press; 2012. p. 236–51.
19. MacIntyre A. After virtue. Notre Dame: University of Notre Dame Press; 1981.
20. Thornton T, Lucas P. On the very idea of a recovery model for mental health. J Med Ethics. 2010;37:24–8.

Chapter 4
Human Rights, Ethics and Values in Person Centered Medicine

W. James Appleyard, George N. Christodoulou, and Francisco J. León-Correa

4.1 Introduction

Recognition of the individual is at the foundation of ethics and is one of the main human motivations. It is based on dialogue but **also** on the fundamental experiences that underlie and sustain most discourses on interculturality, experiences such as identity, recognition, encounter, and solidarity [1].

Bioethics involves this professional dialogue with the communication and the elaboration of universal standards based on each person and built up amongst everyone. The prime feature highlighted in clinical bioethics is human communication in the doctor-patient or professional relationship of health and people served. The importance of a narrative bioethics, (Scholarship, Razmilic, 2014) incorporating

---

W. J. Appleyard
Presidency 2013–2017, International College of Person Centered Medicine,
New York, NY, USA

Presidency 2003-2004, World Medical Association, Ferney-Voltaire, France

St George's University School of Medicine, Grenada, Grenada

Kent and Canterbury Hospital, Canterbury, UK

G. N. Christodoulou (✉)
Department of Psychiatry, Society of Preventive Psychiatry, Athens University, Athens, Greece

World Psychiatric Association, Geneva, Switzerland

World Federation for Mental Health, Occoquan, VA, USA

Hellenic Psychiatric Association, Athens, Greece

International College of Psychosomatic Medicine, Florence, Italy

International College of Person Centered Medicine, New York, NY, USA

F. J. León-Correa
Universidad Central, Santiago de Chile, Chile
e-mail: Francisco.leon@ucentral.cl

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_4

biographical account into deliberation, with a “perspective from context. And the relationship to the particular, the emotional and affective elements that influence decision-making and attitudes” [2] have been highlighted.

Human communication is deepened through texts, “complex processes of argumentation, deliberation and public exchange through which civil society associations are questioned and contextualized, invoked and revocationed, affirmed and positioned claims and principles of universalist rights, both in legal and political institutions and in civil society associations” [3]. The essence of language and writing is ethical, it has more to do with sincerity than truth and of its use for deception or insult [4].

Bioethics is a tool to save conflict and build that intercultural dialogue. It helps us practice ethics as an effort and the component of a human culture of coexistence. Training in Bioethics has among its purposes the ability to establish consensus and avoid dissensions, and therefore can serve intercultural dialogue, based on mutual recognition.

4.1.1 Mutual Recognition

The basis is respect for the other, “the honoring of the dignity of the other” [5, 6] that leads to live not only with the other, but to live towards the other.

Negative recognition [7, 8] involves humiliation, contempt or cruelty to social groups which may be devalued or dismissed by society [9, 10]. There is a need to build a decent society in which institutions do not humiliate individuals but give them positive recognition, as a vindication of different cultures [11, 12] and as an ethical claim that leads to political decisions of justice and advancement in social equality [13].

In his theory of recognition, Honneth [9] suggests three models or spheres of mutual recognition: affective love that leads to self-confidence; the right, with a capacity for moral responsibility that leads to self-respect; and solidarity, referring to a community of shared values, which corresponds to social valuation and leads to self-esteem [4]. The justice of care beyond formal care, focuses on solidarity [14].

There are levels in this recognition: that of the individual, his or her aspirations and way of life, by belonging to one or more groups and the appropriate recognition of the identity of a minority by the host group [15, 16]. It is the recognition by others that builds their identity as people.

4.1.2 Identity

Identity provides, among other things, one more source of value, one that helps us find a path between those reasonable moral choices. To adopt an identity, to make it person, is to see it as the factor that structures my path in life [17, 18].

Taylor affirms “My identity is defined by the commitments and identifications that provide the framework or horizon within which I try to determine, on a case-by-case basis, what is good, valuable, what to do, what I approve of and what I object to” [19, 20].

> "Not only those we allegedly learn from (ourselves), but also those whose behavior we react to with rejection (the others) fulfill the function of modeling our identity, producing both our own self and the us we believe we belong to" [10]

An individual's membership in a community with shared values is an indispensable basis for self-respect, obtained from the recognition of each person's merits by those who are in a position to value them [1, 21].

Bioethics thus should contribute to a universal language that transcends cultural or philosophical differences and be based on 'common sense'. It is also the mission of ethics to orient this language within the concepts of globalization and universalization towards a duty to promote the health and wellbeing of all peoples. This should not be as an absolute for an ideal good life, to which all will have to adjust, but to the particular good life, daily loved and desired by each person.

4.2 Inclusion and Forgiveness

Every state, society and each individual person must be responsible and inclusive. In the gesture of forgiveness, the sovereignty of the autonomous self faces another autonomous 'self,' Forgiveness means the suppression of resentment [22]. It should be possible to forgive the unforgivable and the unconventional [23, 24] Responsibility is the value of thinking about a type of social cohesion such as identity or by appealing to feelings of belonging. A society that guarantees without any discrimination the exercise of individual responsibility by appealing to well-defined human Rights offers its citizens the most pragmatic argument for their aspiration for a common 'good' life, inclusive of All.

To be inclusive it is necessary first to forgive. Considering one another presupposes that certain values are shared because only in the light of these can it be understood why the capacities or properties of the other are of positive relevance to the common practice of life. Community cohesion, depends on the precondition that there is an understanding of intersubjectively shared values [24, 25]. Inclusion reaffirms identity, avoids moral grievance, promotes forgiveness, and enables solidarity.

Only by forgiving the faults of others, an individual person, group, community, or country in this way does forgiveness become possible and enable ourselves to become emancipated [26].

Considering one another presupposes that certain values are shared because only in the light of these can it be understood why the capacities or properties of the 'other' are of positive relevance to the common customs of living together. Inclusion reaffirms identity, avoids moral grievance, promotes forgiveness, and enables cohesion and stability.

4.3 Core Values

Shared values and virtues are absolutely necessary for the common good and at the very least a decent and [22, 27] humane society. They are meta-values in that they allow respect and coexistence even in those who adhere to other visions of life and

Table 4.1 Principles or virtues and positive and negative personal and social consequences

Topics	Items					
Principles or virtues	Living with	Welcome	Care	Identity/ respect	Pardon	Living together
Positive personal and social consequences	Tolerance	Empathy	Compassion	Recognition	Inclusion	Solidarity
Negative personal and social consequences	Conflict	Passivity	Irritability	Moral grievance	Marginalization	No sense

amongst those who accept different material and concrete values; If we understand that There are certain conditions that must be met for a minimum requirement of the health and welfare of individuals living together to be met.

Virtues are not socially pleasing qualities, nor the provisions that strengthen the will to fulfill duty, they are the qualities in which the moral subject has been forged from childhood, from the family community and from school to desire and discover what is right [23, 28]. They play an important moral role in the way people live together socially (Table 4.1).

4.4 The Importance of Dialogue

In a globalized world of social networks, the depersonalization of relationships has been described, where anonymous communication and not respect for the individual prevail. Han maintains that we live in a swarm of noises without permanent meanings, without proper language, where everyone speaks and hears, and hardly anyone listens. There has been a breakdown of social life, with the failure of the social moral conscience, [13] among those who are [29] recognized in different identities.

There is a human desire to communicate: ideas and ideals through language, which integrates us into the family first, in communities and society afterwards, and finally makes us part of something more universal that is called humanity.

In the face of the late liberalism procedure of conventionally substantiating public life, Cortina [25] raises the following objections:

(a) The validity of conventions requires, whether or not it means, a moral basis, because as a condition of possibility of the moral obligation of the conventions, it is necessary to assume, at least, the intersubjective validity of morality to keep the promises made.
(b) Systems of law that cannot be morally legitimized, lose their credit sooner or later.
(c) There is no ethical-normative interpretation of the decisions of individuals, so the sum of decisions does not have to give rise to a rational decision. If private decisions are irrational, more of them can be irrational.
(d) A democratic agreement, based solely on factual consensus, compromises only the participants, and does not bind or take into account those who, affected by the agreement, have not participated in it (marginal classes, third world peoples, future generations) [25, 30].

4.4.1 Consensus

Three fundamental dangers are lurking in the consensus—among many others: to conceive of it as a strategic pact, to reduce it to a mere formal mechanism, and to make it the philosopher's stone that moralizes its touch. The conviction that consensus is strategic pacts, in which everyone defends their individual interests rabidly until they reach a balance, dependent on the correlation of forces, undermines the profound sense of democracy at the root of the process.

However, there is no less error in understanding consensus as a formal procedure, as a legitimizing mechanism of rules, which has nothing to do with the way of life on which it ultimately relies. And not only because the consensus, so understood, tends to be identified with the rule of majorities, which is the lesser evil, in need of major amendments; nor because the factual consensus does not constitute a sufficient guarantee of the correction of decisions. It is necessary to appeal to an ideal consensus as a regulatory idea and as a levy on criticism, which takes on meaning, is an irrelevant mechanism.

Morality is also concerned about highs, not just normative minimums; it is also concerned about the values worth living in [4, 5].

4.5 Human Rights

Human rights are internationally agreed standards, which apply to all human beings. They encompass the civil, cultural, economic, political and social rights of individual persons as set out in the Universal Declaration of Human Rights [31]. Their aim is to safeguard the inherent dignity and equal worth of each person—each right being interdependent, interrelated and indivisible with the others.

The Declaration defines all individuals as equal and entitled to human rights without discrimination of any kind, such as race, colour, sex, ethnicity, age, language, religion, political or other opinion, national or social origin, disability, property, birth, physical or mental disability, health status, sexual orientation or any other status as interpreted under international law.

Inequality and discrimination can slow down economic growth, reduce the capacity to address poverty and create inefficiencies in public institutions [32].

4.6 Highlighting the Articles of the UN Declaration of Human Rights

The Articles of the Declaration embrace all peoples in the World and each person in their social, political, cultural and environmental context. Medical Care is mentioned specifically in Article 25.

Article 1 states that '‘All human beings are born free and equal in Dignity and Rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.’

Article 2 Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a **person** belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty.

Article 3 Everyone has the right to life, liberty and security of **person**.

Article 6 Everyone has the right to recognition everywhere as **a person** before the law.

Article 22 Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his **personality**.

Article 25 Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

4.7 The WHO Constitution

The World Health Organization’s Constitution [33] defines health broadly as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”

Within the Constitution, the Right to Health is defined as “the enjoyment of the highest attainable standard of health,” and enumerates some principles of this Right as healthy child development; equitable dissemination of medical knowledge and its benefits; and government- provided social measures to ensure adequate health.

The WHO Constitution established the right to health as a “fundamental, inalienable human right” that governments cannot abridge, and are obligated to protect and uphold. This encompasses the full spectrum of contemporary international public health [34].

4.8 The UN International Covenant on Economic, Social and Cultural Rights

The United Nations further defines the Right to Health in Article 12 of the 1966 International Covenant on Economic, Social and Cultural Rights, [35] which states:

> "*The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.*"

The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:

- The reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;
- The improvement of all aspects of environmental and industrial hygiene;
- The prevention, treatment and control of epidemic, endemic, occupational and other diseases; the creation of conditions which would assure to all medical service and medical attention in the event of sickness. (i.e. Universal Health Coverage).

In 2000, the United Nations' Committee on Economic, Social and Cultural Rights issued General Comment No. 14, which addresses "substantive issues arising in the implementation of the International Covenant on Economic, Social and Cultural Rights" with respect to Article 12 and "the right to the highest attainable standard of health" [36].

The General Comment provides more explicit, operational language on the freedoms and entitlements included under a right to health.

Article 12 tasks the State with recognizing that each individual holds an inherent right to the best feasible standard of health, and itemizes the 'freedoms from' and 'entitlements to' that accompany such a right; however, it does not charge the State with ensuring that all individuals, in fact, are fully healthy, nor that all individuals have made full recognition of the rights and opportunities enumerated in the right to health. This acknowledges the importance of the underlying determinants of health by stating that the right to health is dependent on, and contributes to, the realization of many other human rights, such as the rights to food, to an adequate standard of living, privacy and access to information.

4.9 Criteria for Right to Health

General Comment 14 sets out four criteria by which to evaluate the right to health.

Acceptability All health facilities, goods and services must be respectful of medical ethics and culturally appropriate, sensitive to gender and life-cycle requirements, as well as being designed to respect confidentiality and improve the health status of those concerned.

Quality Health facilities, goods and services must be scientifically and medically appropriate and of good quality.

Availability Functioning public health and health facilities, goods and services, as well as programs, have to be available in sufficient quantity.

Accessibility Health facilities, goods and services have to be accessible to everyone without discrimination, within the jurisdiction of the State party.

4.10 Limitations of the Health and Human Rights Perspective

Though the field of health and human rights has grown quickly over the last 70 years since the Universal Declaration of Human Rights, there is no clear consensus regarding the most promising directions for the future [37]. The current outcome-oriented assessments lead us to question approaches that rely solely on recourse to formal legal and civil rights. Similarly, unpromising are approaches that rely overmuch on appeals to Governments. State power has been responsible for most human rights violations and most violations are embedded in "structural violence" that is the social and economic inequities that determine who will be at risk for assaults and who will be protected [38]. Global economic inequalities and inequities in the distribution of resources contribute to enormous disparities in the current health and wellness of human populations [39]. Many opportunities are now available to address these inequities by improving health care for all.

A future agenda suited to public health and medicine should be linked not only to the equitable distribution of the benefits of scientific advances but also to a refreshment of the focus on the individual **person** as the fundamental tenet of medicine and medical care within a health system. At the heart of medicine and medical practice lies the person whose relationship with their physician is based on trust and empathy within a framework of values that form the core of medical ethical practice.

In his comparative study of relationship—based Health Care in the US, United Kingdom, Canada, Germany, South Africa and Japan, Magee concluded that the patient/physician relationship is a critical underpinning of stable societies second in importance only to family relationships in all the countries studied. This is captured in the words of the 'Father' of Medicine Hippocrates 500 years BC and one of the greatest protagonists of Modern medicine in the twentieth century Sir William Osler.

> *"Wherever the art of Medicine is loved, there is also a love of Humanity."*
>
> *"It is far more important to know what person has the disease than what disease the person has".*
>
> *——Hippocrates*

> *"Medicine is a science of uncertainty and an art of probability".*
>
> *"The good physician treats the disease; the great physician treats the patient who has the disease".*
>
> *——Osler*

4.10.1 Ethical Principles

Let us now examine briefly the various ethics principles. These are shaped by the Ethics Theories [32, 40], which can be summarized as follows, Virtue Ethics, Casuistry, Deontological Theory, Utilitarianism and Principlism [41].

4.10.2 Virtue Ethics

This theory stems from the teaching of Aristotle in the Greek philosophical tradition. It underlines the importance of developing character traits that promote virtuous behavior, like magnanimity, trustworthiness, integrity etc. Pursuit of wisdom (as intellectual wisdom and as prudence—“phronesis”) is considered of primary importance. This theory supports the primacy of principles over rules and is considered as the only approach that has retained relevance and legitimacy over the course of history [34].

4.10.3 Casuistry

Based on the Aristotelian concept of phronesis, this theory builds on the ideas of the ‘sophists’ and particularly their opinion that moral issues depend on the analysis of particular circumstances. It is a “bottom up” theory in contrast to the rules-based theories which are “top-down”.

4.10.4 Deontological Theory

Immanuel Kant (1724–1804) [31] the chief advocate of this theory (derived etymologically from the Greek word δέον—duty) believed that the obligation to do the right thing should not arise out of fear for the consequences but because the right thing is an imperative in and of itself (binding categorical principle).

4.10.5 Utilitarianism

The essence of this theory developed by Jeremy Benthem (1748–1832) is that the moral value of an action depends on the degree of happiness or pain produced by the action.

4.11 Principlism

A principle is defined as a “Fundamental Truth, or proposition on which many others depend” or “A fundamental assumption forming the basis of a chain of reasoning”.

The theory of Principlism combines principles, two ancient ones (beneficence and no maleficence) and two traditional ones (autonomy and justice). Three more principles can added, namely Truth, Confidentiality and Fidelity [32]. The first two principles, arising from the teaching of Hippocrates have never been disputed but Autonomy and Justice have: autonomy on the grounds that it is subject to cultural factors and justice on the grounds that it is unfair to deal with unequal subjects in an equal way (Aristotle). One of them is that the weak should be offered more protection and the other is that conversely the gifted should be given more advantages to be able to flourish. A combination of these two approaches would perhaps represent the ideal way to resolve existential ethical dilemmas The Hippocratic Code of Ethics would be nonsensical if it was not based on principles.

The values of professionalism are expressed in the doctor patient relationship by the following principles, recognized around the world as essential to ethical practice. These are:

Beneficence Physicians must always aim to do good, look after patients’ best interests and recognize circumstances where conflict of interest may compromise professional judgment.

Non Maleficence Physicians must endeavour to do no harm—“primum non nocere”—avoiding unnecessary risks with treatments and refusing to take advantage of the intimacy of the patient—physician relationship.

Patient Autonomy Patients’ decisions about their care must be respected. Physicians should empower patients to make informed decisions about their treatment.

Justice Physicians must treat all people equally according to their need. Physicians should work actively to eliminate discrimination based on race, gender, socioeconomic status, religion or ethnicity and promote justice in a health system based on individual and community clinical need. This effort demands a commitment to reduce barriers to access to medical care based on education, geography, finances and legal structures.

Fidelity Physicians’ ‘duty of care’ is the free acceptance of a commitment to service. This commitment entails being available and responsive when needed, accepting inconvenience to meet the needs of patients, advocating the best possible care within the available resources regardless of ability to pay, seeking active roles in teaching and professional organizations, and volunteering skills and expertise for the welfare of the community. Medical professionals, therefore, should be encouraged to participate in professional organizations, community programs and institutional committees.

This duty also includes a commitment to competence and lifelong learning. Where appropriate, a physician's duty may require referring the patient on to those that have greater competence in a particular area to meet a patient's needs.

Truthfulness Physicians must ensure that patients are completely and honestly informed before consenting to treatment and after treatment has started. They must not mislead patients when medical errors have occurred. It implies keeping one's word and meeting commitments. It also requires the recognition of possible conflicts of interest and avoidance of relationships that allow personal gain to supersede the best interest of the profession.

Confidentiality Confidentiality is one of the foundations on which the trust between patient and physician is based. It may only be breached where there is a real and imminent threat to the patient or to others if this confidentiality were maintained.

4.12 Practical Application of Ethical Principles

These 'principles' need to be 'internalized' and become a physician's professional conscience, a compass guiding the journey through the complex scientific and medico social scenes.

The physician's individual conscience provides the foundation of the 'trust' given by the patient to the physician. The profession's collective conscience shapes the essential wider 'contract' between the medical profession and society in general.

The 'Art' of Medicine is the application of our knowledge and skills within this framework of our collective conscience to make judgments in the best interests of individuals seeking our help.

In practice it may be enormously difficult to balance these 'principles' as each may internally conflict within the individual person's circumstances. Though they are 'absolutes' to which we aspire, they should not be applied in isolation but in dynamic combination. In this way mistakes can be avoided. For example, telling the truth for the sake of truth alone may have catastrophic effects in some cases (e.g. revealing the full truth about cancer or AIDS to unprepared persons).

The implementation of these ethical principles is filtered through each individual practitioner's "conscience". There is no one right answer. Just the right answer for the individual person based on both the virtues and the morality of the physician's best clinical judgment. The physician is called to implement the Ethics code on the basis of one's individual sense of responsibility which forms the basis of ethical practice. It is the ethical principles of the individual practitioner that play the most important role and not the prevalent legal rules and codes. This of course is in line with the teaching of Immanuel Kant but even before Kant with the principles advocated by the ancient Greek philosophers and physicians. Additionally, it is in line with the person-centered perspective as it emphasizes the importance of the ethical stance of each individual practitioner.

'The Ethics of care' theory is based on the idea of cultivation of virtuous personal traits (Aristotle) and emphasizes "moral emotion" like love, compassion and friendship.

"Virtues" are attitudes, dispositions, or character traits that are developed through learning and through practice. They are habits that, once acquired, become characteristic of a person who becomes naturally disposed to act in ethical ways that are consistent with moral principles within the professional communities and to act in ways that develop certain ideals, such as excellence or dedication to the common good. They enable us to pursue the shared ideals of honesty, courage, compassion, generosity, fidelity, integrity, fairness, self-control, and prudence within local communities.

Fulford et al. [42] have identified as one of the basic challenges in the person-centered approach the harmonization of scientific findings with the values of each individual patient [38]. They have postulated that there are two ethical responses to this challenge, the following:

1. Substantive Ethics, like Utilitarianism, Deontology and Principlism aiming to define "the right values" that should guide clinical practice
2. Analytic Ethics, based on moral reasoning, like the "values based practice" [43]

A synthesis of these two approaches is thought to provide solutions to problems arising from conflicts of guiding principles (e.g. in the case of compulsory admissions between the "purpose" principle that includes safety and the "respect" principle that refers to respect for the patient's wishes. This balance is not easy to achieve and one may ask if attention and respect of the person is a higher principle justifying suspension of the application of other ethics principles. This is particularly relevant to psychiatric Ethics where the ethical justification of coercive treatment and treatment without consent still remain hot issues of debate. Further consideration of these issues should aim at harmonization of the various points of view to "reach conclusions that are theoretically valid but also clinically useful" [39].

Yet another issue that is certainly related to Ethics stems from the need to harmonize the good for the person versus the good for society as a whole. Jeremy Bentham and his school of Utilitarianism has dealt with this issue concluding that whatever is good for the majority is ethical ("the greatest good for the greatest number"). This is perhaps the greatest weakness of this theory because it neglects the needs of the minority. Other theories on the other hand profess the exact opposite by insisting on the well-being of the individual versus benefit to society as a whole, as in the Helsinki Declaration of the World Medical Association [44]. For more details, see Appleyard [40] and Christodoulou et al. [39]. The International College of Person-Centered Medicine has incorporated the societal dimension in its person-centered perspective. Thus, it considers the "person" in the singular but also in the plural by enlarging the Person-Centered Medicine approach to also incorporate the public health dimension [45].

Physicians need to be called to account by their patients and their peers to justify their actions within a delegated professional regulatory framework which respects the difficulty and contradictions of ethical medical practice. Imposition of a political, bureaucratic or business ethic distorts this accountability and works against the best interests of the individual person.

Industries as well as professions acknowledge the importance of such a structured ‘internal regulatory’ framework. External regulation of the medical profession should re-enforce good practice rather than impose inappropriate unprofessional standards. Overregulation leads to poor professional morale when it conflicts with physicians’ duties to their patients and when it imposes unrealistic difficulties that render research and innovation impossible. An alienated profession spends much time attempting to circumvent regulations that interfere with, rather than promote, best practices.

4.13 Instilling Ethics in Medical Education

The World Medical Association has exhorted all medical~~s~~ schools in the world to ensure the teaching of medical ethics within their curricula. Of all the 44 standards required by the American Boards for a medical school to be accredited in the US, the Deans of US medical schools have ranked ethical behaviour the highest.

Undergraduate Medical Curricula have been developed to ensure that ethical issues are always reviewed in medical decision making.

The Arnold Gold Foundation of Columbia University in New York recognized the difficulties of fostering the medical conscience and initiated in August 1993, the White Coat Ceremony in which medical students publicly committed themselves to the profession’s ethics. The ceremony also reinforces the professional culture amongst the teaching faculty and administration of the School. Now 90% of US medical schools have introduced the ceremony, and it is spreading into Europe.

The Association of American Medical Colleges have published a “Compact between Teachers and Learners of Medicine” based on three guiding principles, as follows:

- The duty of medical educators to inculcate the values and attitudes required for preserving the medical profession’s social contract across generations
- The need for integrity and role models that epitomize authentic professional values and attitudes
- Respect for every individual as a fundamental part of the ethic of medicine

Some medical schools have found it helpful to link these concepts with the students’ “code of conduct” and the disciplinary procedures required to re-enforce them. This is important because the social milieu or ‘informal’ curriculum of a medical school has a great influence on the values and professional identities acquired by its students.

The University of Chicago, USA has emphasized six principles in teaching clinical ethics, namely:

- Clinically based—for relevance
- Cases (real)—narratives for fidelity and effectiveness
- Continuous—the reinforcement of learning outcome
- Coordinated—an integrated approach to all issues pertaining to the ‘case’
- Clean (i.e. simple case) for clearer take home messages and better impact and
- Clinicians as Instructors—for source credibility and all round case discussion

Early on in their courses, students are introduced to medical decision making. As they progress, some clinical tasks are delegated to them, within the ethical framework described above. They come to understand through their teachers, mentors and role models that the unifying umbrella of medical ethics does not mean uniformity. It is the very diversity of the clinical problems faced by their patients and the issues surrounding them that make medicine not only such a fascinating and interesting career but a vocation where their individual conscience as ~~a~~ physicians is key to the application of their knowledge and skills in the best interests of their patients.

At Graduation publicly professing the same ethical principles helps to reinforce the importance of maintaining and developing the ethical standards expected of members of the medical profession.

4.14 The Essence of Medical Professionalism

The practice of Medicine is a “vocation whose core element is work based upon the mastery of a complex body of knowledge and skills and whose members ‘profess’ a commitment to competence, integrity, morality, altruism and the promotion of the public good within their domain.”

These commitments form the basis of a social contract or covenant between a profession and society, which in turn grants the professions the right to autonomy in practice and the privilege of self-regulation.

Society benefits by having those who govern the knowledge and skills for providing essential services primarily for the good of others rather than personal gain or political advantage.

In exchange for the privilege and authority to be responsible for key aspects of their professional work including the setting of professional standards, education ,credentialing with a significant influence on the medical market and their working conditions society demands that professionals maintain and develop high standards of competence and moral responsibility.

Public awareness of the professions’ ethical standards serves to maintain the professions’ devotion to medical science and to advocate for health care values in the context of competing social imperatives.

With the vast and increasing amount of information available on the world wide web, some no longer acknowledge the value of professional competence, believing that anyone can find the relevant information on line and follow a protocol, others, especially Heath Service Managers feel it is possible to reduce medicine to its component parts, apply those parts in isolation and save money by deskilling the process.

The profession continues to exist because people, especially when ill, want personalized information from a trustworthy source. As Dr Mike Magee has shown, people still consult doctors for information. They are justifiably uncertain about the validity of the information on the web and are confused by its complexity and contradictions.

Patients need their physicians to help them interpret and apply that knowledge to their own individual circumstances with shared understanding as a foundation for their decisions. Providing coherent, well-informed care is the art of our profession and the foundation of person centred practice.

4.15 The Eight Characteristics of a Profession

4.15.1 Code of Ethics

Code of ethics from the time of Hippocrates represent the applied morality of the Profession governing the behaviour of members.

It has been updated by the World Medical Association's Declaration of Geneva which embraces the core principles of professional ethics, now in the form of the Physicians Pledge.

4.15.2 The Physician's Pledge

I MAKE THESE PROMISES solemnly, freely, and upon my honour

AS A MEMBER OF THE MEDICAL PROFESSION:

I SOLEMNLY PLEDGE to dedicate my life to the service of humanity;

THE HEALTH AND WELL-BEING OF MY PATIENT will be my first consideration;

I WILL RESPECT the autonomy and dignity of my patient;

I WILL MAINTAIN the utmost respect for human life;

I WILL NOT PERMIT considerations of age, disease or disability, creed, ethnic origin, gender, nationality, political affiliation, race, sexual orientation, social standing or any other factor to intervene between my duty and my patient;

I WILL RESPECT the secrets that are confided in me, even after the patient has died;

I WILL PRACTISE my profession with conscience and dignity and in accordance with good medical practice;

I WILL FOSTER the honour and noble traditions of the medical profession;

I WILL GIVE to my teachers, colleagues, and students the respect and gratitude that is their due;

I WILL SHARE my medical knowledge for the benefit of the patient and the advancement of healthcare;

I WILL ATTEND TO my own health, well-being, and abilities in order to provide care of the highest standard;

I WILL NOT USE my medical knowledge to violate human rights and civil liberties, even under threat;

4.15.3 Autonomy

Professions are granted autonomy in order that they may respect the autonomy of each individual patient, provide a professional person centred space in which the patient can be recognised as a person and act in the best interest of both their patients and society, in the face of competing social priorities.

General respect for the personal autonomy of both physician and patient creates trust, ennobles and professionalizes the relationship. Essentially autonomy demands that individual patients have the right to choose both their physicians and their treatment.

Physicians always need to justify what action they take with their patients to the patients themselves and be able to do so to their peers through audit and peer reviews.

Authoritarian governments continually seek to undermine this right because of their concern about the influence the medical profession may exert by independently advocating for the health needs of individuals and society. In more democratic societies, medical autonomy is threatened by capitalist values that place efficiency and the generation and concentration of wealth over sometimes costly, seemingly irrational or apparently inefficient individual preferences and practices.

4.15.4 Morality and Integrity

A fundamental characteristic of any profession is the expectation that its individual members and the associations and institutions representing them are ‘moral’ and carry out their activities with integrity.

4.15.5 Altruism

The trust placed in the profession and medicine’s privileged status are only justified if we consistently place the interests of individual patients and society above our own.

The word “altruism” (*from Latin alter: “other”*) was coined by the French philosopher Auguste Comte, the founder of positivism. He believed that individuals had a moral obligation to renounce self-interest and live for others, the definitive formula of human morality, gives a direct sanction exclusively to our instincts of benevolence, the common source of happiness and duty.

Philosopher W. G. Maclagan defines it as “a duty to relieve the distress and promote the happiness of our fellows...Altruism is to...maintain quite simply that a man may and should discount altogether his own pleasure or happiness as such when he is deciding what course of action to pursue” [36].

4.15.6 Knowledge

Professions are given stewardship over their body of knowledge. They are responsible for the integrity of the knowledge base. In medicine, this requires dedication to scientific evidence and clinical experience. The proper professional application of knowledge includes responsibility for its expansion—(promoting research and development)—and for its transmission to future practitioners—(medical education). The profession must also apply its knowledge to the public good in order to improve public health and the health of nations.

4.15.7 Service

Professional knowledge must be used in the service of others, individual patients and society in general.

4.15.8 Accountability

Physicians are accountable personally to their patients and to their profession for adhering to medicine's time-honoured ethical principles, politically to the public as whole and economically to third party payers.

4.15.9 Professional Associations

Professional collegiality establishes common goals and encourages all members of a profession to comply with them. Independent associations and State sanctioned licensing bodies exist to set and maintain professional standards, discipline unethical behaviour, and establish. educational standards. At their best, they are custodians of the medical professions' conscience and need to ensure that in any Health System there is a continuing professional space that enables the independent practice of medicine that places the person in the centre of medical care.

4.16 Conclusions

Person Centred Medicine means -placing the person in the centre of medicine; of medical practice and health and healthcare. Central to this is the dialogue between the 'person' and his or her physician to elucidate their needs, as opposed to their 'wants', based on trust. Trust depends on a shared understanding of the values that underpin this professional relationship, of respect for each individual and the physician's prime responsibility to be an advocate for the individual persons needs independent of any Health System. Patients need their physicians to help them interpret and apply their knowledge to each person's individual circumstances with shared understanding as a foundation for shared decisions. Providing coherent, ethically based, well-informed care is the art of our profession and the foundation of person-centred practice.

Acknowledgements and Disclosures The authors do not report any conflicts of interest.

References

1. Esquirol JM. One self and the others. From existential experiences to interculturality. Barcelona: Shepherd; 2005.
2. Feyto L. The narrative model as a means of teaching bioethics. In: Feyto L, Gracia D, Sánchez M, editors. Bioética, the state of the matter. Madrid: Triacastela; 2011. p. 79–100.
3. Benhabid S. The rights of others. Barcelona: Gedisa; 2015. 129 and ss
4. Esquirol JM. Intimate resistance, essay of a philosophy of proximity. Barcelona: Cliff; 2015. p. 58–62.
5. Sinay S. Disrespect. Buenos Aires: Intellectual Capital; 2014. p. 115–25.
6. Huntington S. The clash of civilizations and the reconfiguration of the world order. Buenos Aires: Paidós; 2015.
7. Maalouf A. The mismatch of the world. When our civilizations are exhausted. 3rd ed. Madrid: Editorial Alliance; 2011. p. 13.
8. Zagrebelsky G. Against the ethics of truth. Madrid: Trotta; 2010. p. 13.
9. Honneth A. The fight for recognition. Barcelona: Gedisa; 1996.
10. Margalit A. Decent society. Barcelona: Paidós; 1997.
11. He B-C. In the swarm. Barcelona: Herder; 2014. p. 15.
12. Benhabid S. The claims of culture. Equality and diversity in the era global. Buenos Aires and Madrid: Seix Barral Ediciones; 2006.
13. Tourain A. After the crisis. Mexico: Economic Culture Fund; 2013. p. 52 os.
14. Honneth A. Criticism of moral grievance. Buenos Aires: FCE; 2009.
15. Bauman Z. Strangers knocking on the door. Buenos Aires: Paidós; 2016. p. 24.
16. Cruz M. Tolerance or barbarism. West in the face of the challenge of coexistence. Barcelona: Gedisa Editorial; 1998. p. 52–3.
17. Bauman Z. Strangers knocking on the door. Buenos Aires: Paidós; 2016. p. 50.
18. Kwame AA. The ethics of identity. Buenos Aires: Katz; 2007. p. 58.
19. Patocka J. The movement of human existence. Madrid: Encuentro; 2004. p. 40–1.
20. Taylor C. The sources of the self. Barcelona: Paidós; 1996. p. 17.
21. Curtain A. Cordial justice. Madrid: Trotta; 2010.
22. Beuchot M. Tolerance as an ethical companion to human rights. In: Applied ethics topics. Mexico City: Editorial Torres Asociados; 2007. p. 89–106.
23. Bauman Z. Strangers knocking on the door. Buenos Aires: Paidós; 2016. p. 81–8.
24. Derrida J. Forgive the unforgivable and the imprescriptible. Santiago de Chile: Lom Editions; 2017.
25. Cortina A. Minimal ethics. 3rd ed. Madrid: Tecnos; 1993. p. 93–5.
26. Cortina A. Minimal ethics. 3rd ed. Madrid: Tecnos; 1993. p. 155–9.

27. Ricoeur P. Responsibility and fragility. In: Other times. "Paul Ricoeur" social and political ethics papers; 2003. p. 76–7, 129.
28. Mena P. Solidarity and invention of others. Variations on self like everything in Paul's philosophy Ricouer. In: Figueroa M, Michelini D (Comps.) Philosophy and solidarity. Santiago: Alberto Hurtado University; 2007. p. 78–9.
29. Esquirol JM. Intimate resistance, essay of a philosophy of proximity. Barcelona: Cliff; 2015. p. 151–2.
30. Sznaider N. The compassionate temperament: care and cruelty in modern society. Oxford: Rowman & Littlefield; 2001. p. 96.
31. Annas GJ. Health and human rights in the continuing global economic crisis. Am J Public Health. 2013;103(6):967.
32. Appleyard J. Introduction to ethical standards for person centered health research. Int J Pers Cent Med. 2013;3:258–62.
33. WHO. Constitution of the World Health Organization. Geneva: WHO; 1946.
34. Bloch S, Green S. Psychiatric ethics. 4th ed. Oxford: Oxford University Press; 2009.
35. Association of American Medical Colleges. Compact between teachers and learners of medicine. Washington, DC: Author; 2006.
36. Christodoulou G. Moral theories and medicine for the person. Int J Integr Care. 2010;10:48–9. https://doi.org/10.5334/ijic.488.
37. Christodoulou G, Christodoulou A. Person–centered perspective in the Madrid Declaration. Int J Pers Cent Med. 2013;3:266–9.
38. Christodoulou G, Fulford KWM, Mezzich J. Psychiatry for the person and its conceptual bases. Int Psychiatry. 2008;5:1–3.
39. Christodoulou GN, Van Staden CW, Jousset D, Schwartz M, Mishara A. Ethics in person-centered psychiatry. In: Mezzich JE, Botbol M, Christodoulou GN, Cloninger CR, Salloum IM, editors. Person centered psychiatry. Cham: Springer; 2016. p. 35–45.
40. Appleyard J. Who cares? The Declaration of Helsinki and the conscience of physicians. Med Ethics Rev. 2008;4 3:106–10.
41. Christodoulou GN. Moral theories in medicine and psychiatry. Psychiatriki. 2007;18(4):306.
42. Fulford KWM, Christodoulou GN, Stein DJ. Values and ethics: perspectives on psychiatry for the person. Int J Pers Cent Med. 2011;1(1):131–3.
43. Woodbridge K, Fulford KWM. "Whose values?" A workbook for values-based practice in mental health care. London: The Sainsbury Centre for Mental HealthWorld Medical Association; 2004.
44. WMA. WMA Declaration of Helsinki—ethical principles for medical research involving human subjects, amended by the 64th General Assembly, Fortaleza, Brazil, October 2013.
45. Christodoulou GN, Mezzich JE, Cloninger CR, Christodoulou N, Villar E, Appleyard J, Botbol M. Promoting healthy lives and well-being for all. Psychiatriki. 2018;29:52–7.

Chapter 5
Holistic Framework in Person Centered Medicine

C. Werdie Van Staden, C. Robert Cloninger, and John Cox

5.1 Introduction: Zooming-In and Zooming-Out in Medicine

Medicine as a discipline has made remarkable and laudable strides by virtue of zooming-in. It zooms in on specific diseases, organs, cells, genes and nowadays even on sub-molecular activities. It zooms in when acquiring generalizable knowledge as well as in the practical activities of making a diagnosis and devising treatments for an individual patient. These strides have been hard-won by vast research and cumulative practical experiences of indisputable benefits that this zooming-in accrues.

This strength of medicine holds a major risk for its own integrity, however. A failure to zoom out, so to speak, is at risk of suffering from a kind of simultagnosia. Seen also in neurology including patients with dementia, simultagnosia is a kind of blindness by which one is unable to recognize that which one observes, specifically

---

C. W. Van Staden (✉)
Faculty of Health Sciences, Centre for Ethics of Philosophy of Health Sciences, University of Pretoria, Pretoria, South Africa
e-mail: cwvanstaden@icon.co.za

C. R. Cloninger
Department of Emergency Medicine, Department of Psychiatry, Washington University School of Medicine, St. Louis, MO, USA
e-mail: c.robert.cloninger@wustl.edu

J. Cox
World Psychiatric Association, Geneva, Switzerland

International College of Person Centered Medicine, New York, NY, USA

Keele University, Keele, UK

Royal College of Psychiatrists, London, UK

International Marce Society, Brentwood, TN, USA

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_5

perceiving more than a single object at a time and how a perceived object relates to its context.

The holistic framework described in this chapter seeks to avert that a clinician and medicine as a discipline contract this kind of blindness. Instead the chapter deliberately creates space for developing medicine's strengths in zooming-out too. In some respects, the importance of zooming-out is already well-established in medicine. In pathophysiological accounts, for example, focusing on merely the heart without accounting for the cardiovascular system would be plainly naïve, if not clinically irresponsible.

Whilst this example of zooming-out from organs to physiological systems is hardly at issue, this chapter describes a framework on how far medicine should zoom out, not only to avert a professional simultagnosia, but also accrue the benefits of doing so. It considers three key concepts that may be construed too narrowly, resulting in a professional simultagnosia irrespective of being suffered by medicine as a discipline or the individual clinician. These are the concepts 'person-centered medicine', 'person' and 'health'. The chapter describes a framework by which to attain a holistic take on these concepts—that is, zooming out in ways that accrue optimal benefits for both the discipline of medicine and serving patients individually and collectively.

5.2 Zooming-Out from Patient-Centered Medicine to Person-Centered Medicine

Patient-centered Medicine and Person-centered Medicine overlap in part. Both advocate, for example, a deliberate shift from too narrow a focus on merely a disease, symptoms and signs, a bodily organ, a physiological system such as the cardiovascular system, the body, or the mind (as for psychiatric disorders). Patient-centered Medicine advocates a shift from these clinical foci to putting the patient central to clinical practice, attending to what the patient wants and (as it features most commonly in the literature) his or her satisfaction with clinical services [1, 2]. Person-centered Medicine extends further, notwithstanding the overlap [3, 4]. This is presented in the Venn-diagram seen in Fig. 5.1.

Zooming-out from Patient-centered Medicine to Person-centered Medicine extends the holistic framework in terms of six respects. The first four respects concern the concept of a person, for which details are considered in the next section. The fifth and sixth respects will be considered in subsequent sections. The six respects are as follows:

1. *A person is more than a mere patient*

   Person-centered Medicine puts the person before his or her role as a patient. This difference is important in that it recognizes (a) the various roles of the person including his or her roles of patient, parent, citizen, student, etc.; (b) that a specific person is not the same as the next person (as if just another patient for example); and (c) each person is constituted in part by his or her particular circumstances, expressed by the philosopher Ortega as "I am I and my circumstance".
2. *A practitioner is also a person with various roles*

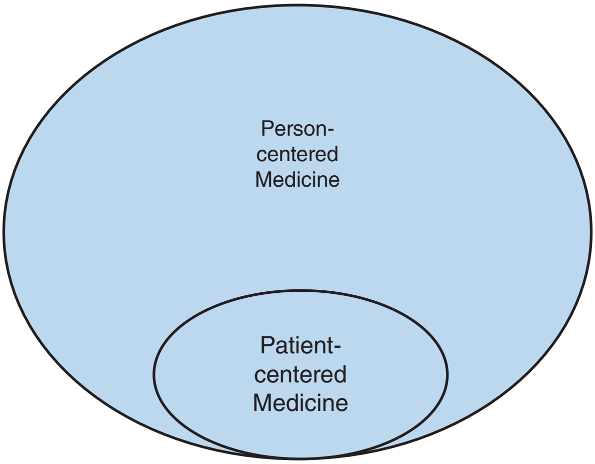


Fig. 5.1 Conceptual Venn-diagram depicting the relation between person-centered medicine and patient-centered medicine

Person-centered Medicine puts central not only one person in his or her patient role, but recognizes that the practitioner is also a person with various roles. These roles are both professional and personal. Professional roles include being a service provider, a representative of his or her profession, an agent of his or her institution or employer, a researcher, or a clinical pedagogue. Personal roles include being a potential patient, a parent, a family member, an employer, an employee, a community member, a citizen, etc.

3. *Other persons are crucial too, also when neither a patient nor practitioner*

   Person-centered Medicine recognizes persons other than the patient or the practitioner as being crucial in healthcare. These include family members, employers, institutional managers, policy makers, etc.

4. *Interpersonal relationships are crucial*

   Person-centred Medicine situates a person not only in his or her roles and circumstances (see above), but also within relationships with other people [5]. As part of healthcare, these relationships should be nurtured [6]. They are furthermore constitutive of person-centered processes [7]. For example, within interpersonal processes shared understanding is pursued, treatment plans are conjointly created, shared decisions are made [8], and informed consent is sought and given (or declined) [9].

5. *Experiences of persons are crucial*

   Experiences of persons are crucial. They are not just about satisfaction, but what it is (like) “for me”, what matters to “me” in “my” specific circumstance. Taking the first person experience of a specific person as crucial means his or her values [10], interests and preferences are given a central place in healthcare, not merely as an add-on but at the core of healthcare and shared decision making [11].

6. *Both positive and negative health should be attended*

   Person-centered Medicine attends to negative health—that is, for example, when someone is diseased. Person-centeredness requires more than this, though. It requires attention to positive health as well. This includes the person’s well-being, strengths and resilience. Congruent with the WHO's definition of health [12], this means health promotion extends beyond the prevention and treatment of disease. Furthermore, attending to both positive and negative health should extend to the experiences of persons (see point 5 above). This means the person's experiences of not only negative health but also his or her well-being feature in a person-centered approach.

Zooming-out in these six respects extends the holistic framework of Person-centered Medicine in its conceptual scope, which should be distinguished from the means and principles by which its scope is addressed [3]. There are of course many means by which to pursue the full scope of Person-centered Medicine as evident in many chapters of this book. These include for example good communication, interpersonal interaction and engagement, and accounting for values and experiences of all the people involved. Principles by which to pursue Person-centered Medicine include for example honoring the dignity, autonomy and rights of the person(s), beneficence, non-maleficence, distributive justice, duty to care, respect for differences and diversity, social and communal responsibility, etc. Means and principles of Person-centered Medicine are also captured in the Person-centered Care Index [3].

In this zooming-out, the concept of a person features centrally. The next section considers zooming-out and zooming-in specifically in relation to the concept of a person.

5.3 The Concept of a Person in a Holistic Framework

In pursuit of a holistic framework, the biopsychosocial model has provided a way in which to zoom-out from the usual biological interests in disease, symptoms, clinical signs, organs, and physiological systems. It served well for zooming-out, bringing into view also the psychological and social aspects of a person. In recent years, further zooming-out added cultural and spiritual interests in respectively an extended bio-psycho-social-cultural and a biopsychosocial-spiritual model [13–16]. The zooming-out of these extended models has helped in capturing a more holistic framework than afforded by mere biological interests.

However, even these extended biopsychosocial models are inadequate in their conceptual reach and scope for addressing the person holistically rather than in a reductionist way. Reductionist thinking impoverishes the concept of a person [17]. This is marked by "nothing but" claims, by which, in this instance, the concept of a person is thought of as being *nothing but*, say, *x*. Through times, there have been various examples of *x*. In law, for example, *x* has been taken as nothing but the bearer of legal rights, meaning that someone who does not have rights would not qualify as a person. By this take in history a slave or a child did not qualify as a person. 'Person' has also respectively been reduced to a self, a human being, a human body, the mind of a person, the psychology of a person, the personality or character of a person, the experiences of a person, a conjunction of mind and body, etc.[17, 18]. All of these reductionist takes on the concept of a person fail the test of its ordinary usage. Ordinary language philosophy appeals to the way in which we ordinarily use a term as a first step in elucidating its conceptual scope [19]. That is, through ordinary language philosophy, all of the above reductionist understandings of personhood have been refuted for being too narrow in scope, for the use of personal pronouns as indication of human personhood extends further [18, 20].

For conceptual adequacy in attending to the person holistically, ordinary language philosophy guides us in zooming-out and recognizing a multitude of attributes ascribed to a person [10]. An incomplete list of these are presented in Table 5.1. For a holistic framework, these attributes inform us on the scope of a holistic approach to a person. It is clear that attributes of a person extend way beyond biological, psychological and social attributes. The rights of a person, for example, are not properly captured among, or entailed within, biological, psychological and social attributes. Similarly, the needs of a person include subjective and objective needs that may or may not be biological, psychological or social needs. Recognizing the various attributes of a person helps in informing us on the richness of personhood, averting a (simult)agnosia and debunking impoverished conceptualizations of a person.

The Venn-diagram in Fig. 5.2 depicts the conceptual relation between a person and his or her attributes. The attributes of a person are conceptually entailed within the concept of a person, but the attributes are not exhaustive of personhood.

Table 5.1 Incomplete list of attributes of a person

Needs	Rights	Mind	Body	Organs
Family	Autonomy	Thoughts	Anatomy	Tissues
Community	Sovereignty	Experiences	Physiology	Cells
Roles	Interests	Emotions	Chemicals	Molecules
Relationships	Values	Behaviours	Genes	Genome
Culture	Beliefs	Actions	Functioning	Illness
Religion	Expectations	Desires	Vulnerability	Resilience
Spirituality	Goals	Satisfaction	Circumstances	Well-being
Faith	Reasons	Life	Living	Health
Attitudes	Beauty	Appearances	Inclinations	Habits
History	Volition	Vigour	Virtues	Personality

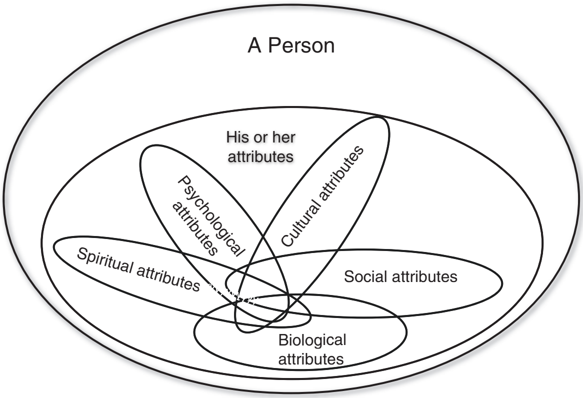


Fig. 5.2 Conceptual Venn-diagram of a person and his or her attributes

Zooming-out in this way informs us on the conceptual adequacy in attending to the person holistically. Ordinary language philosophy also guides us on attending to the person specifically, not only holistically. This is, zooming-in on the person, which is different from zooming-in on the attributes of a person. In other words, a crucial distinction should be observed between a person and his or her attributes. Mere attendance to his or her attributes, does not necessarily entail that one has attended to the person.

This means, moreover, in attending to the person specifically, we should resist a reduction of the person to any of these attributes as if they were a person, or if a person is essentially nothing but any of these. For example, the clinician should caution against essentialist thinking by taking *the person as nothing but*: a body; a set of genes (when doing genetic counselling for instance); a mind (which is a risk particularly in case of psychiatric disorder); a bearer of legal rights; a mere patient (thus restricting the person to his or her role); a life (which is a risk perhaps most relevant in emergency situations); his or her experiences; or as mere exemplar of a particular culture or faith. Similarly, personalized approaches in precision medicine should be cautious, for the personalization speaks to the person's specific biological (or genetic) profile, thus his or her attributes, and not to the person him- or herself.

Nor is a person merely an accumulation of all his or her attributes. A practical and clinical dialogue may make this point convincingly. An intelligent and sincere patient looking at Table 5.1 may respond validly: "Doctor, it's great that you consider and attend to my attributes—my disease, my mind, my roles, my rights, etc. They are after all mine. However, what about me? Attending to any and even all of my attributes, does not necessarily mean you have attended to me. Even if you attend to how I experience my illness or my health, you have not necessarily attended to *me*—I am not only my experiences". This response underscores that a person is not a mere attribute, or collation of attributes. It also underscores that a person, instead, is actively constituted and reaffirmed by reciprocal interpersonal enactment within relationships. This is the reason that Person-centered Medicine (PCM) is crucially based on relationships [5–7] (See above for the fourth respect in which person-centered medicine differs from patient-centered medicine).

Zooming-in on the person is not the same as zooming-in on his or her attributes. In PCM, zooming-in on the person is the core and crucial ethic, but more is required [21, 22]. Zooming-out in recognizing the multiple attributes of a person, provides the holistic framework for PCM. Neither zooming-in on the person, nor zooming-out in recognizing his or her attributes, however, precludes zooming-in on any of the attributes. Actually, it is medically an imperative that we do zoom-in on the attributes too.

Practically, one may anticipate some tension between attending to specifically the person versus attending to his or her attributes. Attending to each, for example, competes for the clinician's time. A virtuous clinician would strike a good balance by applying his or her mind as would be appropriate to the specific patient, as well as by virtue of reciprocal communication between the clinician and patient on this matter.

It may be objected that the multitude of attributes may be overwhelming practically. This is, the clinician would have great difficulty attending to all these attributes, and some attributes may not be clearly within the professional scope of the clinician. A holistic framework, however, does not require the clinician to attend to all attributes, but provides for the recognition of these attributes, their scope, their overlap, their contextual fit, and their potential relevance rather than claiming that they are necessarily relevant. As applicable in case of a simultagnosia and agnosias generally, there is not even the possibility of attending to an attribute if not even recognized as potentially important in the first place.

Attending clinically to all attributes would thus be pursuing a pie in the sky. However, the clinician should recognize among the many attributes those of potential relevance, and necessarily and specifically attend to the person, not merely his or her attributes. The clinician should do so as a person engaging reciprocally with another person (but not merely in his or her patient role) [6, 8].

Zooming-out in recognizing the multiple attributes of a person comes with the insight that the attributes of person have a commonality by which they are connected non-trivially even if obviously so. This is, they all belong to the person. Any zooming-in on an attribute of a person is in doing so, extricating that attribute from a person, and selectively segregating the various attributes that are not so segregated in the first place [18]. The person comes first whereas the extricated attributes are derivatives from the person. The knowledge we obtain of any extricated attribute (for example, the knowledge of a person's vasculature) may thus be understood as an epistemological artifact of our zooming-in on it. The clinician who has insight into this, would appreciate the need for healthcare that is integrative by which coherence may be re-established among the segregated diagnostic and therapeutic "zooming-ins" on the various extricates or attributes of the person [4].

5.4 The Concept of Health in a Holistic Framework

The WHO's definition of health espouses a zooming-out from diseases and disease prevention, and thereby includes well-being and health promotion. It defines health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity [12].

Similar to the inadequate scope of the biopsychosocial model, the WHO's concept of health should also be broadened further in a holistic framework. "Physical, mental and social" in its definition is not exhaustive of the attributes of a person (as considered in the previous section), yet most of the attributes listed in Table 5.1 are contingent matters of health, and may be relevant in disease, illness, injury and disability as well as in well-being and health promotion.

Health does not merely pertain to these attributes, but is itself an attribute of a person. We speak accordingly of the health *of* a person. The preposition "of" in the preceding sentence is one of four practical positional angles between 'health' and 'person' articulated by Person-centered Medicine [3]. The others are "*with* a person", "*by* a person", and "*for* a person", which in short articulate respectively, the interpersonal aspect of health, agency in health (for example, by patient and practitioner), and provisions of health(care) and promoting the fulfillment of the person's life project.

These prepositional angles may be applied to health promotion. Health promotion *of* the person, if it is to be effective, has to increase his or her knowledge and awareness of how to live and function well. Health promotion *with* the person helps a person to identify and accept valued goals. It teaches self-regulatory skills that enhance self-efficacy in functioning. Health promotion *by* the person supports the integration of this factual knowledge and personal values in supporting a commitment to change that cultivates plasticity. Health promotion *for* the person assures that values are directed toward enhanced personal and collective well-being. Values that are optimally healthy and prosocial are self-transcendent and virtuous because social inequality and personal vices are unhealthy for individuals and the social groups in which they live [23]. Thus person-centered health promotion works by activation of synergy among healthy functioning, plasticity, and virtue [24, 25].

The health of a person encompasses the health of his or her attributes. Since the attributes of a person are in the first place not segregated prior to our epistemological zooming-in on them, their connectedness within the health of a person should be expected. The interconnectedness among healthy attributes of a person is commonly considered among biological attributes. For example, there is an abundance of data on the healthy interconnections among genes, cells, tissues and physiological systems. Considered less often are the healthy interconnections among personality, interpersonal relationships, and biological attributes.

Healthy interconnections among personal attributes are evident in specifically well-being. This should be expected considering that well-being is at the core of the WHO's definition of health. Before considering benefits of promoting well-being, the next section on a healthy personality also underscores the interconnections among personal attributes, but without reducing the health of a person as if nothing but the health of his or her personality. A healthy personality cuts conceptually across various attributes of a person.

5.4.1 What Is a Healthy Personality?

Personality provides a reliable way to assess the quality of a person's functioning in the general population as well as with psychiatric and other medical patients with physical disorders [26, 27]. To promote physical, mental, and social well-being, it is necessary to promote the healthy personality development that underlies healthy living. Perhaps the inadequacies of past efforts at health promotion can be explained by the need to more fully accept the fact that a person's well-being depends on the development and maintenance of a healthy personality, not just knowledge, external support, and encouragement although those things represent part of the necessary resources. So we need to know what a healthy personality is.

Three key practices have consistently been shown to lead to the development of well-being: (1) letting go, (2) working in the service of others, and (3) growing in awareness [28, 29]. Letting go involves acceptance of who you really are so that you can develop realistically and calmly without fighting or worry. Acceptance and letting go are expressions of hope, rather than giving in to excessive or insatiable desires. Working in the service of others is expressed as genuine acts of kindness, which are satisfying even when it involves personal sacrifice. Serving others is an expression of love, rather than giving into fear and selfishness. Growing in awareness is the result of using our intelligences to listen to all aspects of our being. Through reflection, meditation, and contemplation a person can discover more about one's self and the mysteries of one's inseparable relations to others and the world as a whole. Awareness is the actualization of the benefits of faith. Such faith is based on the insight and conviction that comes from intuitive understanding, rather than blind acceptance of dogmatic assertions by external authorities.

Each of the practices that lead to well-being are functional expressions of the character traits of Self-directedness, Cooperativeness, and Self-transcendence. Self-directedness (i.e., being resourceful, purposeful, self-accepting, responsible, and foresighted) leads to confidence about one's ability to accomplish valued goals, and such self-confidence is a way of describing hopefulness. Consequently people who are highly self-directed are accept who they are really and can admit to faults and weaknesses, whereas others are too proud or ashamed to admit their faults [28].

Cooperativeness (i.e. being tolerant, helpful, empathic, principled, and compassionate) is an indicator of a person's disposition toward kindness and compassion for one's fellow human beings. Such loving kindness and compassion motivates a person to work in the service of others, rather than for personal gain [28]. Acts of kindness are satisfying and enhance physical, mental, and social aspects of well-being [30–32]. Acts of kindness make people happy [31], and happy people experience less pain [32], have improved cardiovascular health and resilience [30], fewer accidents and suicides, and live longer [33].

Self-transcendence (i.e., being intuitive, imaginative, easily absorbed and engaged in what is valued, and spiritually accepting) indicates capacity for insight from meditation and contemplation. Such contemplation leads to enhanced awareness, self-knowledge, and peak experiences of the inseparability of all things [28]. Mindful meditation has been shown experimentally to reduce stress and enhance objective indicators of well-being [34, 35].

Meta-analysis of longitudinal studies and experimental interventions show that increases in subjective well-being are predictive of reduced morbidity and mortality and of improved objective health and longevity [34, 35]. The effect size of the correlation between changes in subjective well-being with changes in objective physical health is weak (r = 0.14–0.16) in both longitudinal studies and in experimental interventions [35]. An effect size of 0.15 corresponds to an odds ratio around 1.3 for improvement, which indicates that most people are not substantially improved in objective measures of physical health from changes in subjective well-being [36]. Medical morbidity and mortality in 7-year follow-up is more strongly predicted by the absence of positive well-being than by the presence of negative well-being, but the effects are still weak and inconsistent [37].

Personality traits are predictive of later health status and mortality in longitudinal studies using the personality questionnaires measuring three and five factor models [38, 39]. High Neuroticism and low Conscientiousness are often predictive of higher mortality, but the results have been weak and inconsistent [39, 40]. More consistent predictors of health outcomes can be identified using Ryff's measures of psychological well-being (such as autonomy and self-control) [41, 42] and the character measures from the Temperament and Character Inventory (TCI) previously described here [43–45]. The TCI was the strongest predictor of clinical health outcomes among all 14 multidimensional personality inventories tested in a longitudinal study in the USA [46]. The average of the TCI's multiple correlation with six clinical indicators of psychopathology was r = 0.53 compared to the averages for other personality tests (r = 0.27–0.45). Hence the linear prediction of mental health outcomes by antecedent personality traits is moderate in strength.

Multidimensional personality profiles are the most consistent predictors of well-being because they specify synergistic non-linear interactions. Specifically, the combination of all three TCI character dimensions (i.e., high Self-directedness, Cooperativeness, and Self-transcendence) predicts greater physical, mental, and social well-being than any other profile or individual trait [43]. The profiles are more informative than the average (linear) effects of the same traits for both mental health and physical health outcomes [43, 45].

The synergistic quality of all three character dimensions is called creativity and the healthy personality configuration is called the creative character profile [24]. Creativity can be defined as the *original, adaptive, and beneficial innovation* that emerges from the combination of high self-directedness (i.e., resourceful, realistic, and self-accepting), cooperativeness (i.e., tolerant, helpful, and empathic), and self-transcendent (i.e., intuitive, imaginative, and spiritual). Creativity depends on all three of these components of character because it must be (1) *original* (i.e., using imagination or innovative ideas to solve problems or to invent new and better solutions to traditional approaches, as is characteristic of highly self-transcendent people), (2) *adaptive* (i.e., a realistic way to use available resources to make something suitable for a new use or purpose, as is characteristic of highly self-directed people), and (3) *beneficial* (i.e., being favorable, helpful, or advantageous for others so that it becomes adopted by the culture or social group, as is characteristic of highly cooperative people). There is no consensus about a single definition or test for measuring creativity despite much study of the topic, but there is agreement that creative processes are original, adaptive, and beneficial for one's self or others [47–49]. Sometimes the word "adaptive" is taken broadly to imply both realistic and beneficial. In any case, the importance of creative products being socially valued and benefiting others has been well-documented in studies of creative achievement [50–52]. Creativity has been shown to be strongly related to three facets of individual differences: differences in (1) intellectual abilities (e.g., divergent thinking, imagination, aesthetic sensibility), (2) personality traits (e.g., tolerance of ambiguity, desire to grow, desire to work for recognition, willingness to take risks and try to overcome obstacles), and (3) character style or style of mental self-government (e.g., a progressive legislative style, which finds enjoyment in creating one's own rules and ways of doing things, looking for new things to do and for new ways to do old things), and [49, 53, 54].

Overall, creativity is a process that occurs within creative people in particular states of mind in a particular psychosocial context [28, 50]. Specifically, the creative character profile (i.e., the combination of being highly self-directed, cooperative, and self-transcendent) facilitates a person getting in a creative state of mind (i.e., calm alertness with a flowing intuitive awareness that awakens automatic intelligences), thereby helping a person to discover original solutions that are adaptive for one's self and others.

Each of the three TCI character traits contributes to positive affect and life satisfaction regardless of the level of the other two traits, and the combination of all three has a stronger correlation with subjective well-being than expected from the sum of the three individual contributions [43]. In other words, the dynamic non-linear interaction among these dimensions has a synergistic effect to enhance physical, mental, and social aspects of well-being.

The creative process emerging from the healthy character configuration has concrete and practical benefits. People with high Self-transcendence have a vivid imagination, and this leads to creativity when combined with realistic thinking typical of high Self-directedness and with schizotypal or magical thinking when combined with low Self-directedness [55]. In contrast, people who are high in Self-directedness and Self-transcendence, but low in Cooperativeness, are generally regarded as "fanatics" and often act with hostility or in ways that are destructive for themselves and others, so they are not regarded as creative despite their ingenuity. People who are "organized" (i.e., high in Self-directedness and Cooperativeness, but low in Self-transcendence) have often been considered to have healthy personalities, but they are still vulnerable to being self-centered, materialistic, and conventional unless they are also high in Self-transcendence [56]. Creative processes require a freedom of will and thought that is not constrained by past conditioning and traditional beliefs [57, 58].

Creativity must not be regarded as a rare capacity of exceptional individuals. Existential and phenomenological approaches to medicine recognize that each moment in life is a creative process in which all people are transforming their past experiences and future hopes into the more-or-less adaptive actualization of the present moment. Illness provides the opportunity for creative development by increased awareness of our all three aspects of our being (i.e., body, thoughts, and soul), but only if we allow ourselves to accept reality and to grow in its understanding [59]. Our pains and fears force us to enlarge our consciousness if we are to adapt adequately. From this adaptive perspective, health is adequate creativity and an illness is inadequate adaptation [60]. From this person-centered perspective, Victor von Weizsaecker, observed that illnesses revealed meaningful information about reciprocal psychosomatic interactions that create health. From his clinical observations in psychosomatic medicine and his experimental observations about the phenomenology of perception, thought, and movement, he suggested that we become sick when we are not in a creative dynamic state:

> "The health of a human being is not just capital to be consumed;
> rather health is actually present only when it is created in each moment of life.
> If health is not being created, then a person is already sick [61]."

Essentially, when we are not growing creatively, we are consuming what health we have until we become ill, unhappy, and empty. When we are healthy, we are energetic, happy, and fulfilled because we are living creatively in each moment.

5.4.2 Benefits of Promoting Well-Being

Mental Well-being: It is well established that a creative way of living (measured by a creative TCI character profile) is linked with greater subjective well-being, including greater life satisfaction (cognitive aspect of subjective well-being) and a more positive balance between positive and negative affect (the emotional aspect of subjective well-being) [43, 44]. However, higher self-transcendence can also lead to increases in negative emotions, particularly in secular societies where self-transcendent attitudes are in disfavor, but even then positive affect is greater than negative affect in adults [44]. During adolescence, the roles of self-directedness, cooperativeness, and persistence appear to be more important than self-transcendence [62, 63]. The role of self-transcendence becomes clear only when individuals must cope with ultimate situations, like suffering, personal death, or mass extinction, which may occur at any age but only are recognized fully in older adults [56, 64–66].

Physical Well-Being: Both personality profiles and heart rate variability are predictive of physical morbidity and mortality [67, 68]. The impact of personality is not fully explained by people's choice of healthy lifestyles, such as habits about diet, physical exercise, and health care utilization [69]. In order to explore the physiological pathways by which personality influences physical health, we have studied relations between personality profiles and heart rate variability, which is sensitive to a variety of emotional and physiological stressors. We found that creativity, measured as the product of the three character scores in the TCI, was significantly correlated ($r = -0.3$) with healthy autonomic balance with predominance of parasympathetic activity, as measured by the ratio of high frequency (sympathetic) activity to low frequency (parasympathetic activity) [69]. In contrast, other character profiles (in which any one of the character dimensions was low) were not significantly correlated with healthy autonomic balance [69]. Agreeability is associated with greater parasympathetic activity but does not reduce sympathetic activity, whereas forgiveness reduces sympathetic activity but does not increase parasympathetic activity [69].

Greater parasympathetic balance is characterized by a state of calm alertness; it is facilitated by slow, deep breathing and is disrupted by stress or defensiveness. Defensiveness (i.e., fight or flight responses, including both aggression or avoidance) is characterized by sympathetic hyperactivity. All three TCI character traits are correlated with greater parasympathetic activity individually, and the product of the three together was greater than their individual association, indicating that there is synergy among these traits that leads to autonomic balance. Experimental interventions show that psychophysiological training with slow, deep breathing and cultivation of positive affect can enhance heart rate variability and thereby promote healthier outcomes [70, 71].

Dean Ornish has developed multi-modal training programs including diet, emotional self-regulation, and meditation to prevent or reverse coronary heart disease. Ornish has found in longitudinal studies that they lead to improved well-being, including longer telomeres (a predictor of longevity) compared to others who do not change their lifestyle [72–74]. Nevertheless, personality has not been measured with the TCI in Dean Ornish's program of lifestyle change, and the directions of influence among the several changing processes involved in comprehensive lifestyle change remain uncertain. The interactions among the multifactorial processes will need to be considered as components of a complex adaptive system [75].

<u>Social Well-Being</u>: Creativity is associated with perception of warm and satisfying social relationships [43]. The processes underlying the prosocial benefits of creativity have been studied in detail in negotiation and conflict resolution [76, 77]. Stable and satisfying social relationships depend on emotional communication that combines assertiveness with mutual respect, thereby leading to innovative and nonviolent resolution of disagreements. Non-violent communication must begin with establishing a context of mutual respect and shared goals. In order to be authentic, there must be the opportunity to express and assert what each person feels and thinks candidly. Yet to avoid violence and resistance, there must be a freedom and openness to change that involves innovative solutions emerging from respectful dialogue. The same principles of non-violent communication can be applied to negotiation generally. Again in social aspects of health we can recognize a complex adaptive system involving multiple reciprocal feedback systems, in which trust stimulates openness, which in turn reinforces change with increases in trust. Similar mechanisms are involved in the formation and maintenance of a helping therapeutic alliance [78, 79].

<u>Spiritual Well-being</u>: Studies of the benefits of spirituality show that there are positive benefits from spiritual acceptance that there is a divine order like justice in the cosmos [80, 81] because this conviction is a basis for hope and other self-transcendent virtues that are characteristic of people who recover from physical and mental disorders [82]. Meta-analyses show that intrinsic motivations like love, hope, and faith led to positive psychological adjustments, whereas extrinsic motivation (doing outwardly pious acts to be seen by others) and avoidance of dealing with one's problems by withdrawing into religious activities led to negative mental and physical outcomes [83–87]. Religious struggles (like feeling God had abandoned you) has been associated with slightly increased mortality [85]. The effect of spiritual acceptance as a single variable to reduce mental distress or to improve health is weak in large-scale meta-analyses ($r = 0.09$) [83, 87].

Intrinsic motivation is based in inner awareness of a connection with something beyond one's self, which inspires a sense of meaning and commitment to valued action [88]. Creativity is consistently characterized by intrinsic motivation and a sense of meaning in life. Self-transcendence involves awareness of what gives meaning and purpose to a person beyond the selfish acquisition of pleasure, power, and possessions [65, 89]. The spiritual aspects of health are often discussed in secular cultures by reference to the strong human needs for engagement and meaning, as emphasized in Seligman's model of psychological health based on Positive Emotions (i.e., feeling good), Engagement (i.e., being completely absorbed in valued actions), Positive Relationships (i.e., being authentically connected to others), Meaning (i.e., feeling your existence has a significant purpose), and Accomplishments (i.e., feeling successful in what you have done) (PERMA) [90]. Engagement is one of the facets of TCI Self-transcendence; people frequently become so absorbed in doing something they value, that they lose track of time and place for a while, so it is labeled as "self-forgetfulness" in the TCI [28, 88]. When people are asked what has given them the most lasting satisfaction in their life, the feeling of accomplishment is one of the three most common experiences they report, along with satisfaction with warm social relations and discovery of what gives them meaning [28, 91]. All of these aspects of the good life arise from using intuition to grow in awareness of who you really are and what you truly value so that you can flourish (i.e., function with happiness, plasticity and virtue).

In psychoanalytic terms, healthy and wise people function using the mature defenses of sublimation (i.e., letting go of desire for personal pleasure to accomplish something meaningful or beautiful, like an artistic creation), altruism (i.e., serving others unselfishly), hopeful anticipation (i.e., anticipating and preparing for possible future adversity by living moderately) with a sense of humor and humility [92]. People with creative characters are the individuals who are most aware of their need for coherence and self-actualization, which leads them to work on the development of wisdom and integrity [28]. Hence the healthy life is good life, and the good life is also the happy life. Lives that are healthy, happy, and good all involve doing what you value with flexibility, integrity, and wisdom.

5.5 Conclusion: A Holistic Perspective on Both a Person and Health

In attending to a person holistically, we should recognize a multitude of attributes ascribed to a person. The multitude of attributes informs us on the scope of a holistic approach to a person, extending beyond biological, psychological and social attributes addressed by a biopsychosocial model. Recognizing these, averts a professional (simult)agnosia and debunks impoverished reductionist conceptualizations of a person. Instead, a person is recognized as distinct from his or her attributes, even though inseparable from some attributes like his or her mind, for example. In attending to the person specifically, we should resist a reduction of the person to any of his or her attributes. A human person is not merely a mind, or a mind plus a body, or his or her experiences, or "a life", but a specific someone endowed with various attributes, who interacts with others and with whom we may interact.

In a holistic framework, PCM attends crucially and specifically to the person, recognizing his or her many attributes while attending contingently to some attributes as may be clinically prudent. Zooming-in on an attribute of a person is in doing so, extricating that attribute from a person, and selectively segregating it from other attributes and the person. The extricated attributes may thus be understood as epistemological artifacts of our clinically warranted zooming-in on them. This means an integrative approach is needed in which coherence may be re-established among the segregated diagnostic and therapeutic "zooming-ins" on the various attributes of the person.

Congruent with the WHO's definition of health, a holistic framework extends further than providing for diseases and their prevention. It espouses the promotion of well-being, which fosters empirically supported health benefits for individuals and society. One such benefit is developing a health personality. The most consistent and strong predictor of both subjective well-being and objective health status in longitudinal studies is a creative personality profile characterized by a person being highly self-directed, cooperative, and self-transcendent.

Reviews of the scientific literature and professional experience suggest that health and flourishing can be cultivated most effectively by adopting a holistic framework that attends to the person and not only the attributes of a person, and in addition integrates attendance to the various dimensions and attributes of a person. In the absence of a holistic framework and approach, health would not be understood fully and health care and health promotion are likely to have only weak and inconsistent benefits.

Acknowledgements and Disclosures The authors report no conflicts of interest in the preparation of this manuscript.

References

1. Hudon C, Fortin M, Haggerty JL, Lambert M, Poitras ME. Measuring patients' perceptions of patient-centered care: a systematic review of tools for family medicine. Ann Fam Med. 2011;9:155–64.
2. Scholl I, Zill JM, Harter M, Dirmaier J. An integrative model of patient-centeredness—a systematic review and concept analysis. PLoS One. 2014;9:e107828.
3. Mezzich JE, Appleyard J, Botbol M, Salloum IM, Kirisci L. Conceptualization and metrics in person centered medicine. Int J Pers Cent Med. 2017;6:213–8.
4. Mezzich JE, Salloum IM, Cloninger CR, Salvador-Carulla L, Kirmayer LJ, Banzato CE, Wallcraft J, Botbol M. Person-centred integrative diagnosis: conceptual bases and structural model. Can J Psychiatry. 2010;55:701–8.
5. Crepaz-Keay D, Fulford KWM, Van Staden CW. Putting both a person and people first: interdependence, values-based practice and African Batho Pele as resources for co-production in mental health. In: Sadler JZ, Van Staden CW, Fulford KWM, editors. Oxford handbook of psychiatric ethics. Oxford: Oxford University Press; 2015.
6. Gray A, Cox J. The roots of compassion and empathy: implementing the Francis report and the search for new models of health care. Eur J Pers Cent Healthc. 2015;3:122–30.

7. Cox J, Gray A. NHS at the hustings: four quality indicators for a person centred medicine. Eur J Pers Cent Healthc. 2015;3:1–3.
8. Van Staden CW, Fulford KWM. The Indaba in African values-based practice: Respecting diversity of values without ethical relativism or individual liberalism. In: Sadler JZ, Van Staden CW, Fulford KWM, editors. Oxford handbook of psychiatric ethics. Oxford: Oxford University Press; 2015.
9. Van Staden CW. Informed consent to treatment. In: Sadler JZ, Van Staden CW, Fulford KWM, editors. Oxford handbook of psychiatric ethics. Oxford: Oxford University Press; 2015.
10. Fulford KWM, Van Staden CW. Finding a word for it: an ordinary language philosophical perspective on the role of values-based practice as a partner to evidence-based practice. In: Stein D, Singh I, editors. Global mental health and neuroethics. Elsevier: Academic Press; 2020.
11. Kirmayer LJ, Mezzich JE, Van Staden C. Health experience and values in person-centered assessment and diagnosis. In: Mezzich J, Botbol M, Christodoulou G, Cloninger C, Salloum I, editors. Person centered psychiatry. Heidelberg: Springer; 2016.
12. WHO. Definition of health: preamble to the constitution of the World Health Organization. New York: World Health Organization; 1946.
13. Cox J. Conceptual and treatment approaches for a revitalised health service and renewed person-centered perinatal psychiatry. Int J Pers Cent Med. 2012;2:114–9.
14. Hilty DM. Advancing science, clinical care and education: shall we up-date Engel's biopsychosocial model to a Bio-psycho-socio-cultural model. Psychol Cogn Sci Open J. 2015;1:e1–6.
15. Sulmasy DP. A biopsychosocial-spiritual model for the care of patients at the end of life. Gerontologist. 2002;42 Spec No 3:24–33.
16. Wachholtz A, Fitch C. Spiritual dimensions of pain and suffering. In: Moore RJ, editor. Handbook of pain and palliative care: biopsychosocial and environmental approaches for the life course. Cham: Springer; 2018.
17. Van Staden CW. Conceptual and experiential estrangement of the self-a neo-Fregean elucidation. S Afr J Psychiatr. 2006;12:16–21.
18. Van Staden CW. Mind, brain and person: reviewing psychiatry's constituency. Afr J Psychiatry. 2006;9:93–6.
19. Fulford KWM, Van Staden CW. Values-based practice: topsy-turvy take home messages from ordinary language philosophy. In: Fulford KWM, Davies M, Graham G, Sadler JZ, Stanghellini G, Gipps R, Thornton T, editors. Oxford handbook of philosophy and psychiatry. Oxford: Oxford University Press; 2013.
20. Van Staden CW. Linguistic markers of recovery: theoretical underpinnings of first person pronoun usage and semantic positions of patients. Philos Psychiatr Psychol. 2002;9:105–21.
21. Christodoulou GN, Van Staden CW, Jousset D, Schwartz M, Mishara A. Ethics in person-centered psychiatry. Person centered psychiatry. Cham: Springer; 2016.
22. Van Staden W. African approaches to an enriched ethics of person-centred health practice. Int J Pers Cent Med. 2011;1:14–7.
23. Pickett K, Wilkinson R. The spirit level: why greater equality makes societies stronger. New York: Bloombury Press; 2009.
24. Cloninger CR, Cloninger KM. Person-centered therapeutics. Int J Pers Cent Med. 2011;1:43–52.
25. Cloninger CR, Cloninger KM. Development of instruments and evaluative procedures on contributors to health and illness. Int J Pers Cent Med. 2012;3:446–55.
26. Cloninger CR, Svrakic DM, Przybeck TR. A psychobiological model of temperament and character. Arch Gen Psychiatry. 1993;50:975–90.
27. Conrad R, Schilling G, Bausch C, Nadstawek J, Wartenberg HC, Wegener I, Geiser F, Imbierowicz K, Liedtke R. Temperament and character personality profiles and personality disorders in chronic pain patients. Pain. 2007;133:197–209.
28. Cloninger CR. Feeling good: the science of well-being. New York: Oxford University Press; 2004.

29. Cloninger CR. The science of well-being: an integrated approach to mental health and its disorders. World Psychiatry. 2006;5:71–6.
30. Davis MC. Building emotional resilience to promote health. Am J Lifestyle Med. 2009;3:60S–3S.
31. Otake K, Shimai S, Tanaka-Matsumi J, Otsui K, Fredrickson BL. Happy people become happier through kindness: a counting kindnesses intervention. J Happiness Stud. 2006;7:361–75.
32. Zautra AJ, Johnson LM, Davis MC. Positive affect as a source of resilience for women in chronic pain. J Consult Clin Psychol. 2005;73:212–20.
33. Frey BS. Happy people live longer. Science. 2011;331:542–3.
34. Howell RT. Review: positive psychological well-being reduces the risk of mortality in both ill and healthy populations. Evid Based Ment Health. 2009;12:41.
35. Howell RT, Kern ML, Lyubomirsky S. Health benefits: meta-analytically determining the impact of well-being on objective health outcomes. Health Psychol Rev. 2007;1:83–136.
36. Chinn S. A simple method for converting an odds ratio to effect size for use in meta-analysis. Stat Med. 2000;19:3127–31.
37. Huppert FA, Whittington JE. Evidence for the independence of positive and negative well-being: implications for quality of life assessment. Br J Health Psychol. 2003;8:107–22.
38. Abbott RA, Croudace TJ, Ploubidis GB, Kuh D, Richards M, Huppert FA. The relationship between early personality and midlife psychological well-being: evidence from a UK birth cohort study. Soc Psychiatry Psychiatr Epidemiol. 2008;43:679–87.
39. Jokela M, Batty GD, Nyberg ST, Virtanen M, Nabi H, Singh-Manoux A, Kivimaki M. Personality and all-cause mortality: individual-participant meta-analysis of 3,947 deaths in 76,150 adults. Am J Epidemiol. 2013;178:667–75.
40. Cloninger CR. How does personality influence mortality in the elderly? Psychosom Med. 2005;67:839–40.
41. Abbott RA, Ploubidis GB, Huppert FA, Kuh D, Wadsworth ME, Croudace TJ. Psychometric evaluation and predictive validity of Ryff's psychological well-being items in a UK birth cohort sample of women. Health Qual Life Outcomes. 2006;4:76.
42. Fava GA, Tomba E. Increasing psychological well-being and resilience by psychotherapeutic methods. J Pers. 2009;77:1903–34.
43. Cloninger CR, Zohar AH. Personality and the perception of health and happiness. J Affect Disord. 2011;128:24–32.
44. Josefsson K, Cloninger CR, Hintsanen M, Jokela M, Pulkki-Raback L, Keltikangas-Jarvinen L. Associations of personality profiles with various aspects of well-being: a population-based study. J Affect Disord. 2011;133:265–73.
45. Rosenstrom T, Jokela M, Cloninger CR, Hintsanen M, Juonala M, Raitakari O, Viikari J, Keltikangas-Jarvinen L. Associations between dimensional personality measures and preclinical atherosclerosis: the cardiovascular risk in Young Finns study. J Psychosom Res. 2012;72:336–43.
46. Grucza RA, Goldberg LR. The comparative validity of 11 modern personality inventories: predictions of behavioral acts, informant reports, and clinical indicators. J Pers Assess. 2007;89:167–87.
47. Pederson C, Seligman MEP. Character strengths and virtues: a handbook and classification. New York: Oxford University Press; 2004.
48. Sternberg RJ, editor. The nature of creativity. Cambridge: Cambridge University Press; 1988.
49. Vernon PE, editor. Creativity. Baltimore: Penguin; 1970.
50. Csikszentmihalyi M. Flow and the psychology of discovery and invention. Cambridge: Cambridge University Press; 1997.
51. Gabora L. Why blind-variation and selective-retention is an inappropriate explanatory framework for creativity: comment on "Creative thought as blind-variation and selective-retention: combinatorial models of exceptional creativity" by Prof. Simonton. Phys Life Rev. 2010;7:182–3.

52. Simonton DK. Creativity in science: chance, logic, genius, and zeitgeist. Cambridge: Cambridge University Press; 2004.
53. Sternberg RJ. A three-facet model of creativity. In: Sternberg RJ, editor. The nature of creativity. Cambridge: Cambridge University Press; 2004.
54. Taylor CW. Various approaches to and definitions of creativity. In: Sternberg RJ, editor. The nature of creativity. Cambridge: Cambridge University Press; 2004.
55. Smith MJ, Cloninger CR, Harms MP, Csernansky JG. Temperament and character as schizophrenia-related endophenotypes in non-psychotic siblings. Schizophr Res. 2008;104:198–205.
56. Cloninger CR. What makes people healthy, happy, and fulfilled in the face of current world challenges? Mens Sana Monogr. 2013;11:16–24.
57. Krishnamurti J. The first & last freedom. Brockwood Park: Krishnamurti Foundation Trust; 1954.
58. Krishnamurti J. The awakening of intelligence. New York: Harper and Row; 1987.
59. Wilberg P. The illness is the cure: an introduction to life medicine and life doctoring, a new existential approah to illness. Whitstable: New Yoga Publications; 2012.
60. Rimpau W, editor. A reader on Viktor von Weizsaecker's why you get sick? Frankfurt on Main: Suhrkamp; 2008.
61. Weizsaecker VV. Social disease and social recovery (vol. 8 of collected works, 1986). Frankfurt on Main: Suhrkamp; 1930.
62. Garcia D. Two models of personality and well-being among adolescents. Pers Individ Dif. 2011;50:1208–12.
63. Garcia D, Siddiqui A. Adolescents' psychological well-being and memory for life events: influences on life satisfaction with respect to temperamental dispositions. J Happiness Stud. 2009;10:407–19.
64. Cloninger CR. Completing the psychobiological architecture of human personality development: temperament, character, and coherence. In: Staudinger UM, Lindenberger UER, editors. Understanding human development: dialogues with lifespan psychology. London: Kluwer Academic Publishers; 2003.
65. Jaspers K. The way to wisdom: an introduction to philosophy. New Haven: Yale University Press; 1954.
66. Josefsson K, Jokela M, Cloninger CR, Hintsanen M, Salo J, Hintsa T, Pulkki-Raback L, Keltikangas-Jarvinen L. Maturity and change in personality: developmental trends of temperament and character in adulthood. Dev Psychopathol. 2013;25:713–27.
67. Bradley RT, McCraty R, Atkinson M, Tomasino D, Daugherty A, Arguelles L. Emotion self-regulation, psychophysiological coherence, and test anxiety: results from an experiment using electrophysiological measures. Appl Psychophysiol Biofeedback. 2010;35:261–83.
68. Carney RM, Blumenthal JA, Stein PK, Watkins L, Catellier D, Berkman LF, Czajkowski SM, O'Connor C, Stone PH, Freedland KE. Depression, heart rate variability, and acute myocardial infarction. Circulation. 2001;104:2024–8.
69. Zohar AH, Cloninger CR, Mccraty R. Personality and heart rate variability: exporing pathways from personality to cardiac coherence and health. Open J Soc Sci. 2013;1:32–9.
70. McCraty R, Atkinson M, Lipsenthal L, Arguelles L. New hope for correctional officers: an innovative program for reducing stress and health risks. Appl Psychophysiol Biofeedback. 2009;34:251–72.
71. McCraty R, Atkinson M, Tomasino D, Goelitz J, Mayrovitz HN. The impact of an emotional self-management skills course on psychosocial functioning and autonomic recovery to stress in middle school children. Integr Physiol Behav Sci. 1999;34:246–68.
72. Ornish D, Lin J, Daubenmier J, Weidner G, Epel E, Kemp C, Magbanua MJ, Marlin R, Yglecias L, Carroll PR, Blackburn EH. Increased telomerase activity and comprehensive lifestyle changes: a pilot study. Lancet Oncol. 2008;9:1048–57.

73. Ornish D, Scherwitz LW, Billings JH, Brown SE, Gould KL, Merritt TA, Sparler S, Armstrong WT, Ports TA, Kirkeeide RL, Hogeboom C, Brand RJ. Intensive lifestyle changes for reversal of coronary heart disease. JAMA. 1998;280:2001–7.
74. Pischke CR, Frenda S, Ornish D, Weidner G. Lifestyle changes are related to reductions in depression in persons with elevated coronary risk factors. Psychol Health. 2010;25:1077–100.
75. Cloninger CR, Salloum IM, Mezzich JE. The dynamic origins of positive health and wellbeing. Int J Pers Cent Med. 2012;2:1–9.
76. Gottman JM, Gottman JS, Declaire J. Ten lessons to transform your marriage. New York: Crown Publishers; 2006.
77. Rosenberg MB. Nonviolent communication: a language of compassion. DelMar, CA: PuddleDancer Press; 1999.
78. Hilsenroth MJ, Cromer TD. Clinician interventions related to alliance during the initial interview and psychological assessment. Psychotherapy. 2007;44:205–18.
79. Hilsenroth MJ, Peters EJ, Ackerman SJ. The development of therapeutic alliance during psychological assessment: patient and therapist perspectives across treatment. J Pers Assess. 2004;83:332–44.
80. Bach P, Hayes SC, Gallop R. Long-term effects of brief acceptance and commitment therapy for psychosis. Behav Modif. 2011;36:165–81.
81. Ellermann CR, Reed PG. Self-transcendence and depression in middle-age adults. West J Nurs Res. 2001;23:698–713.
82. Amering M, Schmolke M. Recovery in mental health. New York: Wiley; 2009.
83. Ano GG, Vasconcelles EB. Religious coping and psychological adjustment to stress: a meta-analysis. J Clin Psychol. 2005;61:461–80.
84. Koenig HG, Pargament KI, Nielsen J. Religious coping and health status in medically ill hospitalized older adults. J Nerv Ment Dis. 1998;186:513–21.
85. Pargament KI, Koenig HG, Tarakeshwar N, Hahn J. Religious struggle as a predictor of mortality among medically ill elderly patients: a 2-year longitudinal study. Arch Intern Med. 2001;161:1881–5.
86. Pargament KI, Koenig HG, Tarakeshwar N, Hahn J. Religious coping methods as predictors of psychological, physical and spiritual outcomes among medically ill elderly patients: a two-year longitudinal study. J Health Psychol. 2004;9:713–30.
87. Smith TB, Mccullough ME, Poll J. Religiousness and depression: evidence for a main effect and the moderating influence of stressful life events. Psychol Bull. 2003;129:614–36.
88. Cloninger CR. Spirituality and the science of feeling good. South Med J. 2007;100:740–3.
89. Frankl VE. Man's search for meaning. Boston: Beacon Press; 2006.
90. Seligman ME. Flourish. New York: Free Press; 2011.
91. Kobau R, Sniezek J, Zack MM, Lucas RE, Adam B. Well-being assessment: an evaluation of well-being scales for public health and population stimates of well-being among US adults. Appl Psychol Health Well Being. 2010;2:272–97.
92. Vaillant GE. The wisdom of the ego. Cambridge, MA: Harvard University Press; 1993.

Chapter 6
Individualized Care in Person Centered Medicine

Ihsan M. Salloum, W. James Appleyard, and Mohammed T. Abou-Saleh

6.1 Introduction

Advances in medicine in the latter part of the twentieth century have been formidable and on par with advances in all the sciences and have eclipsed advances in centuries of human endeavour: diagnosis of diseases have been well established, their aetiology and pathogenesis elucidated, and pharmaceuticals have been introduced to treat these conditions.

Advances in medicine were made by converging on specific diseases and thus paving the way for the establishment of medical specialities focused on specific systems such

---

I. M. Salloum (✉)
Institute of Neuroscience, Department of Neuroscience, University of Texas Rio Grande Valley School of Medicine, Harlingen, TX, USA

University of Miami Miller School of Medicine, Miami, FL, USA

Section of Classification, Diagnostic Assessment and Nomenclature, World Psychiatric Association, Geneva, Switzerland

International College of Person Centered Medicine, New York, NY, USA
e-mail: ihsan.salloum@utrgv.edu

W. J. Appleyard
Presidency 2013–2017, International College of Person Centered Medicine, New York, NY, USA

Presidency 2003–2004, World Medical Association, Ferney-Voltaire, France

St George’s University School of Medicine, Grenada, Grenada

Kent and Canterbury Hospital, Canterbury, UK

M. T. Abou-Saleh
St George’s, University of London, London, UK

Department of Psychiatry and Associate Dean for Clinical Affairs, Faculty of Medicine, United Arab Emirates University, Al Ain, United Arab Emirates

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_6

as psychiatric medicine. Inevitably this led to fragmentations of care for individual patients who may have more than one medical condition and importantly the whole person of the patient has been overlooked and almost became out of bounds. Individuals with a specific medical condition were reduced in common parlance to being labelled and defined by their disease: a patient may be labelled as asthmatic, diabetic, epileptic, schizophrenic or addict, labels that are reductionist and almost pejorative.

Individualized care centres on the individual. It proposes to tailor the care of the patient as an individual, attending to their health needs recognizing their uniqueness within their context and upholding their dignity, autonomy, and rights. Individualized care focuses on the individual rather than on the disease and takes into considerations the multitude of determinants of health and disease as well as personal values and beliefs and life experiences. It considers the patient's personal characteristics and preferences and respects the patient decision making and promotes participation in their own care. The concept of individualized care, as opposed to a disease and episode-centric care, also calls for a comprehensive, life-long care, aimed at meeting the individual's needs to maintain health and prevent diseases.

Individualized care is a core principle of person-centered medicine which include the following eight key principles: (1) Ethical Commitment; (2) Cultural Sensitivity; (3) Holistic Approach; (4) Relational Focus; (5) Individualization of Care; (6) Shared Understanding and Shared Decision-making; (7) People-centered Organization of Services; and (8) Person-centered Education, Training and Research. Individualized care recognizes that the patient's individuality and unique qualities inform care, that the patient's historical and social context are factored in, and the patient's personal growth and development are promoted. Individualized care has been found highly correlated with the overall concepts of person-centered medicine as measured by the Person-centered Care Index [1].

Person-centered medicine considers the totality of the person, with a bio-psycho-socio-spiritual framework, and attends to the person's dignity, uniqueness, suffering, deficits as well as strength, and desire to be accepted and finding purpose [2]. Person-centered medicine places the person in context at the centre of care, therefore, it further advances the concept of individualized care by focusing on the totality of health, not just ill health, and by highlighting the dynamic nature of the persons' health within his/her unique context and between the patient and the clinician and among all stakeholders. The aims of person-centered medicine have been expressed as a medicine *of the person* (of the totality of the person's health, including its ill and positive aspects), *for the person* (promoting the fulfilment of the person's life project), *by the person* (with clinicians extending themselves as full human beings with high ethical aspirations) and *with the person* (working respectfully, in collaboration and in an empowering manner) [3].

The doctor-patient relationship has been an enduring core value in medicine since ancient times and is the cornerstone of person-centred medicine. For example, from a historical Islamic perspective, it was governed by core values of justice, and "*Ihsan*" which has no equivalent in English "*It means to be good, tolerant, sympathetic, forgiving, polite, cooperative*" [4]. The authors referred to a poignant historical anecdote highlighting the pivotal role of therapeutic alliance that "*Avicenna used to tell his patient: Look!. You, I and disease are "3". If you help me and stand beside me, we become "2", and the disease will be left alone; then we will overcome it and* *compel your illness. But if you stand beside the disease, you will become "2" and I will be alone, then you will overcome me, and I will not be able to cure you*" [4]. Benevolence, justice, providing equal treatment to patients, and "high morality" to "Treat patients just as if they were your own family member" is also a hall mark of Chinese Confucian Medicine doctor-family-patient relationship [5].

Szasz et al. [6] observed that the Hippocratic Oath, in providing a code of ethics for physicians, it has also framed the boundaries of the doctor-patient relationship. Szasz et al. [6] also highlighted the historical context of the medical encounter in the doctor–patient relationship. Such encounter comprises the capacity for self-reflection and communication for both the physician and the patient in addition their technical skills and available means for intervention.

The changing nature of the Patient-Doctor Relationship during the past few decades has been seen as it progresses from mostly a traditional view of a power relationship as "paternalistic", with the power in the relationship residing in the physician, to a "consumer-centred" relationship emphasizing the patient autonomy and power in the relation, and lastly as what is being called "bureaucratic parsimony" [7] reflecting the hegemony of "bureaucracy" in complex health system where neither the doctor nor the patient has power. This latter situation led to a newer doctor-patient relationship, which is now defined in terms of "comradery" [8]. This refers to both doctor and patient as allies, advocating on behalf of the patient's health in the face of dominant bureaucratic health systems or insurance companies where monetization and economic prerogatives takes priority.

The patient–doctor relationship is clearly a process which outcome impact patient's care. A pointed analyses of the factors important in the patient-doctor relationship identified two key aspects. These included the depth of the relationship indicated by characteristics such as knowledge, trust, loyalty, and regards. It also included factors related to developing and maintaining an ongoing, longitudinal care, as well as the patient's consultation experiences [9].

Individualized care requires a comprehensive and integrated approach able to capture the dynamic interplay of the multi-determinants of health and disease that are unique to the person presenting for care. The patient-clinician relationship assumes a central role in establishing the fundamental steps supporting individualized care. A central aptitude in the relationship is the joined construction of the unique "*personal narrative*" of the patient.

6.2 Narrative Competence and Individualized Care

6.2.1 Person-Physician Relationship and the Importance of a Person's Narrative

From earliest times listening to a person's story has been the essence of the patient-physician consultation. Evidence from the literature suggests that it is the core clinical skills of communication through questioning, delineating, interpreting, explaining and discerning meaning that provide a way of bringing together the very different perspectives of patients and health professionals.

These narrative skills facilitate an awareness of both health and disease and take into consideration the biological, social, psychological, spiritual, and pathophysiological dimensions. In this context the science of objective measurements can be successfully integrated with the art of clinical experience and judgment.

6.2.2 *The Inner Consultation*

In 1987, Roger Neighbour, a general practitioner in the UK proposed the “Inner Consultation” model on how to develop an effective and intuitive consulting style. The model describes consulting as a complex behavioural skill that involves goal setting, skill- building and getting it together. Getting it together is needed for the doctor to give themselves over to the inspiration of the moment, trusting their intuitive and unconscious processes to function appropriately and automatically [10].

The clinical consultation is conceived as a process rather than an outcome condensed into a simple metaphor of “the consultation as a journey”. There are five checkpoints on this journey: Connecting, summarising, handing-over, safety netting and housekeeping. Housekeeping deals solely with the doctor’s own internal experience to enable them to take care of themselves and be in good condition to the next patient.

Germane to the model of the inner consultation, is that it proposes the idea of ‘having two heads’: the organiser and the responder head. The organiser head expresses the function of the thinking dominant hemisphere that oversees the process and the responder head that expresses the feeling, intuitive non-dominant hemisphere that facilitates the establishment of rapport and emotional connection with the patient “It is like having two heads—one in charge, and another whispering instructions, advice and criticism in your ear like a back—seat driver”. The inner dialogue of the organiser and responder heads is the essence of the inner consultation.

6.2.3 *The Clinical Consultation*

A person’s story is the key to the physician finding out what may be right and what may be wrong during a consultation with someone who seeks his or her help. A narrative approach encompasses an awareness of health and disease within a storied structure from which the meaning and purpose in both an illness and the experience of recovery emerge. Diagnostic “labels” become secondary to the life of the person.

During a consultation when a person as a “patient” meets a physician a story is recounted in a complicated narrative of illness told in words, silences, gestures, physical observations, overlain not only by the objective findings but also with the fears, hopes and implications associated with it [11]. The narration is a therapeutic central act because to find the words to contain the disorder and its attendant worries gives shape to and control over the uncertainties of the illness. As the physician listens to the patient, he or she follows the narrative thread of the story in all its existential cultural, familial biological social psychological and spiritual dimensions.

6.2.4 Listening

The act of listening so essential to the process enlists the physician's interior resources—memories, association curiosities creativity interpretive powers and allusions to other stories by the person and others to identify meaning. Only then can the physician hear and confront the person's narrative questions "what is wrong with me? Why is this happening to me? And what will be the result?"

Listening to stories of illness and recognizing that there are often no clear answers to patients' narrative questions demand the courage and generosity to tolerate and to bear witness to unfair losses and random tragedies. Accomplishing such acts of witnessing allows the physician to proceed to his or her more recognizably clinical narrative tasks: to establish a therapeutic alliance, to generate and proceed through a differential diagnosis, to interpret physical findings and laboratory reports correctly, to experience and convey empathy for the patient's experience, and, because of all these, to engage the patient for effective care.

If the physician cannot perform these narrative tasks, the patient might not tell the whole story, might not ask the most frightening questions, and might not feel heard. The resultant diagnostic workup might be unfocused and therefore more expensive than need be, the correct diagnosis might be missed, the clinical care might be marked by noncompliance and the search for another opinion, and the therapeutic relationship might be shallow and ineffective. The narrative is absorbing. It engages the listening physician and invites an interpretation. It gives him or her the experience of "living through", not simply "knowledge about" the characters and events in the story.

6.2.5 Effective Practice

The effective practice of medicine therefore requires narrative competence, that is, the ability to listen, acknowledge, absorb, interpret, and act on the stories and plights of other people.

The narrative also provides information that does not pertain simply or directly to the unfolding events. The same sequence of events told by another person to another audience might be presented differently without being any less "true." This is an important point. In contrast with a list of measurements or a description of the outcome of an experiment, there is no self-evident definition of what is relevant or what is irrelevant in a particular narrative. The choice of what to tell and what to omit lies entirely with the narrator and can be modified, at his or her discretion, by the questions of the listener.

This approach gives the physician insight into medicine's four dimensions—physician and patient, physician and self, physician and colleagues, and physicians and society. With narrative competence, physicians can reach and join their patients in illness, recognize their own personal journeys through medicine, acknowledge kinship with and duties toward other health care professionals, and inaugurate consequential discourse with the public about health care. By this approach, physicians can integrate their patients as persons with themselves, their colleagues and people in the wider communities and nations to provide renewed opportunities for respectful, empathic, effective, and nourishing medical care.

6.2.6 Ethical Framework

A key basis for the ethical framework for person-centered care is Immanuel Kant's [12] categorical imperative affirming that the person is always and end or goal, not a means.

Altruism, compassion, respectfulness, loyalty, humility, courage, and trustworthiness become etched into the ethical framework of a physician's being. Physicians learn to understand and reflect the inevitable results of being submerged in pain, unfairness, and suffering while being encouraged by the extraordinary courage, resourcefulness, faith, and love they learn from their patients in their every-day practice.

Through this engagement with their patients as persons, physicians can cultivate affirmation of human strength, acceptance of human weakness, familiarity with suffering, and a capacity to forgive and be forgiven. Diagnosis and treatment of disease require the experienced and practiced use of these narrative competences of the physician. Indeed, it may be that the physician's most potent therapeutic instrument is the self, which is attuned to the patient through engagement, on the side of the patient through compassion, and available to the patient through reflection. When sociologists studied medicine in the 1960s, they observed physicians to practice medicine with "detached concern" and physicians for decades seemed to consider detachment a goal. Since then, relying on newly emerging knowledge and understanding from the fields of primary care and psychiatry and the "medicine de la personne" of Paul Tournier physicians are learning to practice medicine with "engaged" concern, an approach that requires disciplined and steady reflection on one's practice.

6.2.7 Integrating Knowledge into Clinical Practice

Sackett and his colleagues [13] found that those who have studied the phenomenon of clinical disagreement, as well as those of us who practice medicine in a clinical setting, know all too well that clinical judgments are usually a far cry from the objective analysis of a set of eminently measurable "facts."

In the language of empiricism such an observation could be interpreted as ascertainment bias. Evidence supports the claim that doctors do not simply assess symptoms and physical signs objectively: They interpret them by integrating the formal diagnostic criteria of the suspected disease (that is, what those diseases are supposed to do in “typical” patients as described in standard textbooks) with the case specific features of the patient’s individual story and their own accumulated professional case expertise. Narrative therefore provides meaning, context, and perspective for a person’s predicament. It defines how, why, and in what way he or she is ill [11].

The study of narrative offers a possibility of developing an understanding that cannot be arrived at by any other means. It provides a framework for approaching a person’s problems holistically, as well as revealing diagnostic and therapeutic options. Furthermore, narratives of illness provide a medium for the education of both patients and health professionals and may also expand and enrich the research agenda. Indeed, it is thought that anecdotes, or “illness scripts,” may be the underlying form in which we accumulate our medical knowledge. Medical students rely on anecdotes of extreme and atypical cases to develop the essential ability to question expectations, interrupt stereotyped thought patterns, and adjust to new developments as a clinical story unfolds.

Evidence based medicine lacks a way of measuring existential qualities such as the inner hurt, despair, hope, grief, and moral pain that frequently accompany, and often indeed constitute, the illnesses from which people suffer. The increasing pursuit during medical training of skills deemed “scientific” and practical which are readily measurable but inevitably reductionist at the expense of those that are fundamentally linguistic, empathic, and interpretive distorts the clinical method.

It is the core clinical skills of listening, questioning, delineating, organising explaining, interpreting, and discerning meaning that provide a way of integrating the very different worlds of patients and health professionals [14]. Whether these skills are performed well or badly are likely to have as much influence on the outcome of the illness from the patient’s point of view as the more scientific and technical aspects of diagnosis or treatment [15].

Anecdotal clinical experience may be unrepresentative of the average patient and thus a potentially biased influence on clinical decision making. Evidence based clinical decision making involves the assessment of the current clinical problem in the light of evidence from the aggregated results of hundreds or thousands of comparable cases in a defined population sample, expressed in the language of probability and risk.

The “truths” established by the empirical observation of populations in randomized trials and cohort studies cannot be mechanistically applied to individuals or episodes of illness where the symptoms and behaviour need to be seen in context.

The generalizable truths gleaned from clinical research trials relate to the samples and, thereby, the study population’s story, not the stories of the individual participants. There is a danger of erroneously viewing summary statistics as hard realities. What has been termed “misplaced concreteness”. The dissonance we experience when trying to apply research findings to the clinical encounter often occurs when we abandon the narrative-interpretive paradigm and try to get by on “evidence” alone [16].

6.2.8 Gothenburg Model of Person-Centred Healthcare

The University of Gothenburg Centre for Person-Centred Care (GPCC) was established in 2011 by an interdisciplinary group of clinical and non-clinical academics in Sweden as a research centre for the study of person-centred care (PCC) in long-term illness [17].

The Gothenburg framework for PCC was derived from best evidence, experience, and practice “*It is based on an explicit ethical approach that combines the relational aspects of collaboration with facilitating structures. The approach acknowledges the patient with needs but also as a capable and resourceful partner with expert knowledge about their everyday life, goals, and motivation*” [18].

The Gothenburg framework adopted the following three routines in the partnership, derived from best evidence, experience, and practice:

- Initiating the partnership—narratives: The first routine entails eliciting the patient’s narrative and their goals. These are goals arising from everyday life—for example, the wish to return to paid employment or taking walks. This involves listening carefully to the patient’s story to understand their condition, their capabilities, and resources as well as obstacles to achieving good health, giving due consideration to diagnoses and treatments.
- Working the partnership: The second routine uses this narrative or series of narratives with the patient and possibly their carer(s) as the basis of partnership to co-creating a personal health plan consistent with identified resources and barriers and combined with medical and health research evidence. This partnership is intended to support the patient’s self-efficacy and self-management by paying attention to their own priorities and building on their capabilities.
- Safeguarding the partnership—documentation: The third routine entails documenting the health plan, adapting it to changes in the patient’s goals and/or other circumstances over time and in different settings—for example, when moving from secondary to primary care—to support continuity of care. It is documented in the patient’s record, which is accessible for the patient either in paper form or via the national patient accessible electronic health record.

A review of the 27 intervention studies financed by the GPCC and conducted between 2010 and 2016 concluded that “the frameworks, designs and interventions in the studies were in line with the established ethical basis of PCC, whereas outcome measures varied widely. Consensus discussions among researchers in the field are needed to make comparisons between studies feasible” [19].

6.3 Multilevel Person-Centered Assessments and Individualized Care

While the clinical interview and the clinician-patient relationship is the cornerstone of therapeutic alliance which will allow for the formulation of a shared “competent narrative” and resulting effective individualized care plan, there is a need for a thorough, multilevel assessment of the various determinants of health that cut across multiple domains, that reflects and integrate the unique strengths and needs for the individual presenting for care. The Person-centred Integrative Diagnosis Model developed by the International College on Person-centred Medicine [20, 21] is a model that aims at providing such an integrative assessments of the persons positive aspect of health and corresponding bio-psycho-social and spiritual determinants as well as ill health and corresponding determinants, in addition of integrating the subjective, cultural and spiritual aspects of the person seeking care. Thus, it allows for consideration of the dynamic interplay among these domains as they impinge on illness or support recovery.

6.3.1 The Person-centered Integrative Diagnosis Model: From Disease Focus to Whole Health Focus

The primary function of diagnosis is the identification of the problem at hand to direct specific treatment and care efforts with the goal of disease remission and health restoration. Traditional, disease-focused models of diagnosis have emphasized primary focus on illness, acute care and on organ-system based pathology. Preventive and health restorative efforts usually receive secondary attention. Modern classification systems in psychiatry have adopted a bio-psycho-social approach and have attempted to enhance the clinical utility of the diagnosis by incorporating multiaxial schemas include domains such as functioning, stressors and other medical conditions, that impact on presenting ill health condition [22–25]. These schemas remain predominantly disease-centric, as well as episode-focused concerned about stabilizing the acute episode, as opposed to a person-centered approach with attention to ill health and equally important, to positive aspects of health aiming at prevention, health restoration and recovery, especially crucial for addressing chronic, complex diseases and comorbid conditions [26].

Recovery from multiple chronic, relapsing conditions, such as diabetes and hypertension or bipolar disorder and addiction involves a long-term process that requires the mobilization of multiple factors including, as key components, the person’s positive aspects of health such as resources and resiliencies. Barriers to recovery could include a range of factors from societal-cultural issues such as attitudinal difficulties and stigma to behavioural control to prolonged adherence to therapeutic regimen. These dynamics could manifest at multiple levels involving the health care provider, the family and the patient. For example, resistance to taking medications may be manifested by the persons' seeking help, by their families, and or even may be promoted by some support resources such addiction self-help groups.

Furthermore, treatment adherence has been a major challenge in all chronic disease management. These factors highlight the importance of not only considering resource and strength of the individual seeking care but also the importance of the inclusiveness and the "trialogue" approach, including all stakeholders, patient, clinician and carer into the diagnostic process aiming at recovery and health restoration. Mobilizing the person's strengths and resources, which is highly influenced by their expectations, preferences, beliefs, and socio-cultural-spiritual context are crucial for the recovery process, which is often inadequately considered in disease-centric, episode-focused acute care models. An integrated model of care, where all presenting problems are addressed in the same setting and by the same treatment provider, with full partnership and engagement with the persons' seeking care and their caregivers and other stakeholders is most likely to attend successfully to the multiple needs of this population.

6.3.2 Person-Centered Approach as a Promising Model for Individualized Care

The concept of Medicine of the Person as a basic approach to medical care was introduced by Paul Tournier in 1940 [2]. The "Institutional Program on Psychiatry for the Person" of the World Psychiatric Association adopted this concept in 2005 [27]. The goals of this program are to promote psychiatry of the person (of the totality of the person's health, both ill and positive health), by the person (with clinicians extending themselves as full human beings), for the person (assisting the fulfilment of the person's life project), and with the person (in respectful collaboration with the person who consults).

The Person Centered Integrative Diagnosis (PID) model [20, 21] based on the principles and concepts of Psychiatry for the Person aims at providing a clinically useful instrument reflecting a broader understanding of the person's health status, with description of both positive and ill health. The innovative focus on positive aspects of health of the PID, such as adaptive functioning, protective factors, and quality of life, is deemed crucial for enhancing recovery and health restoration: The notion of diagnosis in the PID entails a broader and deeper concept beyond the restricted boundaries of nosological diagnoses. It involves a multilevel formulation of health status through interactive participation and engagement of clinicians, patients, and family. Thus, the PID highlights the interactive role of all protagonists of the clinical encounter as true partners into the diagnostic process. An additional innovative feature of the PID is its inclusion of narratives in addition to the more traditional descriptive tools such categorization and dimensions to document the clinical condition.

The diagnosis of health status in the PID model integrates the dynamic interplay between the two main poles of health, namely “Ill Health” and “Positive Health” with equal emphasis (Fig. 6.1).

This approach is likely to engage better the complexity of factors impacting on health and illness and on the recovery process. What follows is a discussion of the PID domains, how they relate to complex conditions such as comorbid disorders of multiple conditions.

The PID is a multilevel model that assesses the health status (ill and positive aspects of health), contributors to the health status, which include contributors to ill health and to positive health, and the experience of health status that is experience of ill health and of positive aspects of health.

6.3.2.1 Ill Health Status

The “Ill Health Status” in the PID is used to record the ill health status of the individual, documenting the presence of clinical disorders (both mental and general medical) and the presence of disabilities. Disabilities is further assessed regarding self-care, occupational functioning, functioning with family and participation in community activities.

Disability/functioning is measured on a dimensional scale that ranges from very poor functioning (disabled) (0) to best functioning (10) as measured on overall, personal care, occupational, with family and social functioning. The systematic

I. Health Status	**DISEASE**: Physical & Psychiatric Disorders (ICD 10)
	FUNCTIONING (Disability) Overall 0…………………10 PERSONAL CARE 0…………10 OCCUPATIONAL 0………… 10 WITH FAMILY 0………… 10 SOCIAL 0………… 10
	WELLBEING 0…………………10
	NARRATIVE
II. **CONTRIBUTORS TO HEALTH**	**Intrinsic vs. extrinsic (Bio-Psycho-Social)** **Health Promoters**: Diet, Physical Activity, Creative Activity, Social Involvement, Other **Health Risks**: Over WT; H. Lipid, Glucose, BR, Alcohol, Tobacco Use; FAM HX, Early Trauma, Sig. Stress, Other
	NARRATIVE
III. **EXPERIENCE OF HEALTH**	**EXP of Wellbeing**: PERSONAL & CULTURAL IDENTITY **EXP of ill Health:** SUFFERING, MEANING OF ILLNESS, EXPECTATION OF HEALTH CARE.
	NARRATIVE

Fig. 6.1 Person-centered integrative diagnosis (PID) model

recording of this domain will allow monitoring any potential disability issue in this population. For example, cognitive dysfunctions are frequent in chronic alcoholism as well as in bipolar disorder, two conditions that are highly likely to co-occur, however, these dysfunctions are rarely recorded in the traditional clinical disease-centered diagnostic model of care despite the known impact on treatment response and functioning [28].

6.3.2.2 Contributors to Ill Health

Contributors to Ill Health cover risk factors and other contributors to disease and disabilities. These include inner risk factors such as genetic and developmental vulnerability and external risk factors such as stressors. External risk factors range from the role of stressors to that related to poor treatment adherence or poor social support, trauma, violence, and the presence of other comorbidities among others. The interaction between environmental influences and genetic vulnerabilities is an emerging field of inquiry that highlights the importance of systematically documenting internal and external contributors to ill as well as positive aspects of health [29].

6.3.2.3 Experience of Ill Health

The Experience of Ill Health corresponds to the idiographic personalized narrative of topics such as sufferings, values and cultural experience of illness and care. A non-confrontational, empathic and respectful understanding of the patients' experiences, attitudes and beliefs about the illness is crucial for enhancing therapeutic alliance. Increased understanding of the illness, medication, and motivation for treatment impacts on the attitudes and beliefs about the illness and results in enhancing treatment adherence. Furthermore, the partnership approach also enhances the need to understand the beliefs and attitudes of significant others such as family members and clinicians as their view's influences patients' attitudes and beliefs on illness and its treatment [30].

6.3.2.4 Positive Health Status

Well-being and functioning are the two areas that correspond to positive health status. Wellbeing is understood as a state of contented state, satisfaction, contentment, optimism and happiness. Cloninger [31] characterized well-being in four different ways: by the presence of positive emotions and the absence of negative emotions, by the presence of mature character traits, by the satisfaction with quality of life, and by virtuous conduct. He states that positive health is a "state of physical, material, emotional, social, ecological, and spiritual well- being which involves more than reduction of symptoms, but promotes a satisfying quality of life, resilience despite stress, and recovery of positive emotionality". Accordingly, the determinants of positive health are not necessarily the opposite of the determinants of ill health and positive health is more than the absence of disease. Likewise, positive emotions are more than the absence of negative emotions [31]. The most recognized aspects of positive health include functioning, resilience, resources (supports) and quality of life [32].

In the PID, subjective wellbeing may be assessed by the person's marking this on a 10-point scale, from 0 (very poor) to 10 (best). Furthermore, levels of functioning in the various domains discussed above may also be rated on a scale from 0 to 10 scale. Functioning as considered in the ICD-10 Axis II include personal care, occupational functioning, functioning with family and broader social functioning. Furthermore, robustness and resilience are two notions conceptually related to functioning and to positive health more broadly [32].

6.3.2.5 Contributors to Positive Health

This level in positive health status covers protective factors, specific contributors to positive health and health promoters. These include possible inner protective factors such as resilience and external protective factors as social supports. As mentioned for ill health, these factors are also conceptualized in a bio-psycho-social framework.

Resilience is defined as the capacity to withstand loss and/or recover from the impact of adverse events. Robustness is understood as the ability to withstand stress, pressures, or changes. Higher resilience and robustness are likely to lead to faster and more effective recovery. These individual characteristics of resilience and robustness along with family resources and social supports are among the contextual factors associated with successful recovery. Resilience may be enhanced through community involvement that increases wellbeing, through having a purpose in life, and through building strong and positive relationships, especially with family and friends, a source of support and acceptance.

6.3.2.6 Experience of Positive Health

The third level of positive health corresponds to the idiographic-personalized narrative covering the experience of health. This includes nuanced quality of life, particular values and cultural formulation concerning identity and context. As shown in a large population study [33], positive wellbeing (sociability and feeling of life satisfaction, including competence/self-efficacy and coping/contentment) is commonly expressed even in the presence of disability. Thus, these findings support the validity of quality-of-life measures that incorporate both positive and negative aspects [33].

Person-centered medicine and relevant diagnostic models such as the emerging PID, emphasize both positive health and ill health and rely on a partnership approach to diagnosis and care, appear apt to respond to the multiple challenges and complexities of persons with chronic comorbid conditions. The PID model not only allows recording existing pathology, but also presents an integrated, dynamic health profile for the person presenting for care highlighting health promoting factors and the person's direct input into the diagnostic process. This approach offers a complete and more integrated picture of the person's strengths and ill health, and facilitates a collaborative framework among the patient, care givers, clinicians and other stakeholders who are empowered to act as co-equal protagonists in the care process. The PID model focusing on positive health and on empowering the person seeking help to realize his or her own "*life Project*" converges with the multidimentional model of well-being [34, 35], which include six broad components of wellness. These include (1) *Self-Acceptance* with positive evaluations of oneself and one's past life, (2) *Positive Relations With Others* with quality relations with others, (3) *Autonomy* with a sense of self-determination (4) *Environmental Mastery* with the capacity to manage effectively one's life and surrounding world, (5) *Purpose in Life* with the belief that one's life is purposeful and meaningful, and (6) *Personal Growth* with continued growth and development as a person [34, 35].

6.3.3 Shared Decision Making

Shared decision making is based on the available clinical evidence and the patients informed preferences. This dialogue improves patient knowledge and ability to participate in their care with the consequent improvement to those with long term health problems. This more 'Personalized' planning of a person's care is a collaborative process, a conversation, or series of conversations, in which jointly agreed goals and actions are formulated for managing the patient's problems.

Clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences.

It involves the provision of evidence-based information about options, outcomes, and uncertainties, together with decision support counselling and a systematic approach to recording and implementing patient's preferences.

There are many different approaches for achieving common ground which all have a similar emphasis on the importance of creating a formulation or integrated synthesis of the clinical and personal data about the patient that support the diagnosis and serve as a bridge between assessment and the creation of a treatment plan.

Each approach also focuses on the value of a written narrative that captures the essence of the understanding and the importance of dialogue between the patient and the physician that is the foundation of common ground.

Disagreements must be acknowledged and reconciled in the process; without this, the therapeutic alliance central to healing relationships is absent and a meaningful treatment plan based on shared decision- making cannot be achieved.

Synthesizing the data collected in assessment into insight and understanding that can help to establish shared understanding and common ground is essential.

Translating that understanding into effective, individualized and culturally sensitive/informed treatment plans is at the heart of person-centered care.

6.3.4 Life Course and Continuing of Care

The health and wellbeing of a person are complex adaptive processes related to the consequences of genetic, biological, social, cultural, behavioural, and economic determinants throughout the life course. Circumstances change as the person develops with accumulative risk and protective factors especially during critical and sensitive periods. Each stage in the life of a person exerts influence on the next with an emphasis on an integrated continuum of early intervention and education rather than of disconnected and unrelated stages.

Health is a consequence of multiple determinants operating in interrelated genetic, biological, behavioural, social, and economic contexts that change as a person develops. Risk factors are embedded in a person's biological makeup, manifested, and maintained by social, cultural, and economic forces. The effect of many determinants has been shown to interact in various contexts at developmentally sensitive points to influence the health status and health risks are produced and maintained by social ecological systems.

6.3.4.1 Risk and Protective Factors Influencing the Life Course

Long-term health development is influenced by the strong, independent effect of risks, exposures, and adaptive responses during sensitive or critical developmental periods, many of which occur early in life, which again underscore the importance of a person-centered individualized care. Cumulative mechanisms are dose or exposure dependent and are based on the cumulative effects on various outcomes from a lifelong exposure to specific risk factors. Long-term adaptations result from genes and environment interactions in which environmental factors influence and help set the operating parameters of specific genes during critical and sensitive developmental periods. There is a robust body of evidence documenting the impact of early life traumas and adverse experiences on inducing profound neurobiological changes of the developing brain and conferring high levels of vulnerabilities for the development of psychopathology, such as major depression, anxiety, and substance use disorders among others, and multiple physical disorders including cardiovascular diseases, diabetes, asthma and others. Repeated adverse experiences lead to alterations in multiple biological systems including changes in the autoimmune and pro-inflammatory biomarkers, the neuroendocrine and neurotransmitter systems, epigenetic mechanisms, as well in brain neurocicuitry underlying mood and reward regulations [36–38].

6.3.4.2 The Need for a New Perspective on Healthcare

The implication of the developmental features over the life course with a particular emphasis on the early years calls for a framework for the provision of health care that offers a radically different conceptualization of individual and population health. Assessment of the health status of both individuals and populations need to consider the inherent bio-psycho-social potential and differences even in the apparently "healthy". These differences result in varying levels of resilience that have profound implications for future health status and development in the face of risks and adversity. Currently, the health of individuals and populations is measured according to health outcomes—disease, disability, dysfunction, and mortality. The most widely used measures of health are based on deficits, using levels of decline to define health status. Even relatively integrative parameters like the health-related quality of life (HRQL) include instruments that focus on the extent of declines from a hypothetical state of "full health".

Differences in developmental life course projections are likely to explain much of the variance in the nature and rate of later declines in health. A person centered approach not only measures an individual's illness but also focuses on health and wellbeing. Measuring positive health supports health policies based on building both individual and community health, a concept illustrated in the field of community development, which encourages the use of positive health measurements that identify positive health and well-being and not merely disease and deficits.

6.4 Conclusions

Individualized care centres on the individual. It proposes to tailor the care of the patient as an individual, attending to their health needs recognizing their uniqueness within their context and upholding their dignity, autonomy, and rights. Individualized care, as opposed to a disease and episode-centric care, calls for a comprehensive, life-long care, aimed at meeting the individual's needs to maintain health and prevent diseases throughout the life span. Individualized care is a core principle of person-centered medicine which places the person in context at the centre of care. It focuses on the totality of health, not just ill health, and highlight the dynamic nature of the persons' health within his/her unique context. The patient-clinician relationship has been an enduring core value in medicine since ancient times. Depth of the relationship, communication, self-awareness, and the longitude over time are crucial factors in the patient-clinician relationship. This relationship assumes a central role in establishing the fundamental steps supporting individualized care. A central aptitude in the relationship is the joined construction of the unique "*personal narrative*" of the patient. The "personal narrative" and the required "narrative competence" facilitate an awareness of both health and disease, taking into consideration the biological, social, psychological, spiritual, and pathophysiological dimensions and successfully integrate the science of objective measurements with the art of clinical experience and judgment. A narrative approach encompasses an awareness of health and disease within a storied structure from which the meaning and purpose in both an illness and the experience of recovery emerge. A "narrative approach" is also therapeutic by providing meaning to the suffering and by addressing uncertainties of the illness and establishing therapeutic alliance. The “Inner Consultation” is presented as a model on how to develop an effective and intuitive consulting style [10].

As “narrative competence” is essential for the clinician-patient relationship and to establish therapeutic alliance, there is a need for a thorough, multilevel assessment of the various determinants of health that cut across multiple domains, that reflects and integrates the unique strengths and needs for the individual presenting for care. The Person-centred Integrative Diagnosis Model [20, 21] aims at providing such an integrative and holistic assessments across the lifespan. Individualized care would utilize the best science-based evidence, considering bio-psycho-social determinants of health in addition to integrating the subjective, cultural, and spiritual aspects of the person seeking care to support both health restoration as well as recovery and wellbeing.

Acknowledgements and Disclosures The authors do not report any conflicts of interest in the preparation of this manuscript.

References

1. Mezzich JE, Kirisci L, Salloum IM, Trivedi JK, Kar SK, Adams N, Wallcraft J. Systematic conceptualization of person centered medicine and development and validation of a person-centered care index. Int J Pers Cent Med. 2016;6(4):219–47.
2. Pfeifer HR. Paul Tournier and ‘Médecine de la Personne’—the man and his vision. Int J Integr Care. 2010;10(Suppl):e022.
3. Mezzich JE. Psychiatry for the person: articulating medicine’s science and humanism. World Psychiatry. 2007;6(2):65–7.
4. Chamsi-Pasha H, Albar MA. Doctor-patient relationship. Islamic perspective. Saudi Med J. 2016;37(2):121–6.
5. Cong Y. Doctor-family-patient relationship: the Chinese paradigm of informed consent? J Med Philos. 2004;29(2):149–78.
6. Szasz TS, Knoff WF, Hollender MH. The doctor-patient relationship and its historical context. Am J Psychiatry. 1958;115(6):522–8.
7. Siegler M. The progression of medicine: from physician paternalism to patient autonomy to bureaucratic parsimony. Arch Intern Med. 1985;145(4):713–5.
8. Shutzberg M. The doctor as parent, partner, provider… or comrade? Distribution of power in past and present models of the doctor–patient relationship. Health Care Anal. 2021;29(3):231–48.
9. Ridd M, Shaw A, Lewis G, Salisbury C. The patient–doctor relationship: a synthesis of the qualitative literature on patients’ perspectives. Br J Gen Pract. 2009;59(561):e116–33.
10. Neighbour R. The inner consultation: how to develop an effective and intuitive consulting style. 2nd ed. CRC Press; 2018.
11. Appleyard J. Naratives in clinical practice—the essence of person centred care. IJPCM. 2012;3(2):123–8.
12. Kant I. Critique of practical reason. Transl. Werner Pluhar. Indianapolis, IN: Hacket Publishing Company; 2002.
13. Sackett DL, Rosenberg WMC, Gray JAM, Haynes RB, Richardson WS. Evidence based medicine: what it is and what it isn’t. BMJ. 1996;312:71–2.
14. Greenhalgh T, Hurwitz B. Narrative based medicine: dialogue and discourse in clinical practice. London: BMJ Books; 1998.

15. Hurwitz B. Narrative and the practice of medicine. Lancet. 2000;356:2086–9.
16. Cassell E. The nature of suffering and the goals of medicine. N Engl J Med. 1982;306:639–45.
17. Ekman I, Ebrahimi Z, Olaya Contreras P. Person-centred care: looking back, looking forward. Eur J Cardiovasc Nurs. 2021;20(2):93–5.
18. Britten N, Ekman I, Naldemirci O, Javinger M, Hedman H, Wolf A. Learning from Gothenburg model of person centred healthcare. BMJ. 2020;370:m2738.
19. Gyllensten H, Bjorkman I, Jakobsson Ung E, Ekman I, Jakobsson S. A national research centre for the evaluation and implementation of person-centred care: content from the first interventional studies. Health Expect. 2020;23(5):1362–75.
20. Mezzich JE, Salloum IM, Cloninger CR, Salvador-Carulla L, Kirmayer LJ, Banzato CE, Wallcraft J, Botbol M. Person-centred integrative diagnosis: conceptual bases and structural model. Can J Psychiatry. 2010;55(11):701–8.
21. Salloum IM, Mezzich JE. Outlining the bases of person-centred integrative diagnosis. J Eval Clin Pract. 2011;17(2):354–6.
22. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 3rd ed. (DSM III). Washington, DC: APA; 1980.
23. American Psychiatric Association. DSM-IV: diagnostic and statistical manual of mental disorders. 4th ed. Washington, DC: American Psychiatric Association; 1994.
24. Mezzich JE. The WPA international guidelines for diagnostic assessment. World Psychiatry. 2002;1(1):36–9.
25. World Health Organization. The ICD-10 classification of mental and behavioural disorders: clinical descriptions and diagnostic guidelines. Geneva: World Health Organization; 1992.
26. Mezzich JE, Salloum IM. Clinical complexity and person-centered integrative diagnosis. World Psychiatry. 2008;7(1):1–2.
27. Mezzich JE. World Psychiatric Association perspectives on person-centered psychiatry and medicine. Int J Integr Care. 2010;10(Suppl):e003.
28. Salloum IM, Ruiz P. Management of comorbid substance or alcohol abuse. In: Yildiz A, Nemeroff CB, Ruiz P, editors. The bipolar book: history, neurobiology, and treatment. New York: Oxford University Press; 2015.
29. World Health Alliance. The health improvement card; 2011.
30. Berk L, Hallam KT, Colom F, Vieta E, Hasty M, Macneil C, Berk M. Enhancing medication adherence in patients with bipolar disorder. Hum Psychopharmacol. 2010;25(1):1–16.
31. Cloninger CR. The positive health domain in person-centered integrative diagnosis. Int J Integr Care. 2010;10(Suppl):e026.
32. Mezzich JE. Positive health: conceptual place, dimensions and implications. Psychopathology. 2005;38(4):177–9.
33. Huppert FA, Whittington JE. Evidence for the independence of positive and negative well-being: implications for quality of life assessment. Br J Health Psychol. 2003;8(Pt 1):107–22.
34. Ryff CD. Psychological well-being in adult life. Curr Dir Psychol Sci. 1995;4:99–104.
35. Ryff CD, Keyes CLM. The structure of psychological well-being revisited. J Pers Soc Psychol. 1995;69(4):719–27.
36. Gordon JB. The importance of child abuse and neglect in adult medicine. Pharmacol Biochem Behav. 2021;211:173268.
37. Lippard ETC, Nemeroff CB. The devastating clinical consequences of child abuse and neglect: increased disease vulnerability and poor treatment response in mood disorders. Am J Psychiatry. 2020;177(1):20–36.
38. Nemeroff CB. Paradise lost: the neurobiological and clinical consequences of child abuse and neglect. Neuron. 2016;89(5):892–909.

Chapter 7
Communication and Relationships in Person Centered Medicine

Roger Ruiz-Moral and Tesfamicael Ghebrehiwet

7.1 Introduction

Practical clinical communication generally includes phenomenological aspects that are empirically observable, and others that are hermeneutical, taking place within the patient-doctor relationship itself. For example, a doctor can empirically determine that chemotherapy will reduce the size of a patient's tumour, extending their life expectancy by weeks or months and will therefore propose this to the patient. However, in this exchange the doctor may understand that the patient decides to refuse treatment and leave the hospital, choosing to spend their remaining time at home, prioritising a better quality of life. Thus, depending on the explicit course of action, the doctor may respond in one way or another: they may try to convince the patient to receive chemotherapy or they may understand the patient's decision and discuss the arrangements for home care during their final weeks. Thus, different communicative actions should reveal, on one hand, an anthropology (who acts and for whom) while also defining the meaning of the action, that is, the value or values to be achieved, the ultimate and implicit ethical goal. In this chapter we will argue that person-centred communication (PCC) requires, firstly, the consideration of the person as an open, multidimensional and holistic being, considering other dimensions beyond the merely biological, social or psychological as classically understood [1]; and secondly, to achieve through treatment the healing of the patient as well as to enhance the professionalism and personal growth of the doctor.

R. Ruiz-Moral (✉)
School of Medicine, Universidad Francisco de Vitoria, Madrid, Spain
e-mail: r.ruiz.prof@ufv.es

T. Ghebrehiwet
International College of Person Centered Medicine, New York, NY, USA

Formerly, Consultant, Nursing and Health Policy, International Council of Nurses,
Geneva, Switzerland

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_7

This study will explore: (1) the nature of clinical communication (or clinical relationship); (2) the concept of "*health*", its causes and characteristics; (3) the type of truth that PCC seeks to find and how (from a gnoseological perspective) and finally, (4) how different communicative actions reveal the ultimate and implicit ethical goal that gives these meaning. We hope to find a better understanding of the authentic nature of medical care and the doctor-patient relationship as revealed in the doctor's "way of being" with the patient. Furthermore, we will offer a pragmatic model of practices and competencies, the CICAA model (*Connect, Identify & Understand, Agree and Assist*), which favours this therapeutic method and which includes PCC in the clinical practice, and show its potential in each of the aspects mentioned above (ethical, anthropological and clinical pragmatism).

PCC is "*know how*" (*Techné* in ancient Greek philosophy), that is, productive knowledge: in part, an ability that creates a human connection between two people which, when performed correctly, can lead to something more important than the connection itself, that is, an immediate enrichment of the relational exchange between patient (who may feel very isolated by their illness) and doctor (called upon to care for the health of the patient); and creating the opportunity, in a "mediate" way, to identify the key factors for diagnosis and treatment. This consideration of PCC as a form of *Techné* also helps to demonstrate and understand its role and relation to other areas of medicine and the central aspects of the healing process. PCC helps to understand who the patient is, why they are there, and how the doctor should act.

7.2 The Nature of Doctor-Patient Communication

PCC is not a mere abstraction, but something real, occurring in time and space. It is both tangible, empirically demonstrable, consisting of such elements as gestures and manners of speech and intangible, residing within the relationship between two people (doctor and patient). All of this takes place as a dynamic exchange with a multitude of factors, often occurring in a very short period of time.

Furthermore, in communicating the doctor is deploying specific communication skills (tangible aspect) while also manifesting the values of the current medical culture (intangible aspect).

To understand correctly the meaning of the act of communication it is helpful to distinguish its two facets: one is the content, related to the tangible, and the other is relational, related to the intangible. Content refers to the transmission of information between participants, that is, the language and information of the message. The relational refers to the manner of interacting, alluding to intangible aspects such as the building of trust, closely associated with the experience of perceiving emotional support or the impression of agreement or conflict as felt by the participants [2].

These two facets, content and relation, are also reflected in two tendencies in which clinical communication is conceptualised. One focusses on the observable, that is, certain conduct or behaviour on the part of the doctor and patient; the other refers to intangible experiences, such as the reflection of the doctor and the patient or the self-consciousness of mental and physical processes associated with communicative interaction [3].

The “behavioural” focus (communicational component) supposes an emphasis on communicative skills. The possibility to observe directly these “skills” facilitates the “objectification” of communication and its practice. Skills can be acquired, measured, updated, replaced and transmitted. However, the concept of skill alone does not allow the understanding of multiple levels of experience contained within the “relating” (relational component) between doctor and patient which is the crucial aspect of clinical communication. Inversely, without effective communication skills it may be impossible to achieve a satisfactory relation between the two.

If the behavioural focus emphasises what is empirically observable, the “relational” emphasises the internal world of the participants: feelings, thoughts or desires, the perception of the situation, personal values and the vision of the possibilities proposed in a consultation. For example, the impression of being comfortable, feeling a connection, trust, agreement or disagreement, etc.

The manner in which this internal world is revealed is complex. For the doctor, this can be perceived directly and immediately by paying complete attention to their own feelings, through cognitive and emotional self-awareness. However, the internal world of the other cannot be perceived directly and immediately, but through verbal, para-verbal and non-verbal signs which may be extremely subtle. This requires the exercise of “total attention” in carrying out a “dialogue”. It is the dialogue which provides rigorous rational clues as to what is taking place in the internal world of the patient.

Doctors who are “aware” are easily identified by the patient and colleagues because they are attentive (“present”), interested, conversational, without prejudice, genuine, (“being themselves”) natural and without giving the impression they are thinking about the appropriate communication strategy. Within the interaction this is revealed as a form of “relating”, shown in the respect afforded to the other person, the attention and interest in their experiences, ideas or their fears. This chapter aims to offer arguments which help to understand the authentic essence of this form of “relating”. Some authors have affirmed, for example, and especially in the clinical practice of family medicine, that this “relating to the patient” is fundamental and that the actual content of medical care, the reason for the visit or type of care offered, is secondary [4, 5].

7.2.1 Incorporating the Tangible and Intangible in Clinical Communication: The Person-Centred Clinical Method

The importance of communication within this new, person-centred context brings with it the challenge of incorporating this form of “communication” into the clinical method itself, that is, as one of the main diagnostic-therapeutic tools of the doctor. The clinical method is based on observation of symptoms, clinical examination and complementary tests, with the patient's medical history as a principal element. The medical history is structured into specific sections traditionally gleaned by the doctor through a communicative process similar to an interrogation. This new approach to clinical method (now patient-centred) emphasises the bidirectional nature of this process, supposedly incorporating subjective aspects of the ailment (the patient's perspective) and where the doctor-patient exchange involves the consideration of other, personal aspects for purposes beyond the merely curative. Thus, the communication skills and competencies mentioned above must be deployed within a new, broader structure of clinical consultation requiring, firstly, specific actions such as "to identify and to understand health problems" (correlated with the classic anamnesis, the exploration of the patient's perspective and a physical examination), "to help" and "to agree" (explain and plan). Furthermore, throughout the consultation, the doctor must act to "*build the relationship*"; to make a *connection* with the patient, to create a *bond*, fluid communication and a degree of trust that favours *self-perception* to decipher internal phenomena and combining these processes into a coherent *structure* helping to achieve the goals of the clinical consultation (CC) [6]. This structure is illustrated in Fig. 7.1 below.

The aim is to address both the consultation content (language and information transmitted in messages) but also relationships itself, the aspect of "relating", to achieve an effective clinical experience. Self-perception allows the doctor to identify emotional barriers, possible biases in clinical thought or personal attitudes that facilitate or hinder communication (intangibles). On the other hand, aspects related to content and the communication process (tangibles) are also included. The content is obtained through traditional anamnesis along with the patient's medical history,

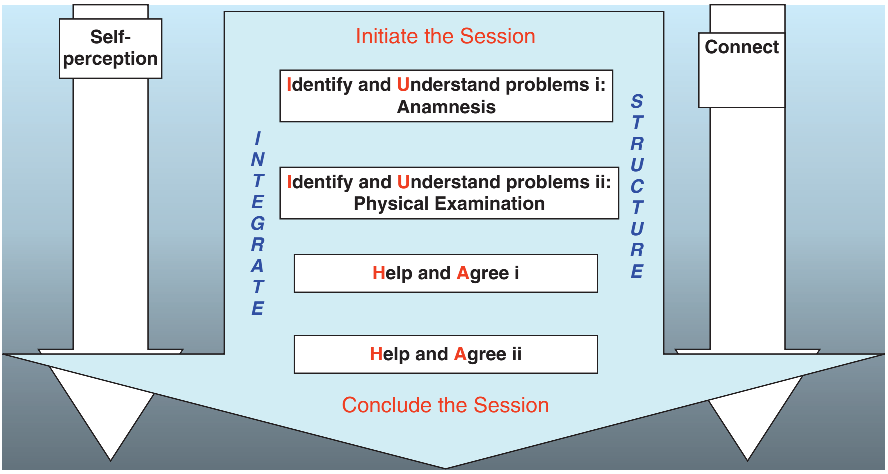


Fig. 7.1 Communicative tasks in the medical consultation, integrating form and content (the tangible and intangible) [6]

oriented to perceive the perspective of the patient. In this process, verbal, para-verbal and non-verbal skills are deployed in the exchange of content (tangibles). These skills are demonstrated, for example, in the ability to pick up and respond to clues, to verify, confirm and integrate information provided by the patient, to synthesise what has been understood and to share this information clearly and appropriately, to invite patient participation, looking for areas of agreement, etc. In turn, these communication skills reflect the internal dynamics of the clinical experience, including respect, authenticity, empathy or active listening (intangibles), intended to generate that effective "presence" or genuine "relating" where the patient feels accepted, understood and treated competently and thus, feels secure and trusting (intangible).

7.3 Inter-professional Relationships for Effective Person Centered Medicine

On the other part, effective person centered communication is the cornerstone of patient safety and quality of healthcare. Whereas ineffective physician-patient and health team communication is the root cause for nearly 66% of all medical errors [7], patient-centred communication diminishes the number and type of complaints and claims to physicians [8], producing in physicians greater well-being and less professional exhaustion [9].

The PCC focus and its strategies and attitudes, improve also clinical practice outcomes and impacts on patient safety. There is evidence that patients' perception and satisfaction of the quality of the health care they receive depends on the quality of interactions with their health care provider [10–14]. This relational approach also improve other clinical outcomes, referred to as diagnostic and therapeutic effectiveness—especially in chronic and cancer patients—[15–17] and saving health expenses [11, 13, 18]. There is evidence on strong person centered relationships between a healthcare team member's communication skills and a patient's capacity to adhere to medical recommendations, self-manage a chronic medical condition, and adopt preventive health behaviors [7].

Effective PCC among healthcare team members influences the quality of working relationships and job satisfaction. When communication about tasks and responsibilities are done well, there is a significant reduction in nurse turnover and improved job satisfaction because it facilitates a culture of mutual support [19]. That's why to centre care on the person, competencies in person centered communication along with other related skills such as those regarding assessment, counselling and behaviour change strategies, supporting self-management of illness and wellness, and in coordinating care across time and with other health professionals is being fostered among clinicians and other health professionals and is given high organisational priority [20].

7.4 The Anthropology of Person-Centred Clinical Communication

To clarify the anthropological model underlying the person-centred communicative focus it may be helpful to take a brief look at a central concept of medicine: the notion of "healing" the patient.

The scientific focus of medicine limits its perspective to the diagnosis, treatment and prevention of illness and doctor's training is predominantly biomedical. Thus, the main purpose of medicine is to "cure" illnesses and the "care" or "healing" of ill people. The term "healing" is closely associated with "ailment" and "suffering". The etymology of the word "healing" points to different meanings; it is derived from the word "heal" meaning "to have meaning or wholeness" which in turn is derived from the root "*healan*" the condition or state of being whole or complete. "*Hal*" is also derived from the root "holy" as is found in other languages, such as the Spanish "salud" of the French "santé". Anthropological research into the concept of "healing" show the different ways in which individuals respond to the loss of "wholeness" (medical or not, scientific or not, religious of not) [21, 22]. Egnew defines "healing" as "the experience of transcending suffering". Thus, the concept of "suffering" arises as a complement and contrary of "healing", referring to the experience of a person when the wholeness of the self is broken [23]. This "breaking" of the "sense of self" is highly variable and depends on each individual's definition but themes which persistently appear throughout human tradition and various anthropological studies and research into "suffering" and "healing" all refer to a "loss of wholeness or completeness of the person", a "crisis of meaning" [24], a spiritual consideration of the ultimate importance of life [25] reflected always in the personal narrative [26–28]. Additionally, themes related to "healing" often refer to the restoration of this completeness or personal wholeness, to living spiritually in peace, understood as the experience of the divine or transcendent, giving profound meaning to life.

Thus, and for the purposes of this work, the nature of suffering and the purpose of medicine allows us to consider the person as a "complex and unique reality" constituted of different dimensions and faculties such as the material (biological body), the corporeal (bodily sensations), psychological (emotions, feelings, etc.), rational or intellective (reason, self-awareness, freedom) and spiritual (values, beliefs, transcendence, etc.). The individual also has the ability to act freely, they "realise", "actualise" or "perfect" themselves, that is, give meaning to what happens to them and to others, acquiring the special dimension of "relationality". From this perspective, Western medicine must resolve the "anthropological problem" of conventional medical practice, first through clarification and then by offering practical solutions to deal with these realities [23]. PCC is just such a proposal, based on the holistic anthropological conception described above, which clarifies which healing actions a doctor should consider. This clearly suggests that to be a "healer" requires qualities and skills beyond those that are purely "curative". Firstly, they must have the diagnostic and therapeutic skills required for physical healing. Thus, the doctor requires a well-defined clinical methodology, a highly predictive nosological classification of illnesses and diagnostic-therapeutic technology that has been objectively validated and increasingly efficient in identifying physical ailments. However, dealing with the other, more personal aspects of suffering requires other tools. Active listening, facilitation and the offer of collaboration and support are crucial to the clinical consultation and dialogue. However, at its highest level, healing is not a technical issue but rather, as indicated above, something which takes place above all within a context of "relationality" and in the nature of a "narrative". The techniques are certainly important but insufficient if the doctor is not clear in their own mind about the purposes that drive their actions and relation with the patient. For example, according to Ian McWhinney [29], the best listening skills are useless if we don't think what the patient has to say is interesting or useful, and, especially if we are not really interested in or worried about the patient as a person. This perspective ultimately defines the ethical scope of what we are referring to and which we will deal with in more detail in the following section.

7.5 The Ethics of Person-Centred Clinical Communication: The Clinical Encounter

"To-be-person-centred" reorients the centre of medical practice from knowledge to ethics which will therefore prevail over the notion of medicine as a mere science or *Techné*. The moral imperative is dictated to the doctor by the manner in which any medical act begins: *"The patient comes presenting…"* The moral duty of the doctor is derived from this "appearing" by the patient, representing "the Levinasian moment" in which ethics precedes knowledge [30] implying the most elemental truth for a doctor: we are doctors attending patients, with the purpose of mitigating the suffering caused by illness. For doctors, the ethics of medical practice is above the epistemology of clinical medicine [31] in the sense that its ultimate objective is estimative, achieving "*good health*", understood as the *welfare* of the patient. The epistemological problem with modern medicine is that its regards the empirically demonstrable as the only truth, remaining superficial without addressing a deeper hermeneutic or philosophical rationality, an intangible but nevertheless "real" reality having to do with "the self", the experience of healing and personal, personal realisation referred to above. Thus, the appropriate use of these skills, including communication skills, in accordance with ethical practice is essential and thus contributing to the ethical medical practice.

We will provide a step-by-step argument of this notion within a general framework of all human action:

Firstly, human action cannot be considered solely as a fact or exclusively an automatic result of physical, chemical or neurological processes but as an external expression of the "intentionality" of the subject. Similarly, the justification of a supposed "person-centred" medicine does not lie in its interactive, participative and collaborative style, that emphasises the autonomy of the patient and their participation in the decision-making process, which reveals the doctor's interest in the perspectives and fears of the patient and achieving positive and scientifically demonstrable health outcomes as has been the justification of this focus until now.

The second step should consist in “revealing” the patterns or stages reproduced in all human action regardless of its particular nature. This pattern depends on two underlying ontologies: substance and relation. When providing patient care, the doctor should initially consider how they are viewing the person; in the context of the relationality used here, the intentionality of the doctor in considering the individual suffering from an illness is dependent on dichotomy either to engage the person or to disregard the person and attend only to the material. The actions of the doctor are always subject to and conditioned by the prior focus with which the professional engages the patient and thus justifies their actions (their intentionality). This may serve to clarify the notion of the “narrative” mentioned above: the doctor explains and justifies to themselves their actions with the particular subject, the patient, and gives meaning and coherence to their actions and so revealing the ethical nature of these actions.

Thirdly, we focus on the ultimate objective of these human actions and will therefore return to the meaning of “*good health*” mentioned above through an integral anthropological approach. We define this as our aspiration to perfecting ourselves and improvement as persons. In this way, the form of communicative action, the manner in relating to the patient has the ultimate aim of this improvement and perfecting of the patient as a person in addition to perfecting ourselves, thus engaging with the true essence of our own selves. Self-perfection and improvement (one could say to “heal” ourselves) through the engagement with the “person” it is necessary to engage our own *BEING* and by doing so as a personal subject in the relationship not only do we not lose or diminish ourselves we are in fact developing and improving. The question is not to obtain “external benefits”. To reconnect with the subject at hand, diagnosis and treatment are a “third good” in the action derived from the previous “good”. Both follow upon the notion that the doctor wishes *to do good well* [32].

7.6 The Essence of Person-Centred Communication

Finally, the *modus operandi* of the dynamic being described, which can be defined simply as “love”, is a structure that can be applied to all human actions (which can thus ultimately be described as acts of love) and so contribute, or not, to achieving the perfection, self-actualisation, the healing, being sought. Following on Thomas Aquinas in *Summa contra Gentiles* (cf. III, 90: “*the nature of love is that the lover wills the good of the one he loves*”), this structure is articulated in three moments: presence-encounter-communion which requires the correlative attitudes of relation, responsibility and commitment. Thus, medical action is always unitary because in this action a person, the doctor, wants and does perform a “specific good” (in this case curing) of other person (the patient) within the broader horizon of “the good of the other person” (in this case healing in its most holistic sense). One of the principal barriers encountered by clinicians is the notion that this is not a technical issue or question of technique but rather a “mentality”, a way of being. Laín Entralgo points this underlying ontological structure when referring to the doctor-patient relation as a “relation of friendship”. According to Laín Entralgo: *“Science, technique and love—love for our fellow man, love for their body and soul—is not always articulated systematically in the actions of a competent doctor. The practice of medicine is always, and should be, a problematic conjunction of technique and love”* [33, 34].

Thus, the most basic and genuine aspects of the doctor-patient relation are expressed in the attitudes of the doctor, perceived by the patient and associated with the doctor’s “way of being” rather than the specific actions a doctor may take, consciously or unconsciously. Notions of “presence”, “dedication” or “openness” are the most revealing manifestation of this type of relation (now fully person-centred). However, these are difficult to define since, as indicated above, they refer not to a specific action but to a state of mind. Arthur Kleinman [35] said that “we know the presence by its absence” while, similarly, Epstein [36] noted that patients perceive “presence” as a sense of “coherence and imperturbability”, Harper [37] also speaks of “presence” as an “attention to the here and now”, that is, complete and undivided attention, when the doctor takes interest in the life story of the patient, forgetting their agenda and hypotheses; the “dedication” when doctors give of themselves, and their true persons is felt: the feeling of “wholeness” understood as a universal and shared human experience and “intimacy” within the personal relationship.

7.7 Conclusions

The “person-centred” clinical relation or communication supposes an attitude on the part of the doctor in response to the challenge represented by the presence of the patient seeking their help. This attitude is open and welcoming to the person in all their dimensions, aiming to help in the healing process, the mitigation of suffering caused by illness. This relationship could properly be termed as “love” or “friendship”, in that the desire of the doctor is to do *good* for the patient.

Also crucial concerning the relational focus of person centered medicine, is to attend to inter-professional education and inter-professional working relations, and to the relationships between the health professional team and the patients and their families.

Furthermore, the practice of medicine is an intimate and ethical task, requiring a continuous exercise of self-exploration with each individual patient, attempting to give meaning and coherence to their actions for the good of the patient. This attitude will be reflected in the practice of a specific form of “relating”, not only by deploying certain communication skills or competencies or any other techniques, which are important and play their part, but through the presence and commitment of the doctor and other health professionals in communion with patients and families.

Acknowledgements and Disclosures The authors report no conflicts of interest in the preparation of this manuscript.

References

1. Engel G. The need for a new medical model: a challenge for biomedicine. Science. 1977;196:129–36.
2. Watzlawick P, Bavelas JB, Jackson DD. Pragmatics of human communication, a study of interactional patterns, pathologies, and paradoxes. New York: WW Norton & Company; 1967.
3. Zoppi K, Epstein RM. Is communication a skill? Communication behaviours and being in relation. Fam Med. 2002;34(5):319–24.
4. Farley E. Voices from family medicine: Eugene Farley. Interview by William B. Ventres and John J. Frey. Fam Med. 1992;24(2):152–5.
5. McWhinney IR. "An acquaintance with particulars...". Fam Med. 1989;21(4):296–8.
6. Ruiz Moral R. Comunicación clínica: principios y habilidades para la práctica. Clinical communication: Principles and skills for the practice (Original in Spanish). Madrid: Médica Panamericana; 2014.
7. Institute for Health Communication. 2011. https://healthcarecomm.org/about-us/impact-of-communication-in-healthcare/. Accessed 26 Dec 2019.
8. Levinson W, Roter DL, Mullooly JP, Dull VT, Frankel RM. Physician-patient communication. The relationship with malpractice claims among primary care physicians and surgeons. JAMA. 1997;277:553–9.
9. Dyrbye LN, Shanafelt TD, Thomas MR, Durning SJ. Brief observation: a national study of burnout among internal medicine clerkship directors. Am J Med. 2009;122:310–2.
10. Rao JK, Anderson LA, Inui TS, Frankel RM. Communication interventions make a difference in conversations between physicians and patients: a systematic review of the evidence. Med Care. 2007;45:340–9.
11. Ruiz-Moral R, Perula de Torres LA, Jaramillo-Martin I. The effect of patients' met expectations on consultation outcomes. A study with family medicine residents. J Gen Intern Med. 2007;22:86–91.
12. Ruiz Moral R, Munguía LP, Pérula de Torres LÁ, Carrión MT, Olloqui Mundet J, Martínez M. Patient participation in the discussions of options in Spanish primary care consultations. Health Expect. 2014;17(5):683–95.
13. Stewart M, Brown JB, Donner A, McWhinney IR, Oates J, Weston WW, et al. The impact of patient-centered care on outcomes. J Fam Pract. 2000;49:796–804.
14. Wanzer MB, Booth-Butterfield M, Gruber K. Perceptions of health care providers' communication: relationships between patient-centered communication and satisfaction. Health Care Commun. 2004;16(3):363–84.
15. Arora NK, Weaver KE, Clayman ML, et al. Physicians' decision-making style and psychosocial outcomes among cancer survivors. Patient Educ Couns. 2009;77:404–12.
16. Muñoz M, Ruiz Moral R, Pérula LA. Evaluation of a patient-centered approach in generalized musculoskeletal chronic pain/fibromyalgia patients in primary care. Patient Educ Counsel. 2002;48:23–31.
17. Ruiz-Moral R, Pérez Rodríguez E, Pérula de Torres LÁ, de la Torre J. Physician–patient communication: a study on the observed behaviours of specialty physicians and the ways their patients perceive them. Patient Educ Counsel. 2006;64(1–3):242–8.
18. Epstein RM, Franks P, Shields CG, Meldrum SC, Miller KN, Campbell TL, et al. Patient-centered communication and diagnostic testing. Ann Fam Med. 2005;3:415–21.
19. Lein C, Wills CE. Using patient-centered interviewing skills to manage complex patient encounters in primary care. Am Acad Nurse Pract. 2007;19:215–20.
20. WHO. Preparing a health care workforce for the 21st century. The challenge of chronic conditions; 2005.
21. Dossey BM, Keegan L, Shields D, Helming M, Barrere C, Avino K. Holistic nursing: a handbook for practice. Sudbury, MA: Jones & Bartlett; 2016.
22. Gordon R. Reflections on curing and healing. J Anal Psychol. 1979;24:207–17.
23. Egnew T. The meaning of healing: transcending suffering. Ann Fam Med. 2005;3:255–62.

24. Barrett DA. Suffering and the process of transformation. J Pastoral Care. 1999;53:461–72.
25. Hiatt JF. Spirituality, medicine, and healing. South Med J. 1986;79:736–43.
26. Brody H. Stories of sickness. New Haven: Yale University Press; 1987.
27. Frank AW. The wounded storyteller. Chicago: Chicago University Press; 1995.
28. Kleinman A. The illness narratives: suffering, healing, and the human condition. New York: Basic Books; 1988.
29. McWhinney IR. A textbook of family medicine. Oxford: Oxford University Press; 1997.
30. Levinas E. Totality and infinity: an essay on exteriority (philosophical series). Dordrecht: Kluwer Academic Publisher; 1991.
31. Montgomery K. How doctors think. Clinical judgment and the practice of medicine. New York: Oxford University Press; 2006.
32. Ruiz-Moral, R. The "Medical friendship" or the true meaning of the doctor-patient relationship from two complementary perspectives: Goya and Laín. Med Health Care and Philos. 2022;25:111–117. https://doi.org/10.1007/s11019-021-10056-x.
33. Laín Entralgo P. Doctor and patient. New York: McGraw-Hill; 1969.
34. Ruiz Moral R, Agejas Esteban JÁ. A reflection about the nature of doctor-patient relationship. Boletin Doctutor de Educación Médica. 2019. http://www.doctutor.es/2019/09/02/goya-y-el-dr-garcia-arrieta-o-el-sentido-profundo-de-la-relacion-medico-paciente/. Accessed 13 Nov.
35. Kleinman A. Presence. Lancet. 2017;389:2466–7.
36. Epstein RM. Attending: medicine, mindfulness and humanity. New York, NY: Scribner; 2017.
37. Harper R. On presence: variations and reflections. Philadelphia, PA: Trinity Press International; 1991.

Chapter 8
People-Centered Health Services

Alison N. Huffstetler, Robert L. Phillips Jr, Christine C. Leyns, Joel S. Willis, and Fredy A. Canchihuaman

8.1 Overview and Definition

In many regions across the world, segmented and fragmented healthcare is common. There is widespread underinvestment in primary health care, the level of care that is fundamental in a functional health system [1]. There are geographic, social and economic barriers to access of health services and shortages of healthcare providers. The historical thread of placing disease as the central marker of healthcare prevented

---

A. N. Huffstetler
Department of Family Medicine and Population Health, Virginia Commonwealth University, Richmond, VA, USA
e-mail: Alison.Huffstetler@vcuhealth.org

R. L. Phillips Jr (✉)
The Center for Professionalism & Value in Health Care, American Board of Family Medicine Foundation, Washington, DC, USA
e-mail: Bphillips@theabfm.org

C. C. Leyns
Department of Public Health and Primary Care, Faculty of Medicine and Health Sciences, Ghent University, Ghent, Belgium

Fundación Vida Plena, Sacaba, Cochabamba, Bolivia

Faculty of Social Sciences, Universidad Mayor de San Simon, Cochabamba, Bolivia

Physician and Community Educator, Cochabamba, Bolivia
e-mail: christine.leyns@ugent.be

J. S. Willis
Division of Family Medicine, George Washington University, Washington, DC, USA

F. A. Canchihuaman
Public Health and Postgraduate Schools, Cayetano Heredia Peruvian University, Lima, Peru

Department of Epidemiology, University of Washington, Seattle, WA, USA

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_8

cohesive and continuous health. The World Health Organization (WHO) reaffirmed that positive health transformation might be achieved if emphasis is placed on people-centered healthcare (PCHC) and therefore called states to take action with passage of the resolution WHA62.12 at the World Health Assembly in 2009 [2]. Evidence and theoretical analysis further suggests that people-centered and integrated systems are paths to more efficient, effective, sustainable, and just healthcare systems [3, 4].

Health services are "all [individual and community] services [related with] promotion, maintenance, and restoration of health" [5]. People-centered health services (PCHS) place people and communities at the center of the system, empowering personalized health decision making and adapting health services to the local sociocultural context. PCHS fundamentally adopt the needs and perspectives of individuals, families, and communities and promote active participation in one's own and community care. PCHS are needs based, investing more in vulnerable groups while removing specific diseases as the central context of health.

In defining PCHS it is important to also introduce two other terms: *patient-centered* and *person-centered* health care. The Patient Centered Medical Home is a construct largely of the United States that has a been a driving force for health policy for more than a decade [6, 7]. The joint principles for the Patient Centered Medical Home were agreed upon in 2007 and assured that each patient has an ongoing relationship with a personal physician trained to provide first contact, continuous, and comprehensive care who leads a team of individuals at the practice level who collectively take responsibility for the ongoing care of patients, all of whom are responsible for providing for the entire patient's healthcare needs and taking responsibility for appropriately arranging care with other qualified professionals [8]. It is focused on the person but without greater context or focus on community. Others claimed that it also "focused on improving the health of whole people, families, communities and populations," but this was not part of the joint principles [8]. The essence of person-centered care is that it extends beyond communication during any one clinical encounter and relies on a more continuous and holistic knowledge of patients, their families, their social world, and the communities in which they live and work [3]. This knowledge accrues over time and is not specific to disease-oriented episodes. Further, this knowledge, and the time spent attaining it, strengthens the relationships between the primary care team and the people seeking care. Compared to patient-centered care, person-centered care has been shown to lead to agreement on care plans, better health outcomes, and higher patient satisfaction [9]. The International College of Person-Centered Care has worked closely with the World Health Organization in defining person-centered care and its relationship to people-centered care (https://www.personcenteredmedicine.org/). As its leadership has explained, "people-centered health and health care extends the holistic perspective of person-centered health care beyond the individual. People-centered care continues to emphasize that the needs of the person is the foremost consideration across all levels of organization of health systems, but also recognizes that persons live together with other people organized in families, communities and populations dispersed around the world" [10].

Health services are defined as a variety of services delivered by institutions or organizations that propose to improve overall health [11]. Instead, PCHS put the person and the community as the focus of all health system management and organizational decisions, as well as in the provision of care. PCHS include community context and cultural beliefs in promoting health both at individual and community levels, giving people more autonomy over their health. The person and the family experiencing healthcare must be equipped to navigate the health system, to understand in depth their health problems or the health problems of their loved ones and to feel empowered to maintain or improve their health. Respecting the level of health literacy in a population is an important step towards universal health care and achieving health as a human right. In this way, people-centered healthcare has the potential to lead to a more just and inclusive universal health care system that will invest more in people with more needs [12, 13].

People-centered health services are dynamic and evolve. This is reflected by the progression of concepts presented by the WHO which include people-centered healthcare, people-centered care, and integrate people-centered health services. People-centered healthcare is defined as care in which "individuals, families, and communities are served by and enabled to participate in trusted health systems that respond to their needs in humane and holistic ways" [4]. People-centered care is "focused and organized around people's needs and expectations, rather than disease" [12, 13]. Integrated PCHS is centered on the "needs, perspectives, and social preferences of people and communities" [14]. Finally, this last concept is the key feature of WHO framework to improve health services. This care should be continued across the course of a lifetime and coordinated at various levels and across sectors [14]. This can be visualized as overlapping sectors, all of which play a role in people-centered care (Fig. 8.1).

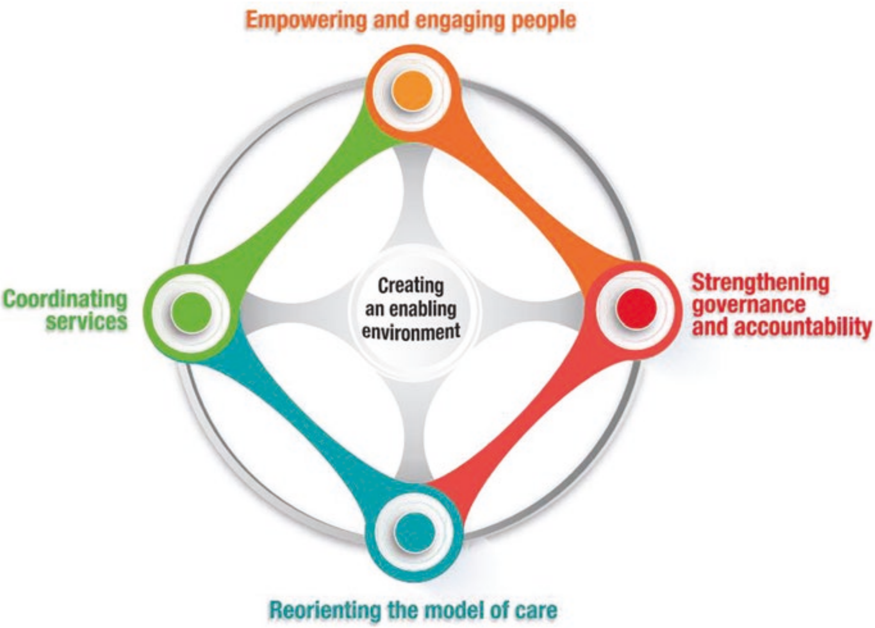


Fig. 8.1 The interdependency of the five strategic directions to support people-centered and integrated health services [15]

This chapter will explore the principles of PCHS, the methods of implementing health services, how specific clinical fields best integrate PCHS, and reflect on related clinician stories. Finally, policy platforms for the global use of PCHS will be provided. Each section will identify practical, scalable, and thus, implementable tools allowing for expansion of PCHS design.

8.2 Context of People-Centered Health Services

Although there is a widespread need to measure PCHS, there is a general lack of consensus as to the appropriate measurement. PCHS is necessarily broader than primary health care and needs different measures [12]. Measures by which people-centered care may be evaluated, in contrast to conventional care, are warranted. Furthermore, tools for assessing how health services are guided by new health approaches and put into practice are needed; tools must address the key components of integrated PCHS [16, 17]. The distinguishing features of conventional healthcare vs. people-centered healthcare are found in Table 8.1. The implementation science surrounding PCHS also is not yet fully defined. However, strategies exist and are here described as a framework for implementation. The strategies are adaptable to meet the specific needs of a community, culture, and beliefs of an area.

The tenants of Community-Oriented Primary Care, pioneered by Kark and Cassel in the 1950s and endorsed by the WHO in the 1970s, are a foundation for PCHS. Measurement of the success of interventions that lead to PCHS vary based on type of community served, economic status of the community and country, and cultural identity of the area. As such, one set of parameters will not objectively and systematically demonstrate implementation of successful PCHS. However, the following paragraphs detail possible measurements and outcomes related to PCHS. Specifically, the necessary attributes include: empowering and engaging people and communities, strengthening governance and accountability, reorienting the model of care, coordinating services within and across sectors, and creating an enabling environment [14]. This should be done with a strong focus on equity to achieve proportionate universalism in health.

Table 8.1 Comparison of care models. From the 2008 World Health Report [13]

Conventional care	People-centered care
Focus on illness and cure	Focus on health needs
Relationship is limited to the visit	Relationship is longitudinal and enduring
Periodic and episodic curative care valued	Comprehensive, continuous, and person-centered care
Responsibility limited to effective, safe advice to patient during a visit	Responsibility for the health within the community is essential, including tackling determinants of health
Users are consumers of the care they purchase	People are partners in managing their health and the health in their community.

8.2.1 Empowering and Engaging People and Communities

The process of engaging communities and individuals in health is to promote meaningful health services with knowledgeable, active users. For individuals and families, empowerment relates directly to their autonomy to make personal health decisions and take on roles as informal caregivers. For communities, empowerment at population level is related to public health measures that are far better accepted when introduced by their trusted primary care providers who take their local knowledge, leadership and beliefs into account. Community health workers decreasing communicable diseases, reducing childhood malnutrition, and improving vaccination uptake, are examples of low-income country approaches to community oriented and people-centered services that could hold similar value if adapted for high-income countries [18].

8.2.2 Strengthening Governance and Accountability

The goal of strengthening governance and accountability is to promote functional and acceptable decisions by policy-makers. The health system operates best when needs and perspectives of policy-makers, providers, and users are included. Community participation in governance, whether through stakeholder meetings, local member election into positions, or community participation in policy making promotes participatory governance. Participatory health councils may offer one avenue for engaging local populations in building policy for their area; however, these councils must have leverage and government support to succeed. When implemented in Brazil, councils were intended to help shape policy for the local health services; however, they fell short of expectations due to lack of support from government and limited interest [19]. Whereas lack of mutual accountability leads to failure, community participation in governance developed with balanced input, education, and afforded an actionable voice, is a tested model for low- middle- and high-income countries.

8.2.3 Reorienting the Model of Care

Prioritizing primary care as the central health system component of PCHS is fundamental for efficient and effective healthcare. Primary care needs adequate funding, training, and integration with public health and community care. Holistic needs-based care that spans the full life course, anchored in healing relationships that respect context of gender, social, and cultural beliefs, should be the goal. Frequent, reliable, and actionable health assessments by health personnel who take responsibility over an area should be used to drive services and allocation of resources.

Additionally, the rapidly evolving technologies that enable healthcare and relationships should be assessed and, as culturally and economically feasible, be integrated into PCHS. Technology and traditional methods combine to enhance population health monitoring and is done best with public, private, and voluntary organization participation and goal alignment.

8.2.4 Coordination of Services Within and Across Sectors

The ideal coordination of services promotes care integration that respects the needs of the people being served. Ideally, by providing this coordination, multiple aspects of health may be addressed, including social determinants, community health, education, and public health. Individuals benefit from addressing the range of their healthcare needs with assistance from healthcare navigators, case managers, care teams, and consented flow of information. Communities, municipalities, and regional networks must also create coordinated care systems that narrow the gap between formal health care and informal community resources. By doing so, diseases may be closely monitored and social service needs may be addressed from relevant sectors outside the healthcare system including housing, labor, education, finance, and law enforcement. A prime example of this coordination across sectors is Hennepin Health System in Minnesota, United States. This model has both reoriented and coordinated care, emphasizing the role of care coordinators, outreach, housing assistance, vocational training, and follow up within the community [20].

8.2.5 Creating an Enabling Environment

The final, and central aspect, of PCHS is creating an enabling environment. All four of the prior strategies must enable a healthcare environment committed to transformation. An enabling environment for health equity is created locally and supported by adequate public policy. Policy-makers should collaborate with community and health care stakeholders and foster a culture of information sharing and regular dialogue. Financial policies that support such change are necessary and both the United Kingdom and New Zealand model this by weighting resources for healthcare and social services based on small-area deprivation scores [21].

8.3 Methods

The Donabedian Model evaluating concepts of (1) structure, (2) process, and (3) outcomes are an originating framework to evaluate quality of care in health services [22, 23]. The evaluation of the quality of health services relies on efficacy (what works) and/or effectiveness (for who and where) [23, 24]. At the turn of the twenty-first century the lens for measuring and improving quality of care focused on ‘patient-centered’ care which highlights patient experience as the outcome centerpiece.

People-centered care has widened the lens through which health services are now driven. Within this framework, WHO seeks evidence-based methodology that utilizes iterative learning and action cycles, tracking changes, and identifying emerging problems so as to bring stakeholders together to evaluate and solve them [25, 26]. This broadened methodology scope seeks to view individual patients in a holistic fashion while simultaneously recognizing the interrelatedness of the whole system and a strong focus on equity to provide care based on needs instead of demand. For example, in an effort to avoid ‘homogenization’ of data, a people centered HSR study evaluating disease management might do so in the context of personal, socioeconomic, religious, ethnic, and gender boundaries [25, 26].

The goal of PCHS methodology is to continue to improve upon quality, efficacy, effectiveness, and equity through multiple tools, that may include, but are not limited to, medical records, patient and population surveys, stakeholders meetings and administrative data [23, 25]. People centered methodologies require coordination and collaboration across several boundaries so as to encompass an ‘integrated framework’ that considers whole spectrums of health and social care [27]. Methodological actions with multi-stake holder perspectives are required between health services, community, and workforce at each level of power with resources understood and shared [28]. Such efforts logically expand Donabedian’s model while promoting WHO efforts to improve health and health services.

8.4 Clinical Fields

The goals of PCHS models are to provide equitable, high-quality, cost-effective care [27]. Unfortunately, current models of care often leave service providers unaccountable to the populations they serve and with little incentive to provide sustainable care. This failure of continuity is worsened through disease-focused, hospital-based systems that enable a fractured ‘silo-mentality’ [14]. Alternatively, systems rooted in robust community oriented primary care have consistently demonstrated coordinated, continuous, and comprehensive services that improve quality for patients, families, communities, and populations [14, 29]. To this end, WHO has prioritized strong primary health care as the centerpiece in strategy for reorienting the model of people centered care [14]. An example of strengthened primary health care models includes proactive public health interventions and preventive medicine addressing patients and populations [30]. People-centered primary health care is well-placed to establish linkages between health services and other private and public sectors. Indeed, at the community level, the opportunity for such intersectoral coordination can assist in targeting social determinants of health within a defined geographical area [14]. Ultimately the goal of all clinical fields, as applied to PCHS, is to meet the needs of patients in their own terms, through both empowerment and proactive participation in their own care where appropriate [31, 32]. Strong primary care, particularly when integrating primary health care and public health, is necessary and uniquely positioned to meet the goals of PCHS.

8.5 Clinician Perspectives on PCHS

In Belgian community health centers, the capitation payment system incentivizes accountability of health providers for health maintenance of their registered population since a healthier population lowers the workload. For example, the case of a 50-year-old Fatima, a Roma woman with diabetes, heart failure, morbid obesity, and COPD, who was brought in nearly once a month with decompensated heart failure urging hospitalization. These events put a severe stress on the woman, her family, the hospital and our health center, that assisted the family and the hospital in the translation between the hospital culture and the Roma culture. It was impossible for her to visit the health center regularly so we had to think of a people-centered solution to prevent recurrent hospitalization by visiting her at home. The care was organized in a way acceptable to her with a simplified supervised medication scheme and clear agreements on smoking at a safe distance from her oxygen tank. The final decision on the limits of her care were made by Fatima, who decided that she didn't want to be hospitalized anymore. We had several meetings with the extensive family and further on with a son, assigned as family representative, before the family understood and accepted their mother and grandmother's decision. Although traditionally Roma people do not trust or respect people outside of their community, this mutual agreed upon health path created a space of mutual respect. Fatima died at home accompanied by her family, who were very grateful about the way she spent her last months.

In Bolivia, the public health system is organized in health networks, wherein primary health care centers are responsible for a defined population. Originally this system only covered services for pregnant women and young children beside some specific diseases like tuberculosis but evolved towards a unified health insurance providing basic coverage for the whole population. Recent health policy reorientation supported a PCHS focus by obliging health personnel to speak indigenous languages, building more health facilities, creation of family health records, and home visits [33]. Cesar, a 50-year-old construction worker whose uncontrolled diabetes led to loss of nearly half his body weight over 4 months, was unwilling to go to the hospital because his family depends on his income. Community health workers convinced him to come to a diabetes education session where they initiated insulin and arranged regular urine glucose monitoring. Cesar could not afford a glucometer (and can't read either) but learned what urine dipstick colors meant for his diabetes. After 4 weeks, his blood sugar levels normalized and he was so grateful because he was finally able to again lift a bag of cement. Community based interventions, respectful education geared to his education level, enabling autonomy, and meaningful outcomes turned his condition around.

Clinical care across the world is often unaccountable to the populations it serves. During the SARS-CoV2 Pandemic, it became evident that the healthcare system in many countries was hospital centric and could not meet the demands of testing, high level care, and response to communities that was needed to curtail a health crisis. Had PCHS been in place, targeted social planning, linkages across public and private sectors, and collaboration with communities could have been achieved. A strong partnership between primary care and public health was lacking in many countries, which is a cornerstone of PCHS. In order to achieve this, trust in authorities is essential making Germany an example of a COVID-19 success story while in Bolivia, a country in the midst of a political crisis, the health system collapsed in the height of the pandemic, causing an excess mortality of over 1800 people in only 2 months' time.

8.6 Alma Ata, Astana *and other Major International Declarations*

The sentinel primary healthcare conference took place in Alma-Alta in 1978 [1]. The declaration clearly established the importance of primary care and the fundamental right of healthcare by reaffirming that "Health, which is a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity, is a fundamental human right." The relevance did not diminish over the next 30 years. In the World Health Report of 2008, primary health cares' prominence in the health system was reiterated, and importantly, the people-centered approach was posed as a main reform to change health systems [13]. The 2008 report additionally broadened the focus on PHC to include universal health coverage, public health, and leadership as goals for health care innovation.

Forty years later, in 2018, the WHO and UNICEF brought together most of the World's health ministers in Astana, Kazakhstan for the 40th anniversary of the Declaration of Alma-Ata. The resulting Astana Declaration of 2018 reaffirmed the principles and values of PHC as stated in the 1978 Declaration of Alma Ata and set up a specific commitment to have services that are sustained, continuous, integrated, and people-centered [34]. People-centered integrated health services are critical to improve primary health care, achieve universal health coverage, and meet health sustainable development goals [35].

In May 2019, the World Health Assembly (WHA) responded to the Declaration of Astana with the passage of three resolutions focused on primary health care, the role of community health workers, and preparation of the UN General Assembly for the next high-level meeting on universal health coverage in September 2019 [2]. Specifically, the primary health care resolution called on the Secretariat of WHO to increase the support of member states and finalize the Primary Health Care

Operational Framework prior to the 2020 World Health Assembly. The WHA acknowledged that community health workers have a key role to play in delivering primary health care, particularly since they typically speak local languages and have the trust of local people. While they have a key role, the WHA also said that community health workers need to be well trained, effectively supervised, and properly recognized for the work they do, as part of multidisciplinary teams. Finally, the UN General Assembly on universal health coverage was to focus on key priorities including health financing, building sustainable and resilient people-centered health systems, and strengthening the health workforce.

On September 23, 2019, the United Nations held "Universal Health Coverage: Moving Together to Build a Healthier World," aiming to accelerate progress towards universal health coverage [36]. The outcomes of that meeting are not yet public, but this meeting took the next step toward international agreement on policies that would support PCHS.

The Astana Declaration inspired many regional reactions as well. During the WHA convention, the Pan American Health Organization (PAHO) published the report of the High-Level Commission, "Universal Health in the 21st Century: 40 Years of Alma-Ata". This regional response framed PCHS as "Integrated Health Services Networks" and many American countries have adopted or are in the process of adopting this initiative.

The international initiatives supported by WHO, the PAHO, the UN, and UNICEF strategically link primary healthcare, universal health coverage and place these priorities high on the world's agenda for health services transformation. How the initiatives change care regionally and locally will depend on the fidelity of health ministers and a commitment to PCHS.

8.7 Policy

Policy is important for developing and improving PCHS within countries. The WHO Framework on the subject identifies six key policy domains, including community engagement, health equity, local governance, prioritization of health services, coordination of care, and the regulatory and funding restructure (Table 8.2) [14]. Other initiatives including the Astana Declaration and the Primary Health Care Performance Initiative (PHCPI), have identified limitations in the framework and recommended solutions. Specifically, the Astana Declaration supports development of the Primary Health Care Operational Framework. The proposed framework revises the traditional WHO paradigm. Additionally, new measures have been proposed by the PHCPI, a collaboration of the Bill and Melinda Gates Foundation, World Bank, and WHO. These measures address high-value key components of PCHS that span low-, middle-, and high-income countries. The measures include resource development, workforce, technology, and research. Policy makers should look to these measures to drive legislation.

Table 8.2 Policy initiatives and opportunities. Adapted from WHO Framework on Integrated, people-centered health services [14]

Policy area/approach	Policy innovations
Individual and family engagement	Health education and literacy
Community engagement	Informed consent
	Shared decision making
	Individualized care planning and self management
	Informal care givers
	Community based care
	Involvement of community health workers
	Social participation in health
Health equity	Aligning health center goals with equitable principles
	Using various technology methods to reach underserved (telemedicine, mobile units)
	Intersectoral programs to address SDOH
	Expansion of primary care
Local governance	Encourage community participation in policies for health systems
	Patient representation as board members
	Decentralization to local areas
	Comprehensive plans and norms across public and private sectors
Prioritization of health services	Actionable health needs assessment
	Gender, cultural, literacy and age-sensitive service provision
	Monitoring of population health status and risk stratification
	Multidisciplinary primary care team generation
	Appropriate use of outpatient and home-based care
Coordination of care	Health navigators, community health workers
	Case management
	Improved care transitions
	Team-based care
	Merging of health sector with social services
Regulatory and funding restructure	Improved financial and human resources allocated to health promotion and disease prevention
	Mixed payment models based on capitation and risk stratification
	Greater proportion of health expenditure allocated to primary care
	Tackling health workforce shortages and maldistribution

An accurate analysis of the financial resources needed to support PCHS is essential for policy development. However, primary health care research financing remains insufficient globally [37]. The difference between primary health care and primary care is not always clear in these international policy discussions and this results in major limitations of healthcare spending analysis. Primary care describes a narrow set of services provided by community clinicians. Primary healthcare is broader and includes public health in addition to clinical services. Recent primary health care financing estimates range from 32 to 88% of total healthcare spend (approximately \$15–\$60 USD per person annually) [36]. In contrast, primary care spend was estimated to range from 12 to 17% of total healthcare spend globally and 5–7% in the United States [38]. The primary care spend estimate is limited; only 24 countries had sufficient data to be included and in most countries ambulatory care data fails to distinguish between primary and specialty care. Policies to reform health care expenditure cannot be well informed by current primary health care spend estimates. Health care leaders must further analyze primary health care spending. An improved capacity to understand investment in primary care and primary health care is important to make sufficient investment and to understand the financial relationship to outcomes.

Workforce development and policies have yet to affect the distribution of qualified healthcare workers in communities. Low-, middle-, and high-income countries have struggled with workforce adequacy. Low-income countries often do not have a basic workforce distribution. Middle- and high-income countries do not have team structures to support PCHS, despite higher numbers of healthcare workers. Workforce theory distinguishes between whether development is either basic or fundamental. A basic workforce includes only the clinical staff necessary to provide essential healthcare services. Conversely, the fundamental approach promotes a robust primary care workforce that provides comprehensive care. Currently, low- and middle-income countries are fielding community health workers to support basic functions of healthcare. In some developed countries, clinical health workers act as team members to address the fundamental tenants of PCHS. Team based models positively effect PCHS, by allowing members of the team work at the top of their license and address the needs of the community, and as a benefit, experience greater joy [39, 40]. Countries struggling with workforce adequacy should look to team- and community-based workforce policies.

Technology may act as an enabler of PCHS with the support of strong policy. Telemedicine and asynchronous communication can support continuity, comprehensiveness, and patient-centered care. Currently, telemedicine is used in some countries as a convenient form of care access but without respect for existing healing relationships. Application of telemedicine in this regard partially meets the goals of PCHS but does so at the expense of relationships. Cell phones in low- and middle-income countries provide a platform to reach remote populations. In addition to primary care, technology supports subspecialty service access. The relationship between subspecialists and telehealth increases higher acuity care for patients and allows for growth of skill sets for specialists. Policies must be in place to support the capacity for technology; primarily, NGO and government collaboration is needed to promote the infrastructure of telehealth.

Finally, advancement and anticipation of novel approaches to PCHS are essential. Research and innovation that span countries are critical components of the future of PCHS, as supported by the Alma-Ata and Astana Declarations [30, 41]. The time gap between research findings and implementation into daily practice has limited the impact that research brings to PCHS. The health of communities stands to be greatly improved with policies that reduce gaps, such as research in implementation science. Implementation science knowledge has grown tremendously in the 2010s and led to the creation of a specialized journal [42]. Local municipalities and governance should work to bringing research to life in their communities by promoting timely uptake of new research.

It is possible that the changes in spending, workforce, technology, and research may have unintended consequences. Selection of primary healthcare performance measures must measure what truly changes health outcomes and encourage accountability. Without consideration of the unintended consequences of policy change, measures to monitor policy progress may fall short. A prime example of this shortcoming is the Quality Outcome Framework in the United Kingdom. The framework gave considerable financial rewards for performance on more than 125 disease and process measures as opposed to primary healthcare functions. The focus on disease and process drove primary car away from PCHS and created considerable patient dissatisfaction and clinician burnout [43, 44]. Thoughtful collaboration between policy makers, clinicians and patient representatives may prevent unanticipated consequences of legislation.

8.8 Conclusions

People-centered health Services is one of the principles of Person Centered Medicine. Such services have triggered integrated global policies aimed to create proportionate universal health coverage, investing more in those with more needs. PCHS implementation has a variable appearance in different countries, however, examples of innovation and implementation are readily available with lessons for both developed and developing countries. There is general agreement from the world's health policy leaders regarding universal health coverage and primary health care—using the examples in this chapter offers avenues to achieve PCHS. This chapter also offers strategic directions from the WHO needed to support PCHS development in health systems across the world. Actions in all of these strategic directions are greater than isolated actions; countries should explore existing practice and search which strategizes first their specific context as a foundation for firm PCHS. While the cost may be significant (estimates from $200 to $330 billion USD), the outcome is likely to produce healthier and more robust communities. The 2019 United Nations Universal Health Care Assembly and 2020 World Health Assembly are providing important steps to drive PCHS across the world.

Acknowledgements and Disclosures The authors report no conflicts of interest in the preparation of this manuscript.

References

1. Pan American Health Organization. Universal health in the 21st century: 40 years of Alma-Ata (report of the high-level commission), revised edition. Washington, DC: PAHO; 2019.
2. World Health Assembly Update. [www.document]. 2019. https://www.who.int/news-room/detail/22-05-2019-world-health-assembly-72-update. Accessed 4 Nov 19.
3. Cloninger CR, Salvador-Carulla L, Kirmayer LJ, Schwartz MA, Appleyard J, Goodwin N, Groves J, Hermans MHM, Mezzich JE, van Staden CW, Rawaf S. A time for action on health inequities: foundations of the 2014 Geneva declaration on person- and people-centered integrated health care for all. Int J Pers Cent Med. 2014;4:69–89.
4. World Health Organization, Regional Office for the Western Pacific. People-centred health care: a policy framework. Manila: World Health Organization, Western Pacific Region; 2007.
5. Fracolli LA, Gomes MFP, Nabão FRZ, Santos MS, Cappellini VK, de Almeida ACC. Primary health care assessment tools: a literature review and metasynthesis. Cienc Saude Colet. 2014;19:4851–60. https://doi.org/10.1590/1413-812320141912.00572014.
6. Agency for Healthcare Research and Quality. Enhancing patient-centered outcomes research (PCOR): creating a national small-area social determinants of health data platform. Office of the Assistant Secretary for Planning and Evaluation; n.d.
7. Davis K, Schoenbaum SC, Audet A. A 2020 vision of patient-centered primary care. J Gen Intern Med. 2005;20:953–7.
8. Stange KC, Nutting PA, Miller WL, Jaén CR, Crabtree BF, Flocke SA, Gill JM. Defining and measuring the patient-centered medical home. J Gen Intern Med. 2010;25:601–12.
9. Ekman I, Swedberg K, Taft C, Lindseth A, Norberg A, Brink E, Carlsson J, Dahlin-Ivanoff S, Johansson I-L, Kjellgren K, Lidén E, Öhlén J, Olsson L-E, Rosén H, Rydmark M, Sunnerhagen KS. Person-centered care—ready for prime time. Eur J Cardiovasc Nurs. 2011;10:248–51. https://doi.org/10.1016/j.ejcnurse.2011.06.008.
10. Appleyard J, Rawaf S. Person centered medicine, primary care, and public health. Int J Pers Cent Med. 2015;5:97–100.
11. Roberts JL. Terminology: a glossary of technical terms on the economics and finance of health services. Copenhagen: World Health Organization; 1998.
12. World Health Organization. People-centered care in low- and middle-income countries. Geneva: World Health Organization; 2010.
13. World Health Organization. Primary health care (now more than ever), the world health report; 2008.
14. World Health Assembly. Framework on integrated, people-centred health services: report by the Secretariat (No. 69); 2016.
15. World Health Organization. WHO global strategy on people-centred and integrated health services: interim report. World Health Organization; 2015. https://apps.who.int/iris/bitstream/handle/10665/155002/WHO_HIS_SDS_2015.6_eng.pdf.
16. Simou E, Pliatsika P, Koutsogeorgou E, Roumeliotou A. Quality indicators for primary health care: a systematic literature review. J Public Health Manag Pract. 2015;21:E8–E16. https://doi.org/10.1097/PHH.0000000000000037.
17. Veillard J, Cowling K, Bitton A, Ratcliffe H, Kimball M, Barkley S, Mercereau L, Wong E, Taylor C, Hirschhorn LR, Wang H. Better measurement for performance improvement in low- and middle-income countries: the primary health care performance initiative (PHCPI) experience of conceptual framework development and indicator selection. Milbank Q. 2017;95:836–83. https://doi.org/10.1111/1468-0009.12301.
18. Perry HB, Zulliger R, Rogers MM. Community health workers in low-, middle-, and high-income countries: an overview of their history, recent evolution, and current effectiveness. Annu Rev Public Health. 2014;35:399–421. https://doi.org/10.1146/annurev-publhealth-032013-182354.
19. Kohler JC, Martinez MG. Participatory health councils and good governance: healthy democracy in Brazil? Int J Equity Health. 2015;14:21. https://doi.org/10.1186/s12939-015-0151-5.

20. Blewett LA, Owen RA. Accountable care for the poor and underserved: Minnesota's Hennepin Health Model. Am J Public Health. 2015;105:622–4. https://doi.org/10.2105/AJPH.2014.302432.
21. Phillips RL, Liaw W, Crampton P, Exeter DJ, Bazemore A, Vickery KD, Petterson S, Carrozza M. How other countries use deprivation indices—and why the United States desperately needs one. Health Aff (Millwood). 2016;35:1991–8. https://doi.org/10.1377/hlthaff.2016.0709.
22. Berwick D, Fox DM. "Evaluating the quality of medical care": Donabedian's classic article 50 years later. Milbank Q. 2016;94:237–41. https://doi.org/10.1111/1468-0009.12189.
23. Steinwachs DM, Hughes RG. Health services research: scope and significance. In: Hughes RG, editor. Patient safety and quality: an evidence-based handbook for nurses, advances in patient safety. Rockville, MD: Agency for Healthcare Research and Quality (US); 2008.
24. Starfield B. Primary care: an increasingly important contributor to effectiveness, equity, and efficiency of health services. SESPAS report 2012. Gac Sanit. 2012;26 Suppl 1:20–6. https://doi.org/10.1016/j.gaceta.2011.10.009.
25. Walji MF, Karimbux NY, Spielman AI. Person-centered care: opportunities and challenges for academic dental institutions and programs. J Dent Educ. 2017;81:1265–72. https://doi.org/10.21815/JDE.017.084.
26. World Health Organization. Health Systems Service Delivery [www.document]. WHO. 2019. https://www.who.int/healthsystems/topics/delivery/en/. Accessed 10 Oct 19.
27. World Health Organization. Health Services [www.document]. WHO. 2019. http://www.who.int/topics/health_services/en/. Accessed 10 Oct 19.
28. Leyns CC, De Maeseneer J, Willems S. Using concept mapping to identify policy options and interventions towards people-centred health care services: a multi stakeholders perspective. Int J Equity Health. 2018;17:177.
29. Bitton A. The necessary return of comprehensive primary health care. Health Serv Res. 2018;53:2020–6. https://doi.org/10.1111/1475-6773.12817.
30. World Health Organization. Declaration of Astana, global conference on primary healthcare. Astana: World Health Organization; 2018.
31. English J. Training doctors for person-centered care. Acad Med J Assoc Am Med Coll. 2016;91:294–6. https://doi.org/10.1097/ACM.0000000000001073.
32. Santana MJ, Manalili K, Jolley RJ, Zelinsky S, Quan H, Lu M. How to practice person-centred care: a conceptual framework. Health Expect. 2018;21:429–40. https://doi.org/10.1111/hex.12640.
33. Tejerina H, Soors W, De Paepe P, Santacruz EA, Closon M-C, Unger J-P. Socialist government health policy reforms in Bolivia and Ecuador: the underrated potential of integrated care to tackle the social determinants of health. Soc Med. 2009;4:226–34.
34. World Health Organization. Declaration on Primary Health Care [www.document]. 2019. https://www.who.int/primary-health/conference-phc/declaration. Accessed 10 Oct 19.
35. World Health Organization, UNICEF. A vision for primary health care in the 21st century: towards universal health coverage and the sustainable development goals. Astana: World Health Organization; 2018.
36. Universal Health Coverage | General Assembly of the United Nations. [www.document]. UN High Level Meet. Univ. Health Cover. N.Y. 2019. https://www.un.org/pga/73/event/universal-health-coverage/ Accessed 4 Nov 19.
37. Goodyear-Smith F, Bazemore A, Coffman M, Fortier RDW, Howe A, Kidd M, Phillips R, Rouleau K, van Weel C. Research gaps in the organisation of primary healthcare in low-income and middle-income countries and ways to address them: a mixed-methods approach. BMJ Glob Health. 2019;4:e001482. https://doi.org/10.1136/bmjgh-2019-001482.
38. National Academies of Sciences, Engineering, and Medicine. Implementing high-quality primary care: rebuilding the foundation of health care. Washington, DC: The National Academies Press; 2021.
39. Sinsky CA. Designing and regulating wisely: removing barriers to joy in practice. Ann Intern Med. 2017;166:677–8. https://doi.org/10.7326/M17-0524.

40. Sinsky CA, Willard-Grace R, Schutzbank AM, Sinsky TA, Margolius D, Bodenheimer T. In search of joy in practice: a report of 23 high-functioning primary care practices. Ann Fam Med. 2013;11:272–8. https://doi.org/10.1370/afm.1531.
41. Declaration of Alma-Ata. International conference on Primary Health Care, Alma-Ata, USSR, 6–12 September 1978. Development. 2004;47:159–61. https://doi.org/10.1057/palgrave.development.1100047.
42. Eccles MP, Mittman BS. Welcome to implementation science. Implement Sci. 2006;1:1. https://doi.org/10.1186/1748-5908-1-1.
43. Marshall M, Roland M. The future of the quality and outcomes framework in England. BMJ. 2017;359:j4681. https://doi.org/10.1136/bmj.j4681.
44. Roland M, Campbell S. Successes and failures of pay for performance in the United Kingdom. N Engl J Med. 2014;370:1944–9. https://doi.org/10.1056/NEJMhpr1316051.

Chapter 9
Person-Centered Health Education and Research

Simone Hauck, Luis Salvador-Carulla, Alberto Perales, Javier Saavedra, Carlos Salcedo, and Tamires M. Bastos

9.1 Introduction

Besides political, socio economic and ecologic crisis seen all over the world, we face challenges regarding both the provision of health care for the population, and the need to properly train professionals able to deliver culturally sensitive and technically competent care—without giving up their own health in the process. Burnout, depression and rising suicide rates among physicians, nurses, students, and other health care professionals are a major concern. These rates are climbing and suggest a looming crisis

---

S. Hauck (✉)
Department of Psychiatry, Medical School, Federal University of Rio Grande do Sul,
Porto Alegre, RS, Brazil
e-mail: shauck@hcpa.edu.br

L. Salvador-Carulla
Health Research Institute, Faculty of Health, University of Canberra,
Canberra, ACT, Australia
e-mail: luis.salvador-carulla@canberra.edu.au

A. Perales
Institute of Ethics in Health, School of Medicine, San Marcos National University,
Lima, Peru

J. Saavedra
Psychiatry and Mental Health Section, Academic Department of Clinical Medicine,
Universidad Peruana Cayetano Heredia, Lima, Peru

Office for Research Support and Specialized Teaching, National Institute of Mental Health,
Lima, Peru

C. Salcedo
General Health Studies, San Marcos National University, Lima, Peru
e-mail: csalcedoe@unmsm.edu.pe

T. M. Bastos
Federal University of Rio Grande do Sul, Porto Alegre, RS, Brazil

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_9

[1–6]. One of the major questions is that, despite increasing recognition of the problem, and the numerous initiatives that have been implemented in various locations to address the mental health of health care professionals, the rate of psychological distress is still growing. A recurring concern is that institutions and governments are focused on treating symptoms instead of the ‘disease’ and not paying adequate attention to health systems’ neglect of health workers health [7, 8]. In such an alarming scenario, the impact of the COVID-19 pandemic on the health of students and professionals is still unfolding and may have consequences for the teaching-learning process of the current generation. Illustratively, a study by Lai et al. [9] that evaluated 1257 healthcare workers that treated patients exposed to COVID-19 in China showed symptoms of depression in 50.4%, anxiety in 44.6% and distress in 71.5% of the sample.

Thus, the objective of this chapter is to invite the reader to go deeper into how person-centered education and research can contribute to cultural changes that are needed for more humanized care of patients and health professionals themselves. We begin with an *overview* of the context in which health professionals work, summarizing the evidence related mainly to mental health and its consequences in the care offered to patients. Then, we present what is already consolidated in terms of the *concepts and the positive impact* of person-centered health education—including models of action. Later, a section is dedicated to *person-centered health research*. Finally, the *practical implications* are listed, as well as the issues that still require international collaboration so that we can move forward.

9.2 Overview of Health Care Today and Its Impact on Health Care Professionals

Contemporary health care has evolved in the direction of a dehumanized and market-oriented outlook that leads professionals to treat and discharge patients as fast as possible, figuring out billing codes, worrying about litigation, handling electronic medical records, and responding to a constant flow of emails or texts around the clock (and even on vacations). Moreover, the flood of new information that must be assimilated and mastered is leaving the “person” inside the professional with a feeling that he/she is always falling short [10, 11]. Many concerned professionals are raising the specter of “moral injury” because of the way health care is now being delivered. Moral injury results from having transgressed or violated core moral boundaries, imposing a challenge of reconciling the gap between what IS happening and what SHOULD happen, especially in highly stressful, high-stakes circumstances. For some health professionals this gap challenges their own values and norms, giving way to painful feelings like shame, guilt, self-condemnation, feelings of betrayal, difficulty trusting, and difficulty forgiving [12].

The aforementioned scenario leaves patients and the ones who treat them under the risk of lacking time or energy for meaningful empathic communication, sacrificing the core principle of doctor-patient communication. The emergence of Patient-Centered Care in the early 1970s raised the importance of bringing back a comprehensive look at the patient, one that respects autonomy and uniqueness. However, it left the professionals out of the equation. Hence, inattentive management practices, guided by the idealized and unrealistic model of the health professionals as selfless martyrs that ignore the care of themselves, are still common. Furthermore, the culture of perfectionism and invincibility among physicians imposes additional resistance to change. Even those who suffer the most have difficulties in acknowledging their own suffering and seeking help [10, 11, 13, 14].

Burned-out professionals are known to provide lower quality and less empathic care. Physicians suffering from burnout make more mistakes, prescribe more unnecessary drugs, and order more unnecessary tests [15, 16]. Burnout leads to early retirement and reduced clinical hours, increasing costs for healthcare organizations [17]. Facing such a crisis in healthcare demands a deep look at the person inside the healthcare provider and encompasses a profound revision of the structure of healthcare systems. Systems are made by people, and by the relations among them. An effective change must confront the negative aspects of the culture and omnipotent and dehumanized expectations at all levels, from patients, families, health providers, and administrators to society itself.

The importance of the person in relationship with others is central to the understanding of Person-Centered Care (PCC) [18, 19]. The key concepts of person- and people-centered care, such as ethical commitment, a holistic framework, cultural awareness and responsiveness, focus on dialogue, fostering communication at all levels, individualization of care, establishment of a common ground for collaborative diagnosis and share decision-making and people-centered organization of integrated services are essential to guide health education and health research in a person-centered manner [20].

A robust effort to include person-centered principles in health education is urgent, not only for the students to learn how to better treat their patients and benefit their communities, but especially to highlight the relevance of self-care for one to provide the best possible assistance for others. Understanding how individual perspectives interact with the learning process and the health care systems is possible through person-centered research, which will be described further.

9.3 Person-Centered Health Education: Concepts and Practice

Person-centered health education (PCHE) has been a key topic in person centered medicine since early outlines [21] and systematic efforts at conceptualizing and measuring it [22]. A series of perspectives on person-centered medical education have been highlighted and are listed below in Chart 9.1.

PCHE can contribute significantly to contemporary healthcare, precisely by placing the person as THE reason for medicine—therefore, the reason that one becomes a doctor and a health professional. PCHE requires an emphasis on communication, and dialogue at all levels. Early contact with “the person” through

- ✓ Education based on the principles and strategies of Person-centered Care (PCC), such as ethics, holistic frameworks, communication and relationships, individualized care, common ground for collaborative diagnosis and care.
- ✓ Student and teacher selection processes focused on qualities valued by PCC;
- ✓ Person-centered institutional culture;
- ✓ Mentoring programs;
- ✓ Curriculum changes, such as including the humanities, training in communication and empathy skills, decision-making training respecting patient autonomy and dignity and empowering families and communities;
- ✓ Inter-professional training programs;
- ✓ Worthy educational activities;
- ✓ Diverse teaching settings;
- ✓ Adequate infrastructure and research programs.

Chart 9.1 Person-centered health education topics [23]

patients, families and community is essential as part of the formation and the reason for learning. The person as "the core" brings with it a great ethical commitment and cultural sensitivity. Values, experiences, preferences, well-being and life projects are also a concern and part of caring for patients. Moreover, they are relevant elements to be deeply understood among the students, assistants, and every person that is part of the healthcare system [24].

In PCHE there must be a clear reason for what is learned, and the student must be aware of it. Longitudinal and transversal curriculum approaches should make it possible to see the application of what is learned in the care of the patient all along the way. A person-centered health perspective towards students, faculty and employees, and a commitment to personal development in addition to technical training is vital. Academics and teachers must be aware they are role models, and carefully teach that health professionals are also persons, and not superheroes. It is a central aspect, because although apparently obvious, this view goes against decades of an omnipotent culture in health professions [10, 13].

Many authors in the field of medical education are placing person-centered principles in the core of what needs to be tackled to improve health outcomes. In this sense, Harden [25] stated that we should go from an "ivory tower" to the real world, and health professionals are to be formed according to society's real needs. He also claimed that instead of learning just-in-case, we should move to just-in-time learning. In other words, instead of learning "everything" just in case you need it, learn "what you need as you go". The integration of basic science with clinics and the value of teaching are described as crucial. In addition, dialogue and collaborative learning should be the rule.

We must shift to a paradigm in which students are part of the decision of what they learn, how, when, and why. Furthermore, technology should be used in a creative and effective way: not to do the same in a different way, but to create a new ecosystem that favors education, patients, and community assistance. This takes us from compartmentalized to program-focused assessment of learning, and from a relative *isolation to greater collaboration* [25].

These values are related to extremely important goals that include the promotion of health as a state of physical, mental, socio-cultural, and spiritual well-being as well as the reduction of disease, and the assurance of mutual respect for the dignity and responsibility of each individual person [26, 27]. Aspects such as interdisciplinary work and perspectives, collaboration, and ethics must be largely present from the beginning of education, just as the recognition of the vital importance of communication, both verbal and non-verbal. Educators must learn how to speak *with* the students rather than speak *to* the students, while also becoming committed to be role models [18]. In fact, such formulations by health scholars are supported by educators and philosophers in the field of pedagogy: Paulo Freire has a long-standing work emphasizing the need to respect the knowledge of those we intend to teach—making them critical and autonomous agents of learning itself [28].

Some initiatives suitable to achieve a PCHE model have already been tested with positive results, such as the Pass/Fail grading system, curriculum structure changes, mental health and wellness programs, and advisor/mentoring programs [29]. When teaching a PCC perspective to the new health professionals one must remember that it demands high self-awareness in teachers, professors and other role models. As one values the encounter, such as when teaching and fostering empathy, it is crucial to also consider the enormous value of non-verbal communication. What is taught and what is conveyed to patients transcend the domain of mere words: there is always communication by many other means. So, one really needs to BE it, not only to KNOW it. It also implies dealing with the impact of contact with others' minds and realities. As can be seen in compassion fatigue, it is central to be authentically in contact with the other, but it is also extremely necessary to learn how to deal with it. The inclusion of perspectives from other disciplines can contribute in this sense: humanistic content, psychodynamic psychiatry understanding, neuroscience apprehension of the encounter,—all can add to the skills required to a deep contact with the other [24].

9.3.1 A Proposed Path: The Third or Emerging School

> *Let the children decide for themselves what is right for them. They know it no less well than you do.—Leon Tolstoi*

> *Let patients decide on their own what's right for them. They know it no less well than you do.*

The vital process of intellectuality follows the ubiquitous spiral path, according to which one point is based to reach another such on a certain subject or knowledge, which it achieves with the particularity of doing so in another time and space. This is even more forceful in the educational field, so much so that "I know something" would go through "I educate myself" and culminate in another "I know something". The path between each step is supported by instruments (education) and products (the knowledge or competence acquired) that are formed and validated during the same process.

Education as a discipline went through a paradigm change during the late 1960s. While the previous school pivoted on teaching and the teacher, the new model focused on learning, that is to say the student. However, this bimodal approach may detach the instrument from the product. As a matter of fact it is the application of the product that confers usefulness. Its application should not be the sole responsibility of the teacher or the student as agents, but should incorporate the actor or principal who receives the product (i.e. in healthcare the person/patient). Therefore a "Third School" should be needed, in which the actor or principal is the object to which health and education will provide well-being and consideration as a human being (see Table 9.1).

In the health sector, the patient is the leading person and medical education should be aimed at ensuring well-being conditions. Thus, patients views should be consulted when defining the teaching profile and the curriculum of medical education. Patient's dissatisfaction with their health care adds on claims for equal, fair, compassionate, assertive and respectful treatment [30].

> *Science without conscience is nothing but ruin of the soul. F. Rabelais* [31]

> *To infect the ordinary person with the spirit of the humanities is the greatest and most unique gift of education—W. Osler* [32].

The emerging person-centered approach to education may contribute to solve educational problems. Medical and health related faculties should plan educational process considering patients' experience and opinions.

Table 9.1 Comparison among schools with key criteria related to who is the center of the educational process

Traditional School	Revised School	Emerging School
Teacher-centered	*Student-centered*	*Person-Centered*
Knowing how to know	Know-how	Knowing how to be
Theorizing	Practice	Integrate humanities
Science	Technology	Philanthropy
Authoritarianism	Liberality	Determines needs
Memorization	Technology	Humanization
Verbalism	Technicality	Real applicability
Passive learning	Active learning	Integrated learning
Acriticism	Criticism	Constructivity
Imposed planning	Logical planning	Rational planning
Meets teacher needs	Meets student needs	Meets person needs

9.3.2 Illustrative Competence-Based Training in Intensive Care Medicine in Europe (CoBaTrICE)

CoBaTrICE was founded 2003 to define the results of the training of specialists in Intensive Medicine and to develop an international training programme for Europe and other regions of the world. The fundamental principle of this project is that a specialist in Intensive Medicine trained in one country must possess the same basic skills and abilities as one trained in another country, for a common standard of clinical competence. It was a global consultation and consensus process, involving physicians and specialty students, nurses and other health professionals, patients, family members and national and international organizations. By consensus, the combined experience of 535 clinical specialists and 1391 patients and family members was collected. In the process, common competencies were identified in Intensive Medicine specialists from different countries with a group of experts to correct and determine the level of importance and experience required. After the detailed review, a final system of 102 capacities was generated grouped into 12 domains that form the heart of this international training program.

Consideration of the *emerging* school immediately brings the following concerns:

(a) *Who should decide what competences a doctor should achieve?*
Historically it has been a unilateral decision of the academic authorities. Following the criteria of the “Revised School”, students should participate in this decision. However, should the students themselves decide what competencies they should acquire? It may be advisable to consult with all appropriate stake-holders.

(b) *How should this previous training be considered?*
The proposal to train healthcare professionals in non-technical competences would include the following “common areas of training”.

1. Social Personal
2. Training Assistance
3. Social Projection
4. Teaching
5. Research
6. Management

(c) *Where to raise them?*
They may be included in the curriculum, as follows:

1. Social personal area
    - Non-technical competences as curricular axes
    - Ethics as a discipline should be cross-cutting to all subjects
    - Bioethics as a specific course
    - Strengthening emotional intelligence with the resources provided by psychology and other sciences
    - Include humanities subjects

2. Healthcare area
   Teaching care for a patient with organic failure in an integral way should consider the environment, the context and the mood of the patient and the family, without undermining current professional standards and scientific evidence.
3. Area of social projection
   Design student participation in the various stages of health promotion programs, at the community, local, regional and national level, enhancing quality and respect for human dignity.
4. Teaching area
   Consider here university teaching, professional training, continuing medical education and scientific events of the specialty.
5. Research area
   Design research on the problems related to the humanization of the professional or specialist individually and as a team. Propose active participation in the development of proposals to improve humanized patient care. Formulate and apply investigative protocols in compliance with current ethical and legal standards, respecting and safeguarding the rights of the patient and his family.
6. Management area
   Include in the curriculum participation in the planning and programming of administrative activities aimed at humanizing services. It proposes administrative measures that allow for changes in infrastructure that favors the flexibility of the family visit.

(d) Evaluation of training
The following Table 9.2 is an example of evaluation of training in a critical care specialty:

The emerging third approach to education could shift the focus towards the person and humanization, and raise awareness of the professional.

Table 9.2 Educational evaluation in a critical care specialty

Minimum achievement type	Evaluation procedures	Evaluation instruments
Minimum performance	1. Observation of work in actual or simulated situations	1. Checklist for performances
	2. Analysis of products or documents	2. Valuation scale for performances
		3. Interviews
	1. Critical incident or case analysis reporting	Scale
		Questionnaires
		Interviews
Minimum knowledge for courses	Request for responses	Objective tests
		Trial tests
		Open book trials

9.4 Person-Centered Health Research

Research is one of the key principles of Person Centered Medkcine [20]. This approach opens up a new and broader perspective to clinical and epidemiological research as it promotes health in its wholeness [33, 34]. Epidemiological research should not only seek the dynamics involved in the development of the disease but also explore the determinants of health and well-being and their relationship to health problems. It also includes the need to integrate qualitative research and quantitative research that could evaluate narrative aspects of the disease and health experience and identify from the point of view and experiences of people the understanding of their conditions and their conduct linked to their individual and public health [35].

Qualitative methods may be used during the learning process itself. Van Dulmen et al. [36] have described an enlightening guideline based on lessons learned from teaching experiences in the Netherlands, Norway, and the United Kingdom. The authors state that information technologies enable a new level of supervision and teaching of communications skills by recording human interactions. However, experiences of others are rarely availed for such a challenging endeavor. They detail four key aspects that must be covered and well planned before starting: (1) Recording purpose and patient recruitment; (2) Provider and patient recruitment; (3) Ecological validity and representativeness, and (4) Data observation, storage, and use. Researchers elaborate on strategies to deal appropriately with ethical concerns—e.g., never allow observers to learn from recordings of people they know—, and also on more procedural tips, such as using systems that can remotely switch on cameras or audio recorders, keep paper work for the practitioner to a minimum or non-existent level, etc. [36].

Mixed qualitative and quantitative research outcomes can support the implementation of person-centered strategies in clinical practice by addressing aspects of patient encounter such as therapeutic partnership, empathy development, and more humanistic interactions between the clinician and the person seeking health care [37]. It is also important to integrate evidence-based medicine with clinical practice based on values, involving preferences, concerns, desires and needs of patients and their families, which encompasses a more complex dimension of research but considering the uniqueness of the person [38]. Evidence-based medicine tends to standardize clinical decisions and reduce the decision-making span on what should be done in a particular situation. In turn, persons-centered medicine promotes greater discretion and variability in clinical care, with research having the opportunity to examine the person-centered and evidence-based intersection and how to deal with both to achieve higher quality health care [39].

There is evidence that person-centered clinical care improves patient experience, communication and greater involvement in clinical decisions [40], and that person-centered approaches have an impact on the outcome of health problems in primary care [41]. However, some authors argue that these findings are not entirely consistent due to problems of internal and external validity with the studies carried out and, therefore, it is necessary to delve even deeper into this association and how to measure this approach [42]. This includes the development of appropriate measurement tools that not only take the positivist quantitative paradigm of research, but that seek a better understanding of the individual through health self-reports, narrative assessments, and notions of well-being [43].

The development of research tools for that purpose is beginning to grow, as will be shown illustratively next.

9.4.1 Systematic Conceptualization and Measurement of Person Centered Medicine

The Person-centered Care Index (PCI), a questionnaire developed by a research group from the International College of Person Centered Medicine with support from the World Health Organization [22] measures advancement towards person-centered care on the bases of eight key features of person centered medicine (PCM) elucidated through a systematic conceptualization study involving critical reviews of the literature, consultations with international scholars, patients and relatives, and reflections and debates within a broad international research group. The eight PCM principles are ethical commitment, cultural awareness and responsiveness, holistic framework, relational and communicational focus, individualized care, common ground for collaborative diagnosis and treatment, people-centered integrated health services, and person-centered education and research. Building from this conceptualization study, the Index is composed of 8 items and 33 sub-items, each measured on a 4-point scale. The PCI has an efficient metric structure in terms of internal consistency (Cronbach 0.95) and an information-rich single factorial structure, as well as internationally documented reliability and validity.

In Latin America, there is increasing interest on person centered medicine [44], with an emphasis on empirical research. In a keynote lecture at the first Latin American Conference on Person Centered Medicine in 2015, Perales concluded that to evaluate the development of PCM, it was necessary to obtain more systematic data on this programmatic perspective through scientific research. He recommended that national academies of medicine and medical schools in the region join forces on such efforts [45].

Other authors have outlined the need for indicators and instruments that best measure each of the components of person-centered health and their outcomes, the places where this assessment should be conducted and the relationship of each of the person-centered medicine dimensions with the results to be obtained [46]. In line with this research, consideration should be given to the study of the priorities, preferences and expectations of people or communities in health where clinical outcomes are determined by the person or the community [47]. Assessments of strategies to combat service fragmentation should also be considered under the principle of a centralized attention to the interests of individuals and not to the administrative or insurance system or structure [48, 49].

The Second Latin American Conference of Person Centered Medicine held in Lima in 2016 considered, among other conclusions, to move forward with a research program on person-centered care pointedly in health systems, starting with those in Lima, where the most active group of cultivators of this programmatic perspective had appeared under the guidance and stimulation of the just established Peruvian Association of Person Centered Medicine and the Latin American Network for Person Centered Medicine [50].

For this purpose, and using the Spanish version of the PCI, a comparative appraisal of person-centered care in four prototype hospitals, was carried out in Lima, Peru (Perales et al., 8.1). In each of the four evaluated health institutions: a public general hospital, a public specialized hospital, a social security hospital, and a private hospital, 30 physicians and 30 nurses, working in clinical medicine and surgery services in each prototype institution, were requested to rate the corresponding institutions using the PCI.

In an attempt to place the findings of the present study in perspective, one can consider that quality of healthcare is a difficult concept to define although it has been described and evaluated in different ways [51]. A traditional perspective has focused on patient satisfaction. This measurement, however, has been criticized because, such a parameter is insufficient to adequately measure the wide spectrum of feelings, values and experiences that a person experiences when he or she is receiving care in a health institution and that many health professionals believe they have dispensed person-centered clinical care, without adequate evidence of such [52, 53], which, again, suggests the need to base those views on explicit and systematic ratings as those afforded by the use of adequate instruments as the PCI.

Finally, it seems essential to consider the importance of using systematic approaches for the evaluation of Person-centered quality of care, particularly in regions and countries where the dehumanization and commercialization of society and care threatens the goals of genuine care, as is the case in Latin America. Such evaluations may be enhanced in the future through the additional engagement of other types of raters such as patients and family members although these different types of raters may also have their own biases and limitations.

9.4.2 Other Person-Centered Health Research Considerations

Research on the teaching strategies of people-centered medicine and the related assessment tools is also important. The development of communication skills is a key topic when teaching the people-centered approach to medical students. However, some studies have reported conflicting results regarding the teaching of communication skills in medical students and their subsequent performance in these aspects [54]. This brings up the importance of improving evaluation tools in terms of validity, reliability, as well as their generalization and possibilities of application in different physical and cultural contexts [55].

The 2013 Geneva Declaration sponsored by the International College of Person Centered Medicine identified ten priority areas for person-centered medicine research: (1) conceptual, terminological and ontological topics in the quest to achieve a common conceptual language and the relationship with other fields of study; (2) evidence on the main components of person-centered medicine taking into account the complexities of this approach, including negative health and positive health in their domains of disease and well-being, disability and functioning, resilience, health experiences and health and well-being contributors, and their interaction with other fields of biological and psychosocial medicine; (3) studies of the various components of the patient medical relationship, in particular the communicative aspect considered a key element of person-centered medicine; (4) diagnostic models on person-centered medicine, including the development and validation of guidelines and assessment tools; (5) research to assess the scope of interventions in person-centered medicine, in terms of the empowerment of individuals and their families, the usefulness of models, the achievement of effectiveness, efficiency, equity, parity, and quality; (6) research on people-centered public health and care, such as people's involvement in health policies or care for vulnerable groups; (7) research in training and curriculum development for the teaching of people-centered medicine; (8) dissemination of people-centered medicine through scientific publications; (9) organization of scientific events; and (10) development of online internet-based tools that promote inter-agency communication and academic collaboration [56].

Health promotion is a key goal of person centered care. Studies should include subjective indicators of health, like feeling ill or well, whether or not a disease is present. Recovery, sense of hope, empowerment, resilience and other measures of well-being and strengths should be contemplated. In this sense, the non-linearity and complexity of person-centered care has been recognized and highlighted and instruments like the "Person-Centered Care Index" and the "Expert-Based Collaborative Analysis" have been suggested [18, 22, 57].

Another aspect to be encompassed by the person-centered research field is the use of proper methodology to understand phenomena in depth from the perspective of the person. This should include patients, families, providers, administrators, and community perspectives that can be heard through carefully conducted qualitative studies. It is worth noting that the process of research itself has the potential of changing the environment through the reflection brought about to the subjects and its ramifications [58].

In summary, research in person-centered medicine is a challenge for medical and health education due to the multiple dimensions of person-centered care, and the individual's own complexity. On the other hand it provides a unique he opportunity to return to the fundamental principles of medicine that places the attention on the individual, with the primary perspective that health is not only an end in itself, but a means to achieve and promote the highest aspirations of people seeking care.

9.5 Practical Implications of Person-Centered Health Education and Research

Person-centered health education and research can lead to a learning environment that contributes to wellbeing in opposition to stress, burnout, depression and illness. It is also a way to spread the changes throughout the whole system and throughout educational and research processes . It is necessary to raise awareness of this approach among stakeholders and those in charge of organizations, as well as professors and teachers in general [24]. Health educational reform needs to occur to achieve better balance between health promotion (including health literacy, self-care, primary care and specialty care), disease prevention and management, and between cognitive and other personal skills.

Healthcare professionals need more than facts in order to understand themselves and to interact authentically and collaboratively, including participation in multidisciplinary healthcare teams. To promote well-being of the whole person we must shift the current emphasis on organ- and disease-based instruction to a more balanced and person-centered approach to both healthcare and health promotion. Students and trainees need to be given a more influential role in their own education. This can be accomplished with the help of national and international student organizations with input from local trainee groups so that education is continuously "updated" [59–61].

- Dialogue, spaces where every person that is part of the health education system can be truly heard (role of institutions, leaders, peers, qualitative research)
- Barriers: different generations, socioeconomics, unconscious (resistance to change, defenses, omnipotence, vulnerability, contact with disease and death,—the demand—for the professor/preceptor—of getting in contact with one's authentic self and the authentic other)—potential help of other fields such as psychodynamic understanding

The horizon described in this chapter points out to possible paths for overcoming the problems of dehumanized care through actions such as the medical curriculum reform, educational system considerations and PCHE principles.

9.6 Conclusions

Person-centered health education and research is one of the most challenging subjects to be taught and learned. It encompasses complex issues ranging from the need for self-care and mental health promotion, the responsibility of professors and staff as role models, and includes the duty to rethink the toxic aspects that still permeate an omnipotent culture in the health field. A comprehensive, humanized and culturally sensitive approach of the teaching and learning process is key to cultivating a humanistic approach of healthcare—in which professionals are able not only to care for their patients, but also of themselves. In that sense, person-centered research may contribute greatly by providing evidence- and experience-informed contributions for developing improved care and health actions in a range of contexts.

Acknowledgements and Disclosures The authors report no conflicts of interest in the preparation of this manuscript.

References

1. Brazeau CM, Shanafelt T, Durning SJ, Massie FS, Eacker A, Moutier C, Satele DV, Sloan JA, Dyrbye LN. Distress among matriculating medical students relative to the general population. Acad Med. 2014;89:1520–5.
2. Del Grosso B, Boyd AS. Burnout and the nurse anesthetist: an integrative review. AANA J. 2019;87:205–13.
3. Peckham C. Medscape physician lifestyle report 2015. Medscape [Online]; 2015.
4. Shanafelt TD, Dyrbye LN, West CP, Sinsky CA. Potential impact of burnout on the US Physician Workforce. Mayo Clin Proc. 2016;91:1667–8.
5. Shanafelt TD, Hasan O, Dyrbye LN, Sinsky C, Satele D, Sloan J, West CP. Changes in burnout and satisfaction with work-life balance in physicians and the general US working population between 2011 and 2014. Mayo Clin Proc. 2015;90:1600–13.
6. Wilkes C, Lewis T, Brager N, Bulloch A, Macmaster F, Paget M, Holm J, Farrell SM, Ventriglio A. Wellbeing and mental health amongst medical students in Canada. Int Rev Psychiatry. 2019;31(7–8):584–7.
7. Slavin SJ. Medical student mental health: culture, environment, and the need for change. JAMA. 2016;316:2195–6.
8. Squiers JJ, Lobdell KW, Fann JI, Dimaio JM. Physician burnout: are we treating the symptoms instead of the disease? Ann Thorac Surg. 2017;104:1117–22.
9. Lai J, Ma S, Wang Y, Cai Z, Hu J, Wei N, Wu J, Du H, Chen T, Li R, Tan H, Kang L, Yao L, Huang M, Wang H, Wang G, Liu Z, Hu S. Factors associated with mental health outcomes among health care workers exposed to coronavirus disease 2019. JAMA Netw Open. 2020;3(3):e203976. https://doi.org/10.1001/jamanetworkopen.2020.3976.
10. Hauck S, Gabbard GO. Institutional factors in the medical burnout epidemic. Braz J Psychiatry. 2019;41:191–2.
11. Post SG, Roess M. Expanding the rubric of “patient-centered care” (PCC) to “patient and professional centered care” (PPCC) to enhance provider well-being. HEC Forum. 2017;29:293–302.
12. Kopacz MS, Ames D, Koenig HG. It’s time to talk about physician burnout and moral injury. Lancet Psychiatry. 2019;6:e28.
13. Dyrbye LN, Eacker A, Durning SJ, Brazeau C, Moutier C, Massie FS, Satele D, Sloan JA, Shanafelt TD. The impact of stigma and personal experiences on the help-seeking behaviors of medical students with burnout. Acad Med. 2015;90:961–9.
14. Gabbard GO. The role of compulsiveness in the normal physician. JAMA. 1985;254:2926–9.
15. Post SG, Byrne J. Compassionate care. J IMA. 2011;43:148–59.
16. West CP, Huschka MM, Novotny PJ, Sloan JA, Kolars JC, Habermann TM, Shanafelt TD. Association of perceived medical errors with resident distress and empathy: a prospective longitudinal study. JAMA. 2006;296:1071–8.
17. Dewa CS, Jacobs P, Thanh NX, Loong D. An estimate of the cost of burnout on early retirement and reduction in clinical hours of practicing physicians in Canada. BMC Health Serv Res. 2014;14:254.

18. Christodoulou GN, Mezzich JE, Cloninger CR, Christodoulou N, Villar E, Appleyard J, Botbol M. Promoting healthy lives and well-being for all: the contribution of the International College of Person-Centered Medicine (ICPCM). Psychiatriki. 2018;29:52–7.
19. Cloninger CR, Salvador-Carulla L, Kirmayer LJ, Schwartz MA, Appleyard J, Goodwin N, Groves J, Hermans MHM, Mezzich JE, Staden CWV, Rawaf S. A time for action on health inequities: foundations of the 2014 Geneva declaration on person- and people-centered integrated health care for all. Int J Pers Cent Med. 2014;4:68–89.
20. Mezzich JE, Perales A. [Person centered clinical care: principles and strategies]. Rev Peru Med Exp Salud Publica. 2016;33:794–800.
21. Mezzich JE, Snaedal J, Van Weel C, Heath I. The international network for person-centered medicine: background and first steps. World Med J. 2009;55:104–7.
22. Mezzich JE, Kirisci L, Salloum I, Trivedi J, Kar SK, Adams N, Wallcraf J. Systematic conceptualization of person centered medicine and development and validation of a person-centered care index. Int J Pers Cent Med. 2016;6:219–47.
23. Mezzich JE, Appleyard J, Botbol M, Salloum IM, Perales A. Ibero-American perspectives on person-centered medical education. Int J Pers Cent Med. 2017;7:73–9.
24. Hauck S. Medical curriculum reform. Paper presented at the 12th Geneva conference on promoting well-being and overcoming burn-out. Canterbury: International College of Person Centered Medicine; 2019.
25. Harden RM. Ten key features of the future medical school-not an impossible dream. Med Teach. 2018;40:1010–5.
26. Cloninger CR, Salloum IM, Mezzich JE. The dynamic origins of positive health and wellbeing. Int J Pers Cent Med. 2012;2:179–87.
27. Mezzich JE, Appleyard J, Botbol M, Salloum IM, Kirisci L. Conceptualization and metrics in person centered medicine. Int J Pers Cent Med. 2016;6:213–8.
28. Freire P. Pedagogia da Autonomia: Saberes necessários à prática educativa. 59th ed. Rio de Janeiro: Paz e Terra; 2019.
29. Wasson LT, Cusmano A, Meli L, Louh I, Falzon L, Hampsey M, Young G, Shaffer J, Davidson KW. Association between learning environment interventions and medical student well-being: a systematic review. JAMA. 2016;316:2237–52.
30. Miles A, Mezzich JE. The care of the patient and the soul of the clinic: person-centered medicine as an emergent model of modern clinical practice. Int J Pers Cent Med. 2011;1:207–22.
31. Rabelais F. Gargantua and Pantagruel. Chicago: William Benton Publisher; 1922. p. 83. https://archive.org/details/in.ernet.dli.2015.126311/page/n1/mode/2up. Accessed 12 Nov 2021.
32. Osler W. The old humanities and the new science: the presidential address delivered before the Classical Association at Oxford, May, 1919. Br Med J. 1919;2(3053):1–7. PMID:20769536.
33. Cloninger R, Cloninger KM. Development of instruments and evaluative procedures on contributors to illness and health. Int J Pers Cent Med. 2011;1(3):446–55.
34. Herrman H, Saxena S, Moodie R, editors. Promoting mental health: concepts, emerging evidence, practice. Geneva: WHO; 2005.
35. Saavedra JE, Uchofen-Herrera V. Percepciones sobre la atención de salud en personas con problemas autoidentificados de salud mental en zonas rurales del Perú. Rev Peru Med Exp Salud Publica. 2016;33(4):785–93. https://doi.org/10.17843/rpmesp.2016.334.2566.
36. van Dulmen S, Humphris G, Eide H. Towards a guideline for person-centered research in clinical communication: lessons learned from three countries. Int J Pers Cent Med. 2011;2(1):58–63.
37. Saavedra JE. In: Perales A, editor. Humanismo en la Atención de Salud: una Propuesta de Investigación. Lima: Academia Nacional de Medicina; 2018. p. 45–55.
38. Fulford KW. Bringing together values-based and evidence-based medicine: UK Department of Health Initiatives in the ‘Personalization’ of care. J Eval Clin Pract. 2011;17(2):341–3. https://doi.org/10.1111/j.1365-2753.2010.01578.
39. Hasnain-Wynia R. Is evidence-based medicine patient-centered and is patient-centered care evidence-based? Health Serv Res. 2006;41(1):1–8. https://doi.org/10.1111/j.1475-6773.2006.00504.x.
40. Wolf A, Vella R, Fors A. The impact of person-centred care on patients’ care experiences in relation to educational level after acute coronary syndrome: secondary outcome analysis

of a randomised controlled trial. Eur J Cardiovasc Nurs. 2019;18(4):299–308. https://doi.org/10.1177/1474515118821242.

41. Cooper LA, Roter DL, Carson KA, Bone LR, Larson SM, Miller ER III, Barr MS, Levine DM. A randomized trial to improve patient-centered care and hypertension control in underserved primary care patients. J Gen Intern Med. 2011;26(11):1297–304. https://doi.org/10.1007/s11606-011-1794-6.
42. Mead N, Bower P. Patient-centered consultations and outcomes in primary care: a review of the literature. Patient Educ Couns. 2002;48:51–61.
43. Martin CM, Félix-Bortolotti M. Person-centred health care: a critical assessment of current and emerging research approaches. J Eval Clin Pract. 2014;20(6):1056–64. https://doi.org/10.1111/jep.12283.
44. Wagner P, Perales A, Armas R, Codas O, de los Santos R, Elio-Calvo D, Mendoza-Vega J, Arce M, Calderón JL, Llosa L, Saavedra J, Ugarte O, Vildózola H, Mezzich JE. Latin American bases and perspectives on person centered medicine and health. Int J Pers Cent Med. 2015;4:220–7.
45. Perales A, Mendoza J, Armas R, Cluzet O. Perspectivas Latinoamericanas sobre Medicina Centrada en la Persona. Revista Peruana de Medicina Experimental y Salud Publica. 2016;33:801–10.
46. Rittenhouse DR, Thom DH, Schmittdiel JA. Developing a policy-relevant research agenda for the patient-centered medical home: a focus on outcomes. J Gen Intern Med. 2010;25(6):593–600. https://doi.org/10.1007/s11606-010-1289-x.
47. Tinetti ME, Fried T. The end of the disease era. Am J Med. 2004;116(3):179–85.
48. Stange KC, Nutting PA, Miller WL, Jaén CR, Crabtree BF, Flocke SA, Gill JM. Defining and measuring the patient-centered medical home. J Gen Intern Med. 2010;25(6):601–12.
49. The Lancet Psychiatry. Deeper understanding. Lancet Psychiatry. 2019;6:713.
50. Red Latinoamericana de Medicina Centrada en la Persona: 2016. Lima declaration on science and humanism in Latin America. Int J Pers Cent Med. 2017;7:147–50.
51. Steffen GE. Quality medical care: a definition. JAMA. 1988;260(1):56–61.
52. Kirisci L, Hayes J, Mezzich JE. Evaluation of person-centered health services. In: Mezzich JE, Botbol M, Christodoulou GN, Cloninger CR, Salloum IM, editors. Person centered psychiatry. Basel: Springer; 2016.
53. Kirisci L, Vanyukov M, Mezzich JE. Introduction to metrics in person centered medicine research. Int J Pers Cent Med. 2016;6:248–9.
54. Humphris GM, Kaney S. Assessing the development of communication skills in undergraduate medical students. Med Educ. 2001;35(3):225–31.
55. Brouwers M, Rasenberg E, van Weel C, Laan R, van Weel-Baumgarten E. Assessing patient-centred communication in teaching: a systematic review of instruments. Med Educ. 2017;51(11):1103–17. https://doi.org/10.1111/medu.13375.
56. Salvador-Carulla L, Cloninger CR, Thornicrofta A, Mezzich JE, The 2013 Geneva Declaration Consultation Group. Background, structure and priorities of the 2013 Geneva Declaration on Person-Centered Health Research. Int J Pers Cent Med. 2013;3(2):109–13. https://doi.org/10.5750/ijpcm.v3i2.401.
57. Gibert K, Garcia-Alonso C, Salvador-Carulla L. Integrating clinicians, knowledge and data: expert-based cooperative analysis in healthcare decision support. Health Res Policy Syst. 2010;8:28.
58. Bastos TM, Padoan CS, Pessi C, Laskoski PB, Terra L, Lago PF, Siqueira AM, Hauck S. The pathway from well-being to burnout and depression in college: a qualitative evaluation of medical students' perception. Paper presented at the 12th Geneva conference on promoting well-being and overcoming burn-out. International College of Person Centered Medicine, March 25–27, 2019.

59. International College of Person Centered Medicine. Geneva declaration on person-centered promotion of well-being and overcoming burn-out. Int J Pers Cent Med. 2019;9:5–8.
60. Cloninger R. Implications of comorbidity for the classifications of mental disorders: the need for a psychobiology of coherent. In: Maj M, Gaebel W, et al., editors. Psychiatric diagnosis and classification. Chichester: Wiley; 2002.
61. Perales A, Kirisci L, Mezzich JE, Sánchez E, Barahona L, Zavala S, Amorín E. Comparative study of prototype hospitals in Lima with the person-centered care index rated by health professionals. Int J Pers Cent Med. 2018;8(1):47–61.

Part II

Methods for Person Centered Clinical Care

Chapter 10
Establishing Common Ground, Engagement, and Empathy

Michel Botbol, Neal Adams, and Juan E. Mezzich

10.1 Introduction

Common ground among clinicians, patient and family for collaborative diagnosis and shared decision-making has been identified as a core component of person-centered medical practice. Together these participants make-up the core of the treatment team—with the patient as the most essential member. Establishing a shared understanding of the individual seeking care, including but not limited to a diagnostic formulation, is the essence of common ground [1]. There is a substantial

---

M. Botbol (✉)
Child and Adolescent Psychiatry, University of Western Brittany, Brest, France

World Association for Dynamic Psychiatry (WADP), Berlin, Germany

International College of Person-Centered Medicine, New York, NY, USA

World Psychiatric Association, Geneva, Switzerland

N. Adams
California Institute of Mental Health, Berkeley, CA, USA

J. E. Mezzich
Presidency 2009–2013, International College of Person-Centered Medicine,
New York, NY, USA

Presidency 2005–2008, World Psychiatric Association, Geneva, Switzerland

Division of Psychiatric Epidemiology and International Center for Mental Health, Icahn
School of Medicine at Mount Sinai, New York, NY, USA

Hipolito Unanue Professor of Person Centered Medicine, San Fernando School of Medicine,
San Marcos National University, Lima, Peru

Professor of Epidemiology, Graduate School of Public Health and Professor of Psychiatry,
School of Medicine, University of Pittsburgh, Pennsylvania, PA, USA

Department of Psychiatry and Behavioral Sciences, Stanford University School of
Medicine, Stanford, CA, USA

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_10

consensus in the field about the centrality of this concept. Adams and Grieder [2], recognized experts on treatment planning, describe common ground as a shared understanding and acceptance of a diagnosis, causative and exacerbating factors, and of the potential risks and benefits of any treatment or intervention.

Establishing common ground is the keystone for assuring that care planning is indeed person-centered. In her work, van Dulmen argues that effective bidirectional communication and dialog are key to building the therapeutic alliance and promoting person-centered care [3]. McCormack et al. [4], find that person-centeredness is "an approach to clinical practice that is established through the formation and fostering of therapeutic relationships underpinned by values of respect for persons and the individual right to self-determination, mutual respect and understanding".

This chapter will articulate the basis, features and strategies for establishing a common ground and promoting person-centered care for clinicians, patients and families. The following pages draw upon a selective review of relevant articles, monographs and books; this includes papers specific to the practice of person-centered medicine and, more generally, the literature involving clinical care with a focus on relationship issues, communication, and collaborative care. Informed by systematic studies, there is notable concurrence amongst a range of experts about the role of common ground in person-centered care. It is clear that organizing and providing person-centered care should be informed by values and be driven by an ethical commitment to respect and appreciate the personhood each patient; at the same time, the role of professionals and family members involved promoting health and treating illness needs to be respected [5–7].

10.2 Strategies

The task of establishing common ground and promoting person-centered clinical care can be guided by attention to four inter-related key activities:

- A commitment to clear and effective communication between patient, families and healthcare professionals
- Promoting empathy and empathic responses
- Engaging patients and families in the process of establishing a culturally informed diagnosis
- Shared decision making and joint commitments

10.2.1 Communication

Open, free and transparent exchange of information is an essential component of good medical care and lies at the heart of the person-centered paradigm [3]. In person-centered medicine, the patient comes first; this means that the needs, preferences, beliefs and values of someone seeking healthcare is considered primary in discussing clinical complaints, establishing a diagnosis and considering treatment [3]. Person-centered communication allows the patient to express experiences, thoughts and ideas, and makes it possible for the health professional to adapt the communication to the patient's emotional and informational needs [8]. This means that equal attention is given to the patients' physical symptoms as well as the experiences and concerns evoked by these symptoms. Communication should be shaped by an appreciation for a person's strengths and resources in response to illness; this may also include consideration of their resilience, social connectedness, coping skills and lifestyle, amongst other factors, that often impact effective communication [3].

10.2.2 Empathy

Although important in and of itself, effective communication is not sufficient to support person-centered approaches to care. Beyond the more cognitive task of exchanging important information, person-centered care and communications should also include consideration of both verbal and non-verbal expression [9], as well as account for the emotional and cognitive dimensions of the relation and its context.

Many researchers have considered the effects of communication that go beyond mere cognitive and affective sharing, particularly in relations of high emotional intensity—especially when patients are seeking the comfort that comes with understanding and sharing with others [9]. The importance empathic responses to patients' and families' concerns has been well documented [3]. For example, the length of time a patient is listened to before being interrupted by the professional dramatically impacts the patient's experience of the medical interview; feeling understood by the professional increases when the patient is allowed to talk freely [10–12].

Patient/caregiver and professional interactions frequently occur in emotionally charged circumstances and this calls for the creation of a more or less temporary common space. In this common space, the border between the patient and the professional (or carers) are temporarily porous and confused. However, they are not eradicated; i.e., they do not lose sight of each participant's "otherness" or "alterity". In other words, communication does not take place in a vacuum; rather it occurs in a context [13]. Appreciation of and respect for that context, is central to empathic connections between patients, families and providers.

In the past, empathy was described as the professional's ability to listen sympathetically to what the patient says about his experience of illness; however, overtime, the notion of empathy has gradually become differentiated from sympathy [14, 15]) to include the interpretations that a physician (or other health professional) may consider about the feelings, experiences and understandings of the person in need of care.

This mechanism is well described by the concept of "metaphorizing-empathy" proposed by Lebovici [16] from his work with babies and their mothers. It is also close to the notion of "narrative empathy" proposed by Hochmann [17] in which a physician of health professional is engaged when, in highly emotional relationships (i.e. the relation with a suffering patient), he is sincerely affected by the experiences and emotions of the patient but, nevertheless, does not merge with her/him (as it would do in the merging of feelings and affects characterizing sympathy) [3]. This is reinforced by Paul Ricœur's insights [18] detailed in his book "Time and Narrative" and is also consistent with Kleinman's [19] assumptions about illness narratives.

10.2.3 Comprehensive Collaborative Diagnosis

In 2003 the World Psychiatric Association (WPA) published the International Guidelines for Diagnostic Assessment (IGDA) which describe a diagnostic model articulating standardized multiaxial and idiographic personalized components [20]. These guidelines describe the optimal interaction among clinicians, the patient and the family to reach consensus in the diagnostic formulation that includes consideration of not only the presenting problems but also the patient's overall health and wellbeing as well as expectations for health promotion and restoration.

This diagnostic model has been one of the starting points for the design of a Person-centered Integrative Diagnosis model [21]. In this model, diagnosis goes beyond the mere identification of a disease (i.e., nosological diagnosis); it also involves achieving some understanding of the physical, emotional mental and social experience of the person seeking care. In this framework, establishing a person-centered diagnosis also requires a process of engagement and empowerment that recognizes the agency of the participation patient, family and health professionals. To effect person-centered care, the of development a care plan must begin with collaboration among clinicians, the patient and his/her family in establishing a diagnosis and a nuanced understanding of the problems.

This nuanced understanding should be informed by issues of culture [22] and the importance of a cultural formulation as described in the DSM-5 [23]. The cultural formulation is divided into four domains that consider.

- A cultural definition of the problem.
- The cultural perceptions of cause, context, and support (including cultural identity).
- Cultural factors that affect self-coping and past help seeking.
- Cultural factors that affect current help seeking.

In the DSM-5, culture refers to systems of knowledge, concepts, rules, and practices that are learned and transmitted across generations. Culture includes language, religion and spirituality, family structures, life-cycle stages, ceremonial rituals, and customs, as well as moral and legal systems. Cultures are open, dynamic systems that undergo continuous change over time; in the contemporary world, most individuals and groups are exposed to multiple cultures, which they use to fashion their own identities and make sense of experience.

Culture is therefore a multifactorial set of overlapping systems made up of many components beyond race and ethnicity, including not only the characteristics mentioned above but also gender identity, sexual orientation, and even generational cohort and occupational group. The views and practices associated with the confluence of these cultural characteristics affect how all participants in the health care process-patients and their relatives, as well as clinicians, administrators, and policy makers-understand illness and engage in care. This is central to establishing common ground and implementing person-centered care.

10.2.4 Shared Decision Making

Experienced clinicians suggest that he most important and valuable purpose of diagnosis is to support the collaborative development of an efficacious treatment plan. Historically, the primary purpose of diagnosis was to identify an existing disorder which also informed and supported the concept of the validity of a diagnostic system. More recently, what has been known as "physio-pathogenic validity" is now being augmented if not replaced with an approach described as "clinical validity" as a basis for the shared information and understanding [24]. The most recent edition of the Diagnostic and Statistical Manual of Mental Disorders, DSM-5 [23], was largely developed to better link diagnosis and the provision of clinical care.

As pointed out by Adams [25], treatment plans are at the heart of any care process and are critical in guiding treatment decisions; they also have an important role in patient engagement and treatment success. Furthermore, Arora and McHorney [26] have argued that treatment plans should be built upon and reflect both shared understanding and decision-making between the patient and the health professional. Shared understanding and shared decision-making should be reflected in the joint-commitment of all key players to the implementation and follow-up evaluation of treatment plans. These crucial clinical care activities should be built on the common ground established among clinicians, patient and family if care is to be truly person-centered.

10.3 Guiding Considerations

Helpful guiding considerations for establishing *common ground,* as outlined by Adams [25], may include, but are not necessarily limited to the following:

- *Holistic integration of information*. This pertains to the understanding of both illness and as well as general health and well-being. It corresponds to one of the key principles of person-centered medicine as described by Mezzich et al. [1].
- *Addressing the person's longitudinal and cross-sectional circumstances.* For Person centered medicine a whole person includes his circumstances. It is predicated on Ortega y Gasset's [27] dictum about how circumstances can contribute to the person's identity: "I am I and my circumstance; and if do not save it, I do not save myself". Complementing this dictum, the scope of these circumstances may be optimized by referring to both cross-sectional and longitudinal dimensions. The latter extend from the person's historical roots and affiliation to his/her life project [28].

Attending to health experience, preferences, and values. This brings the key principles of person-centered medicine to the foreground involving an ethical commitment to honor and respect each individual's personal values [29] This includes consideration of factors that define identity such as cultural awareness, race/

ethnicity, religion, sexual orientation, gender, disability status, etc. [30, 31]. A possible history of trauma, in all of its forms, should also be considered.

10.4 Implementation

Effective implementation of person-centered clinical care, influenced by the principles of *common ground,* should be guided by engagement of the four strategies detailed above—in particular: (1) Identifying, assembling and engaging the key contributors/participants for each individual, and (2) fostering empathic communication among them. Success in organizing a participatory diagnostic process as well as cultivating shared decision making and joint commitments should result in the formal completion of a *narrative integrative synthesis* of clinical and personal information. This should reflect a shared and consensus-based distillation of a person-centered assessment processes and serve as the foundation of person-centered care planning [32].

This kind of narrative was proposed as part of the International Guidelines for Diagnostic Assessment (IGDA) [20]. The comprehensive diagnostic statement included in the IGDA Guidelines encompassed a standard multiaxial formulation and, of particular relevance to the idea of common ground, i.e., a *personalized idiographic formulation*. This narrative should integrate the perspectives of the clinician, the patient and the family into a jointly understood summary of the clinical problems; it should also include consideration of the patient's strengths as well as their expectations for the restoration and promotion of health. This can be a highly effective approach to address the complexity of illness, the patient's whole health status and expectations, within the individual's cultural framework.

Using the Person-Centered Integrative Diagnostic Model [21], as well as a web-based approach to recovery and shared decision making developed by Deegan [33], Adams [25] has articulated and illustrated the essentials of an integrated narrative synthesis that includes a patient's clinical and personal data as part of a comprehensive diagnostic statement. Such a synthesis serves as a bridge between assessment and the creation of a treatment plan and reflects the value of a written narrative in its ability to capture the essence of joint understanding and the importance of dialog between key players. This is the foundation of common ground. Adams [25] points out that any disagreements amongst the members of the care team must be acknowledged and reconciled in the process; without this consensus potentially, healing relationships may dissolve. The process of moving from un-distilled information and bits of data to synthesis, shared understanding, shared planning and joint commitment is at the heart of what it means to be person-centered. Effective clinical solutions that are endorsed by the patient and supported by family may only come from this process.

Adams further argues that bridging the gap between current conventional practice and what should be regular person-centered care is possible and practical. Citing Davidson et al. [34], he submits that given adequate time for completing the integrative summary, most clinicians can develop the skills necessary to be more holistic and person-centered in routine care. Success depends in large part on providing the support and training necessary to include a formulation or narrative in the process of moving from assessment to creating treatment plans.

The considerations on common ground presented above can help to promote a person-centered clinical relationship. Generally based on a first interview with the patient and his carers, the process should include a preparatory phase to ensure a quiet and reasonably comfortable environment; patients and families should feel welcomed [32] and the patient should be given enough time to express his/her concerns [13]. It is important to conduct the interview in a respectful, warm, empathetic and empowering manner. In this way the clinical interview, conducted in a comfortable, respectful and dignified manner, can promote the exploration of different topics and domains relevant to the ultimate elaboration of a diagnostic formulation and initial treatment plan. It is essential that this process is guided by empathic inquiry and response; in this way issues of subjectivity and inter-subjectivity can be addressed.

The completion of these steps should lead to the formulation of a jointly understood initial diagnostic assessment which may be modified as the clinical care process unfolds, and more information becomes available. This sets the stage for making shared decisions about next steps and helps to assure the patient's and family's awareness, involvement and satisfaction with such a formulation and plan. The interview should conclude with a warm farewell along with a plan for future visits or other clinical activities.

One has to be aware, however, that, in a person-centered perspective, this process cannot limit itself to consider only the conscious, acknowledged and expressed part of the subjectivity of the persons involved in the health relationship (the patient, the carers and the health professional); in this perspective, it is indeed crucial to consider as much as possible, the totality of these persons' subjectivity, that is to take into account as well what for a reason or another, remains implicit in them. The problem is that the ways to doing it in a sufficiently rigorous manner are limited. It is one of the endeavors of person-centered medicine to address this dimension trying to find a "scientific" or at least "a non-metaphysical" way to appreciating and managing this additional dimension. The concept of Narrative Empathy is the basis of such a "non-metaphysical" project, provided that it clearly differentiates Empathy from sympathy (as already discussed).

10.5 Conclusions

Establishing common ground amongst all members of the treatment team is a core component of person-centered care; this includes the participation of not only the patients but also families/carers and health professionals [35]. The practice of person-centered care/medicine draws on several principles that include an ethical commitment, holistic framework, cultural awareness and responsiveness, empathic relationships and effective communication, to name but a few. Together they create the foundation of person-centered and collaborative care.

Clinician subjectivity can be a barrier to success in establishing common ground. While subjectivity can have a potentially negative impact on the patient and other members of the treatment team, it can also be a powerful clinical tool in person-centered diagnostics and care. Accordingly, subjectivity should be actively monitored and managed; this means that clinicians must be properly trained on how to use their reactions as tools to better understand the patient and his carers. It is close to the principles of what psychoanalysis and dynamic psychiatry define as the "analysis of counter-transference", but does not impose to share the psychoanalytic assumption that transference and counter-transference are related to a repetition « here and now as elsewhere and then » of previous subjective relational experiences.

While empathy is critical for engagement, there is no empathy without subjectivity [36]; in other words, recognizing and working with the subjectivity of the clinician is also crucial. This has important consequences for clinical practice and care organizations, and should be considered in the education and training of clinicians. Traditional curricula tend to ignore the subjective dimensions of clinical practice; this often leaves providers without the knowledge and skills necessary to promote person-centered care. Medical education should recognize the importance of subjectivity and help future clinicians to develop the skills needed for success in person-centered care.

It is well documented [3] that daily confrontations with pain and suffering patients can render clinicians more vulnerable to stress or sometimes indifferent to the distress of the patient or his carers [37]. Although such responses are understandable, and even sometimes self-protecting, they also appear to be associated with a higher risk of burn-out, poor job satisfaction and can result in suboptimal care [38]. On the other hand, research has shown that being compassionate and involved in meaningful relationships, finding common ground, promoting collaborative treatment alliances and providing person-centered care actually contribute to the clinician well-being and performance as well as improved patient outcomes [39].

Acknowledgements and Disclosures The authors declare no conflict of interest.

References

1. Mezzich JE, Kirisci L, Salloum IM, Trivedi JK, Kar SK, Adams N, Wallcraft J. Systematic conceptualization of person-centered medicine and development and validation of a person-centered care index. Int J Pers Cent Med. 2016;6:219–47.
2. Adams N, Grieder DM. Treatment planning for person-centered care. Amsterdam: Elsevier; 2005.
3. Botbol M, van Dulmen S. Communication and empathy within person-centered medicine: a developmental point of view. Int J Pers Cent Med. 2020;8:17–29.
4. McCormack B, McCance T. Person-centred practice in nursing and health care: theory and practice. 2nd ed. Oxford: Wiley Blackwell Publishing; 2016.

5. Appleyard J. Introduction to ethical standards for person-centered health research. Int J Pers Cent Med. 2013;3:258–62.
6. Bouësseau M-C. Strengthening research ethics review systems. Int J Pers Cent Med. 2013;3:263–5.
7. Cassell E. The person in medicine. Int J Integr Care. 2010;10(Suppl):50–1.
8. Eide H, Eide T. Kommunikasjon i relasjoner. In: Samhandling, konfliktløsning, etikk [Communication in relationships]. Oslo: Gyldendal Academic Press; 2007.
9. Cosnier J. Communication et empathie. In: Botbol M, Garret N, Besse A, editors. L'Empathie au Carrefour de la Science et de la Clinique. Doin; 2014.
10. van Dulmen AM, Bensing JM. Health promoting effects of the physician-patient encounter. Psychol Health Med. 2002;7:289–300.
11. Langewitz W, Denz M, Keller A, Kiss A, Rüttimann S, Wössmer B. Spontaneous talking time at start of consultation in outpatient clinic: cohort study. BMJ. 2002;28:682–3.
12. Marvel MK, Epstein RM, Flowers K, Beckman HB. Soliciting the patient's agenda. Have we improved? JAMA. 1999;281:283–7.
13. Bensing JM, van Dulmen AM, Tates K. Communication in context: new directions in communication research. Patient Educ Couns. 2003;50:27–32.
14. Botbol M and Lecic Tosevski D. Person-Centered Medicine and Subjectivity in Jeffrey H.D. Cornelius-White, Renate Mosschnig-Pitrik, Michael Lux (eds) Interdisciplinary Application of Person-Centered Approach. Springer New-York, NY; 2013. https://doi.org/10.1007/978-1-4614-7144-8_8.
15. Berthoz A. Une théorie spatiale de la différence entre la sympathie et les processus de l'empathie (A spatial theory of the difference between sympathy and the process of empathy); 2014.
16. Lebovici S. L'arbre de vie - éléments de la psychopathologie du bébé [The tree of life—principles of infant psychopathology]. Toulouse: Eres; 1999.
17. Hochmann J. Une histoire de l'empathie [A history of empathy]. Paris: Odile Jacob; 2012.
18. Ricoeur P. Temps et récit [Time and narrative]. Paris: Le Seuil; 1983.
19. Kleinman A. The illness narratives. New York: Basic Books; 1988.
20. Mezzich JE, Berganza CE, von Cranach M, Jorge MR, Kastrup MC, Murthy RC, Okasha A, Pull C, Sartorius N, Skodol AE, Zaudig M. Essentials of the WPA international guidelines for diagnostic assessment (IGDA). Br J Psychiatry. 2003;182(Suppl):45.
21. Mezzich JE, Salloum IM, Cloninger CR, Salvador-Carulla L, Kirmayer L, Banzato CE, Wallcraft J, Botbol M. Person-centered integrative diagnosis: conceptual bases and structural model. Can J Psychiatr. 2010;55:701–8.
22. Mezzich JE, Kirmayer LJ, Kleinman A, Fabrega H Jr, Parron D, Good B, Lin KM, Manson S. The place of culture in DSM IV. J Nerv Ment Dis. 1999;187(8):457–64.
23. American Psychiatric Association. Diagnostic and statistical manual of mental disorders, fifth edition (DSM-5). Arlington, VA: American Psychiatric Association; 2013.
24. Schaffner KF. The validity of psychiatric diagnosis: etiopathogenic and clinical approaches. In: Salloum IM, Mezzich JE, editors. Psychiatric diagnosis: challenges and prospects. Chichester: Wiley-Blackwell; 2009.
25. Adams N. Finding common ground: the role of integrative diagnosis and treatment planning as a pathway to person-centered care. Int J Pers Cent Med. 2012;2:173–8.
26. Arora NK, McHorney CA. Patient preferences for medical decision making: who really wants to participate? Med Care. 2000;38(3):335–41.
27. Ortega y Gasset J. Meditaciones del Quijote. In: Obras Completas de José Ortega y Gasset, vol. 1. Madrid: Editorial Santillana; 1914. p. 745–825.
28. Mezzich JE, Botbol M, Christodoulou GN, Cloninger CR, Salloum IM, editors. Person centered psychiatry. Basel: Springer; 2016.
29. Mezzich JE, Appleyard J, Botbol M, Ghebrehiwet T, Groves J, Salloum IM, Van Dulmen S. Ethics in person centered medicine: conceptual place and ongoing developments. Int J Pers Cent Med. 2013;3:255–7.

30. Kirmayer LJ, Bennegadi R, Kastrup MC. Cultural awareness and responsiveness. In: Mezzich JE, Botbol M, Christodoulou GN, Cloninger CR, Salloum IM, editors. Person centered psychiatry. Heidelberg: Springer Verlag; 2016.
31. Mezzich JE. Towards a health experience formulation for person-centered integrative diagnosis. Int J Pers Cent Med. 2012;2:188–92.
32. Mezzich J. Setting a common ground for collaborative care and clinical interviewing. Int J Pers Cent Med. 2020;8:29–41.
33. Deegan P. A web application to support recovery and shared decision making in psychiatric medication clinics. Psychiatr Rehabil J. 2010;34(1):23–8.
34. Davidson L, Tondora J, Lawless MS, Rowe M, O'Connell MJ. A practical guide to recovery oriented practice: tools for transforming mental health care. New York: Oxford Press; 2009.
35. Mezzich JE. The dialogal bases of our profession: psychiatry with the person. World Psychiatry. 2007;6:129–30.
36. Botbol M, Lecic-Tosevsky D. Person-centered medicine and subjectivity. In: Cornelius-White JHD, Motschnig-Pitrik R, Lux M, editors. Interdisciplinary applications of the person-centered approach. New York: Springer; 2013. p. 73–82.
37. Botbol M, Garret N, Besse A. L'empathie au carrefour des sciences et de la clinique (Empathy at crossroads of science and clinic) Ed Doin-John Libbey; 2015.
38. Bensing JM, van den Brink-Muinen A, Boerma W, van Dulmen S. The manifestation of job satisfaction in doctor-patient communication; a ten-country European study. Int J Pers Cent Med. 2013;3:44–52.
39. Smith-MacDonald L, Venturato L, Hunter P, Kaasalainen S, Sussman T, McCleary L, Thompson G, Wickson-Griffiths A, Sinclair S. Perspectives and experiences of compassion in long-term care facilities within Canada: a qualitative study of patients, family members and health care providers. BMC Geriatr. 2019;19(1):128.

Chapter 11
Person-Centered Interviewing and Diagnosis

Juan E. Mezzich, Ihsan M. Salloum, Michael T. H. Wong, Marijana Braš, Veljko Đorđević, and C. Ruth Wilson

---

J. E. Mezzich (✉)
Presidency 2009–2013, International College of Person-Centered Medicine, New York, NY, USA

Presidency 2005–2008, World Psychiatric Association, Geneva, Switzerland

Division of Psychiatric Epidemiology and International Center for Mental Health, Icahn School of Medicine at Mount Sinai, New York, NY, USA

Hipolito Unanue Professor of Person Centered Medicine, San Fernando School of Medicine, San Marcos National University, Lima, Peru

Professor of Epidemiology, Graduate School of Public Health and Professor of Psychiatry, School of Medicine, University of Pittsburgh, Pennsylvania, PA, USA

Department of Psychiatry and Behavioral Sciences, Stanford University School of Medicine, Stanford, CA, USA

I. M. Salloum
Institute of Neuroscience, Department of Neuroscience, University of Texas Rio Grande Valley School of Medicine, Harlingen, TX, USA

University of Miami Miller School of Medicine, Miami, FL, USA

Section of Classification, Diagnostic Assessment and Nomenclature, World Psychiatric Association, Geneva, Switzerland

International College of Person Centered Medicine, New York, NY, USA
e-mail: ihsan.salloum@utrgv.edu

M. T. H. Wong
Department of Psychiatry, LKS Faculty of Medicine, The University of Hong Kong, Pokfulam, Hong Kong, China

Neuropsychiatry Program, Queen Mary Hospital, Pokfulam, Hong Kong, China

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_11

Section of Philosophy & Humanities in Psychiatry, World Psychiatric Association,
Geneva, Switzerland
e-mail: mthwong@hku.hk

M. Braš · V. Đorđević
Center for Palliative Medicine, Medical Ethics and Communication Skills, University of
Zagreb School of Medicine, Zagreb, Croatia
e-mail: marijana.bras@mef.hr; veljko@empatija.hr

C. R. Wilson
Department of Family Medicine, Queen's University, Kingston, ON, Canada

Presidency, North America Region, World Organization of Family Doctors (Wonca),
Singapore, Singapore
e-mail: ruth.wilson@dfm.queensu.ca

11.1 Introduction

It has been proposed and demonstrated that the organization of person-centered clinical care should be substantiated and guided by philosophical and conceptual principles such attention to the personhood of the patients, health professionals and family members involved in caring for life and health [1]. Based on clinical and research experience, Tempier [2] and Mercier et al. [3] have proposed that what is good for the persons is what is good for their health and mental health.

Among the key principles of person centered medicine helpful to guide clinical care are those elucidated through systematic studies [4], which start with ethical commitment [5, 6]. This is usually formulated based on Aristotelian and Kantian insights as well as on fundamental human rights. The remaining principles are strategic and science-based.

One of the latter principles involves establishing common ground among health professionals, the patient and family members, in order to organize key clinical tasks in a collaborative fashion. These involve, first, the basic task of diagnosis aimed at having all protagonists jointly understanding the clinical situation and not only identifying existing illnesses, and second, collaborative treatment planning conducted as shared decision making. The crucial establishment of a common ground as keystone for person centered care has been highlighted most cogently by Adams and Grieder [7].

11.2 Person-Centered Clinical Interviewing

The core of the medical act has always been and shall continue to be the relationship between the health professional and the person seeking assistance. The physician-patient relationship has changed throughout history, as the role of physician has been transformed This relationship evolved from a paternalistic model to current model of collaborative partnership, which highlight the importance of informed consent and shared decision making partnership, which highlight the importance of informed consent and shared decision making [8]. Twentieth-century medicine has created hyperbolic specializations within each health profession. Twentieth-first century medicine seems to be moving towards integration. This means observing biological, psychological, social and spiritual dimensions in each human being. One should never look at a human being only through the prism of the biomedical model, because it tends to be quite reductionist in its dimensionality. One should look at a human being as a full person, not as a disease carrier. The patient should be an active partner in solving medical problems, because all such problems are really personal. It is also important to develop and promote a culture of health instead of a more restricted culture of illness, working through a patient-doctor collaborative partnership, as well as partnerships among professionals. Furthermore, one should regard a human being in reference to the relationship that he/she creates towards health professionals.

Only good communication can provide and establish good relationship between the health professional and patient, and the most important aspect of communication is medical interview, as a bridge from bench to bedside to community (Đorđević, 2012). The medical interview provides a framework through which physicians can explore and understand patients' concerns, fears, misconceptions, and what they bring to their illness, while taking into consideration their culture, the availability of various treatment options, and financial considerations. The interview must include a complete range of biological, psychological, social and spiritual components In medical interview it is important to focus not only on the disease but on patient's quality of life in the context of health and disease (Pjevač, 2019).

In both personalized medicine and person-centered medicine initiatives, the emphasis is on the person. However, personalized medicine is more focused on science and person-centered medicine on holistic and humanistic approach. Person-centered medical interview is an important bridge between personalized and person-centered medicine. Since communication skills can be learned and mastered by practice, experiential learning is important, and individualized and interactive format of teaching should be applied adhering to the principles of evidence-based and person-centered medicine (Ferreira-Padilla, 2015.) Human relationships are what matters most. *Homo homini remedium*.

From the viewpoint of family medicine, Stewart et al. [9] described four key elements of what they call the patient-centred clinical method. The encounter must include an assessment of the patient's feelings (especially any anxiety s/he may be experiencing), his/her perceptions about what is wrong, the effect of the current health status on his/her functioning, and his/her expectations of the health care practitioner.

11.2.1 Organization of the Clinical Interview

The considerations on common ground presented above [7, 8] may be helpful for setting the bases, organizing and conducting a person-centered clinical interview. The World Psychiatric Association's International Guidelines for Diagnostic Assessment (IGDA) [10] offer additional helpful guidelines.

The interview process should include a preparatory phase to ensure a quiet and reasonably comfortable environment where patients and families are received by health professionals cordially and respectfully.

The body of the interview should cover in an effective, smooth and considered manner the different areas of information relevant to an adequate diagnostic formulation and an initial treatment plan. It is essential to establish empathy, to attend to subjectivity and inter-subjectivity, and to listen carefully to the patient and available family. This phase should conclude with the formulation of a jointly understood initial diagnostic assessment (which would continue later as the clinical care process unfolds), and shared decisions on what the next steps would be, as well as ensuring that the patient and family are aware, involved and satisfied with such formulation.

The closure phase of the interview should include a warm farewell connected to future visits or clinical activities. It is important to conduct the interview in a respectful, empathetic and empowering manner.

11.3 The Development of Person Centered Diagnosis

11.3.1 Multiaxial Diagnosis and Comprehensive Diagnostic Models

The basic objective of designing and using a comprehensive diagnostic model is to meet the multiple purposes and applications of diagnosis in psychiatry and general medicine in an effective and efficient manner. The main purpose of the assessment is to serve as a basis for thorough, ethical and responsible clinical care. Complementary purposes include communication inter-professionally and with the patient, professional training, service planning, and clinical and epidemiological research. Diagnostic models are expected to help in achieving joint diagnostic understanding and shared decision-making for clinical care in collaboration with patients and families.

11.3.2 Methodological Advances Leading to the IGDA and GLADP Diagnostic Models

The diagnostic model of the World Psychiatric Association's International Guidelines for Diagnostic Assessment (IGDA) and the original GLADP encompass a standardized multiaxial formulation as well as a complementary idiographic and personalized diagnostic component.

One of the incentives for generic idiographic conceptualization was the design and publication of the DSM-IV Cultural Formulation as a narrative supplement to a standardized diagnostic formulation [11, 12]. Table 11.1 displays the elements of the DSM-IV Cultural Formulation, which attempts to describe the cultural context of the patient's identity, illness experience, psychosocial environment and functioning, and the clinician-patient relationship. The DSM-IV Cultural Formulation Outline has taken the form of an interview in DSM-5. The Cultural Formulation does not cover all

Table 11.1 Cultural formulation outline for DSM-IV

A. Cultural Identity.
B. Cultural Explanations of the Disease
C. Cultural Elements of Social Context.
D. Intercultural Elements of the Clinician-Patient Relationship.
E. Cultural Essentials for Diagnosis and Clinical Care.

relevant aspects of a comprehensive idiographic diagnosis, but it demonstrates the possibility of supplementing a standardized diagnosis with a structured narrative formulation.

A comprehensive diagnostic model as composed of standardized and idiographic components is at the core of the International Guidelines for Diagnostic Assessment (IGDA), developed by the World Psychiatric Association [10]. The structure of this diagnosis model is presented below, starting with its standardized multiaxial component:

Axis I: Clinical Disorders. These include both mental disorders and general medical conditions formulated in separate sections and coded according to ICD-10 [13, 14].

Axis II: Disabilities. These are assessed dimensionally in four separate areas (personal care, and occupational, family and general social functioning) according to a combination of the intensity and frequency of their recent presence, as specified in the Multiaxial Presentation of the ICD-10 [15].

Axis III: Contextual Factors. These mainly include psychosocial and environmental problems which are relevant to the presentation, course and treatment of disorders. They can be denoted with the Z codes of ICD-10 [13, 14].

Axis IV: Quality of Life. This axis is not included in the Multiaxial Presentation of the ICD-10 (from which the above first three axes come). Quality of life has emerged in recent years as important to describe the health of a person and as an index of treatment outcome. It is widely accepted that the assessment should be based mainly on the perception of the person concerned about the level of his/her physical and emotional well-being, functioning, social supports and satisfaction of personal and spiritual aspirations. It can be directly measured globally (e.g., in a continuum of bad to excellent) or through appropriate multidimensional tools such as the WHO Quality of Life Instrument [16] and the Multicultural Quality of Life Index [17].

The idiographic and narrative component of the diagnostic model of the WPA International Guidelines for Diagnostic Assessment (IGDA) is based on the following contributions:

- The clinician perspective: This represents a synthesizing effort of the clinician to understand and explain the patient’s problems from biological, psychological and social perspectives.
- Perspectives of the patient and family: This represents an opportunity for the patient (and family) to present their views as they want to be heard about their illnesses and problems, development and current state of health, and quality of life, as well as their expectations for care.

- Integration of the perspectives of the patient, clinician and family: This integration is predicated on establishing a close rapport between the participants in order to obtain a shared understanding of the clinical condition, treatment plan, and evaluating their results over time.

11.3.3 The Person-Centered Integrative Diagnosis (PID) Model

Person-centered Integrative Diagnosis (PID), as developed under the auspices of the International College of Person Centered Medicine, is inscribed within a paradigmatic effort to place the whole person at the center of medicine and health care [18, 19]. The PID model [20] articulates science and humanism to obtain a diagnosis of the person (of the totality of the person's health, both its ill and positive aspects), by the person (with clinicians extending themselves as full human beings, scientifically competent and with high ethical aspirations)), for the person (assisting the fulfillment of the person's health aspirations and life project), and with the person (in respectful and empowering relationship with the person who presents for evaluation and care). This notion of diagnosis goes beyond the more restricted concepts of nosological and differential diagnoses. A conceptual appraisal of the bases of the PID model has been conducted through various international consultations [21].

The Person-centered Integrative diagnostic model is defined by three key features: (a) broad informational domains, covering both ill health and positive health along three levels: health status, contributors to health, and health experience and values (see Fig. 11.1), (b) pluralistic descriptive procedures (categories, dimensions

ILL HEALTH	*POSITIVE HEALTH*
I. Health Status	
Illness & its Burden a. Disorders b. Disabilities	Well Being Recovery/Wellness Functioning
II. Contributors to Health	
Contributors to Illness (Intrinsic/Extrinsic: Biological, Psychological, Social)	Contributors to Health (Intrinsic/Extrinsic: Biological, Psychological, Social)
III. Experience to Health	
Experience of Illness (e.g. suffering, values, perception, understanding and meaning of illness)	Experience of Health (e.g. identify, contentment, & fulfillment)

Fig. 11.1 Key structural levels covering ill health and positive health in the Person-centered. Integrative Diagnostic Model

and narratives), and (c) evaluation partnerships among clinicians, patients and families.

11.3.4 The GLADP-VR Diagnostic Formulation

The diagnostic model prepared and published by the Latin American Psychiatric Association Section on Diagnosis and Classification [22] at the core of the Latin American Guide of Psychiatric Diagnosis, Revised Version (GLADP-VR) was built starting with the original GLADP [23] and largely incorporating the basic elements of the Person-centered Integrative Diagnosis (PID) model [24]. The main difference between the PID model and the GLADP-VR schema is that the former has Health Experience as the second informational domain level while the latter has Health Experience as the third level (Fig. 11.2).

The **key information domains or levels** of the GLADP-VR diagnostic schema are summarized below.

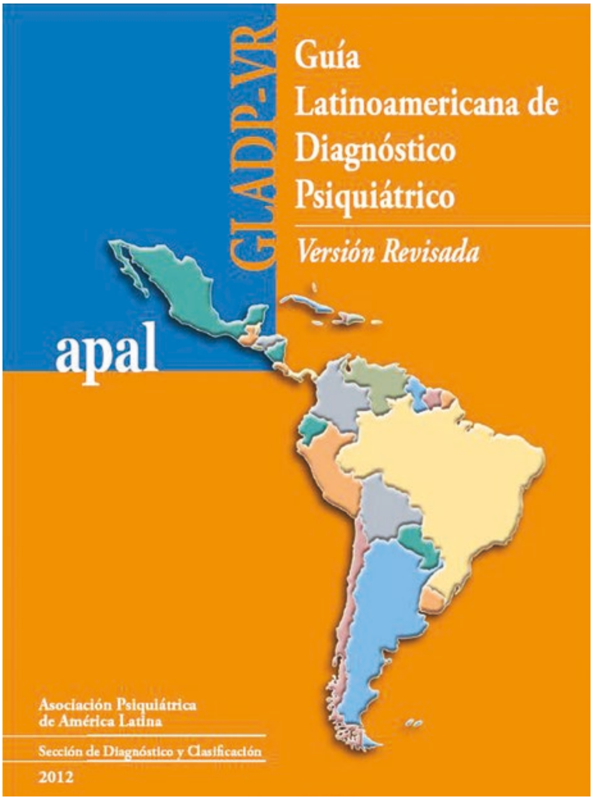


Fig. 11.2 Cover of the Latin American Guide of Psychiatric Diagnosis. Revised version (GLADP-VR)

11.3.4.1 Health Status

The first component of this model corresponds to Health Status. This includes standardized coverage of pathological and positive aspects of health, the former with official classifications and the latter with dimensional scales.

As the GLADP-VR/PID Personalized Diagnostic Formulation shows, the presentation of Health Status starts with a listing of mental and general medical disorders and other significant clinical conditions. These disorders and conditions are to be coded according to the categories of the various chapters of ICD-10 (and of the upcoming ICD-11), including, in addition to standard disease codes, the special codes for non-disease conditions (such as childhood negative events, legal circumstances, and life style and life management problems) that may require clinical attention.

Next comes the evaluation of Personal Functioning in four areas, i.e., personal care, and occupational, family and social roles, each measured with a 10-point scale marked as follows: 0: poor functioning, 2: minimal functioning, 4: marginal functioning, 6: acceptable functioning, 8: substantial functioning, and 10: optimal functioning.

The Health Status component finally assesses degree of the person's well-being, from worst to excellent, by directly marking on the 10-point line displayed on the Form or with the help of an appropriate scale. This assessment is principally based on the self-perception and judgment of the person involved, modulated collaboratively with perceptions of the clinicians and family.

11.3.4.2 Health Contributing Factors

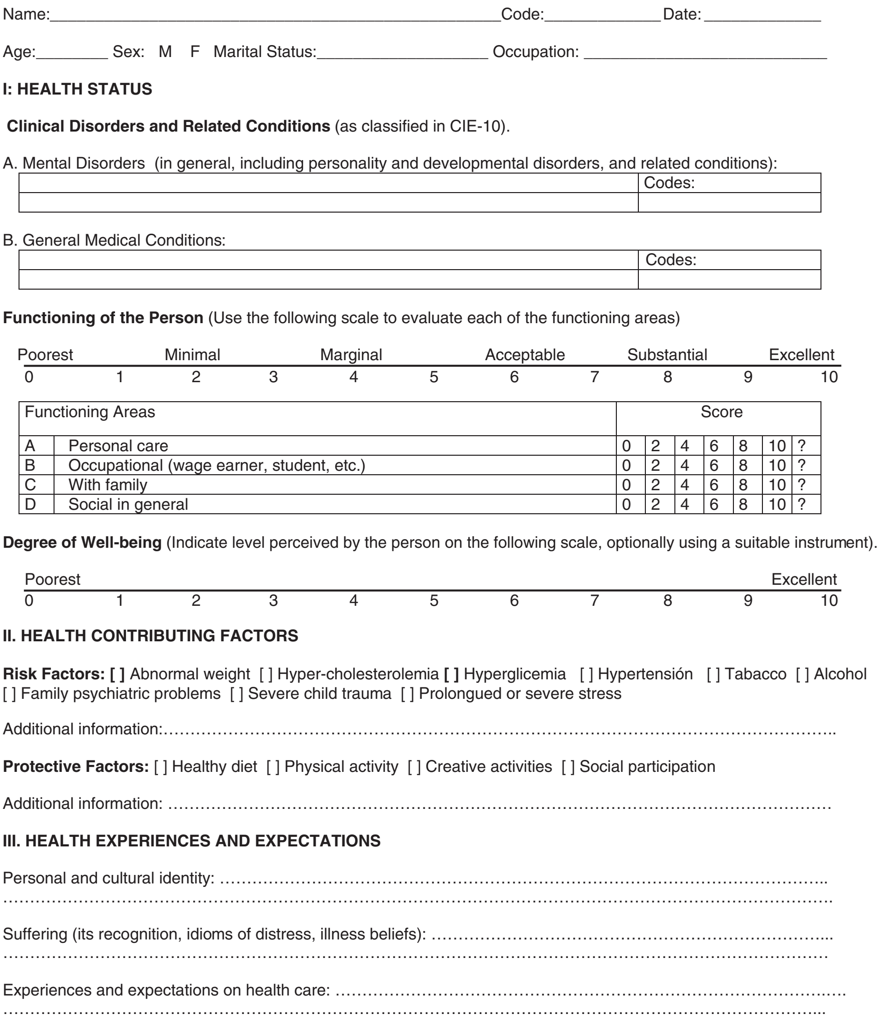
The second component of the Personalized Diagnostic Formulation corresponds to Health Contributing Factors. These include Risk Factors as well as Protective and Health Promotion Factors. Assessment in each case starts with the identification of relevant factors from the list presented on the form. These factors come from the Health Improvement Card prepared by the World Health Professions Alliance [25], supplemented by some factors particularly relevant to mental health. It continues with a narrative formulation of additional information about the identified factors and others that could also be found.

11.3.4.3 Health Experiences and Expectations

The third component of the Personalized Diagnostic Formulation assesses Experience and Expectations on Health. This is based on the combination of elements of the experientially described Cultural Formulation [18, 19, 26] and of patient's needs and preferences [27, 28]. This assessment is obtained through the narrative presentation of the following three points: (a) Personal and cultural identity (self-awareness and its potentials and limitations), (b) Suffering (its recognition, idioms of distress, and beliefs on illness), and (c) Experiences with and expectations for health care [29].

11.3.5 GLADP-VR Formats for Personalized Diagnostic Formulation

The version in English of the GLADP-VR Personalized Diagnostic Formulation form is displayed in Fig. 11.3. As shown, it is arranged within one page to facilitate visualization at a glance. It starts with usual demographic and chart identification information modifiable for the clinical setting at hand. Then it presents the lay out to cover the three key informational levels of the GLADP-VR (Health Status, Health Contributors, and Health Experiences and Expectations) and to facilitate their



Name:______________________________Code:__________ Date:__________

Age:______ Sex: M F Marital Status:______________ Occupation: ____________________

I: HEALTH STATUS

Clinical Disorders and Related Conditions (as classified in CIE-10).

A. Mental Disorders (in general, including personality and developmental disorders, and related conditions):

	Codes:

B. General Medical Conditions:

	Codes:

Functioning of the Person (Use the following scale to evaluate each of the functioning areas)

Poorest		Minimal		Marginal		Acceptable		Substantial		Excellent
0	1	2	3	4	5	6	7	8	9	10

Functioning Areas		Score						
A	Personal care	0	2	4	6	8	10	?
B	Occupational (wage earner, student, etc.)	0	2	4	6	8	10	?
C	With family	0	2	4	6	8	10	?
D	Social in general	0	2	4	6	8	10	?

Degree of Well-being (Indicate level perceived by the person on the following scale, optionally using a suitable instrument).

Poorest										Excellent
0	1	2	3	4	5	6	7	8	9	10

II. HEALTH CONTRIBUTING FACTORS

Risk Factors: [ ] Abnormal weight [ ] Hyper-cholesterolemia **[ ]** Hyperglicemia [ ] Hypertensión [ ] Tabacco [ ] Alcohol
[ ] Family psychiatric problems [ ] Severe child trauma [ ] Prolongued or severe stress

Additional information:……………………………………………………………………………………………..

Protective Factors: [ ] Healthy diet [ ] Physical activity [ ] Creative activities [ ] Social participation

Additional information: ……………………………………………………………………………………………

III. HEALTH EXPERIENCES AND EXPECTATIONS

Personal and cultural identity: ……………………………………………………………………………………..
…….

Suffering (its recognition, idioms of distress, illness beliefs): ……………………………………………………...
…….

Experiences and expectations on health care: ………………………………………………………………………
……...

Fig. 11.3 GLADP-VR Personalized Diagnostic Formulation Form assessment utilizing, as appropriate, categorical, dimensional, semi-structured, and narrative descriptions.

Evaluations of the GLADP-VR in comparison with standard international diagnostic systems (the original ICD-10, DSM-IV and DSM-5) among Latin American psychiatrists have shown that the GLADP-VR is preferred reportedly because it is person-centered and culturally-informed [30].

11.4 Exploration of the Bases for Person-Centered Diagnosis in General Medicine

For this exploration of documentary bases, a review of the literature was conducted concerning papers that presented concepts and procedures relevant to the development of person-centered diagnosis in general medicine. It was based on the Google Scholar data base. The search was focused on papers dealing with “person-centered or patient-centered diagnosis in general medicine”.

11.4.1 Overview of the Literature Towards Person-Centered Diagnosis in General Medicine

The main findings of this literature review are displayed on Table 11.2. The first column identifies each paper by its authors, title, and publication vehicle; the full reference of each is included in the list of References at the end of body of the paper. The second column provides information on the study areas addressed by each paper in terms of Health Scope (ill health, positive health, or both), Health Fields (relevant to a specific field, such as mental disorders; or all fields in general, such as general medical disorders), and Diagnosis Scope (discussing broad diagnostic concepts or specific diagnostic concepts and procedures). The third column briefly describes the key diagnostic proposals presented or discussed in the paper. Such proposals may refer to diagnosis scope (ill health or positive health); diagnosis levels, domains or dimensions such as health status (disease categories, functioning and quality of life); health contributors (risk and protective factors), and health experience and values; diagnosis processes (collaboration arrangements and description tools); overall health evaluation plans such as collaborative narrative summaries; and other innovative diagnostic proposals.

The literature search yielded 29 pertinent papers. Their publication years ranged from 1985 to 2017. The publication vehicles were quite diverse and international.

The study areas covered by the papers reviewed are presented on the second column of Table 11.2. Concerning Health Scope, all 29 papers reviewed dealt with ill health (diseases, disabilities), and 27 of them also dealt with positive health (mainly functioning, well-being and quality of life). In regard to Health Fields

Table 11.2 Literature review results on person- and patient-centered diagnosis in general medicine

Authors, publication year Abbreviated paper title, and publication vehicle	Study areas: health scope and fields, diagnosis proposal scope	Key diagnostic proposals
Lolas F. (*1985*) [31]	**A: Health Scope**	Multiaxial schemas proposed for diagnosis in general medicine
The psychosomatic approach and the problem of diagnosis. Soc Sci Med.;21(12):1355–1361.	Total health	
	B: Health Fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	
Ford P, McCormack B. (2000) [32]	**A: Health Scope**	Consider person-centered nurses' assessment such as major complaints and acuteness of the situation.
Keeping the person in the centre of nursing. Nurs Stand.;14(46):40–44.	Total health	
	B: Health Fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
Jeffrey H.D. et al. (2004) [33]	**A: Health Scope**	It proposes that person-centered care include both the identification of disorders as well as experiential and interpretation/heuristic aspects.
Maintain and Enhance: An integrative view of person-centered and process-differentiated diagnostics. Person-Centered & Experiential Psychotherapies	Total health	
	B: Health Fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	
Galland L. (2006) [34]	**A: Health Scope**	It emphasizes the aspects that predispose to the disease, triggering of symptoms and the modulation of biochemical mediators.
Patient-centered care: antecedents, triggers, and mediators. Altern Ther Health Med.;12(4):62–70.	Total health	
	B: Health Fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	

(continued)

Table 11.2 (continued)

Authors, publication year	Study areas: health scope and fields, diagnosis proposal scope	Key diagnostic proposals
Abbreviated paper title, and publication vehicle		
Hui KK, Hui EK, Johnston MF. (2006) [35]	**A: Health Scope**	Based on Traditional Chinese Medicine, it proposes the evaluation of the imbalance in various body systems that result in an alteration of the homeostatic reserve and a decrease in therapeutic opportunities.
The potential of a person-centered approach in caring for patients with cancer: a perspective from the UCLA center for East-West medicine. Integr Cancer Ther.;5(1):56–62.	Total health	
	B: Health Field	
	Cancer disease	
	C: DxPropScope	
	2. SpCon&Pro	
Mezzich and Salloum [20]	**A: Health Scope**	It proposes that the challenging clinical complexity be assessed, understood and formulated according to its various aspects and levels to adequately inform the development of crucial clinical tools as an effective person-centered integrative diagnosis.
Clinical complexity and person-centered integrative diagnosis. World Psychiatry.	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	
Cloninger CR (2010) [36]	**A: Health Scope**	The positive health approach is essential for a holistic framework to person-centered medicine.
The positive health domain in person-centered integrative diagnosis. Int J Integr Care.	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
Michael Klinkman, Chris van Weel (2010) [37]	**A: Health Scope**	It proposes the biopsychosocial model to integrate the person-centered diagnosis in routine clinical practice attending to both person and disease and using information technology tools.
Prospects for person-centred diagnosis in general medicine. Journal of Evaluation in Clinical Practice	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	

Table 11.2 (continued)

Authors, publication year	Study areas: health scope and fields, diagnosis proposal scope	Key diagnostic proposals
Abbreviated paper title, and publication vehicle		
Mezzich JE, Salloum IM, et al. (2010) [24]	**A: Health Scope**	This is the standard presentation of the original PID model, covering ill and positive health, standardized health status, contributory health factors, and health experience and expectations. It also proposes a collaborative diagnostic process and using categories, dimensions and narratives as description tools.
Person-centred integrative diagnosis: conceptual bases and structural model. Can J Psychiatry.	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	
Sturmberg JP, Martin CM, Moes MM (2010) [38]	**A: Health Scope**	It offers a comprehensive vision of health with bodily, mental, social and environmental factors, resulting in bodily homeostasis and personal internal coherence.
Health at the center of health systems reform: how philosophy can inform policy. Perspectives in Biology and Medicine 53(3):341–56 June	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	
Stewart M, Ryan BL, Bodea C. (2011) [39]	**A: Health Scope**	It reveals that the costs and effectiveness of patient-centered diagnostic procedures are more favorable than those not centered on the patient.
Is patient-centred care associated with lower diagnostic costs? Healthc Policy;6(4):27–31.	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
Adams, N. (2012) [40]	**A: Health Scope**	It proposes a collaborative narrative diagnostic summary that also serves to inform the treatment plan.
Finding common ground: the role of integrative diagnosis and treatment planning as a pathway to person-centered care. International Journal of person Centered Medicine	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	

(continued)

Table 11.2 (continued)

Authors, publication year Abbreviated paper title, and publication vehicle	Study areas: health scope and fields, diagnosis proposal scope	Key diagnostic proposals
Mezzich JE, (2012) [29]	**A: Health Scope**	It proposes that the patient's experience, culture, and values be incorporated into the core of clinical diagnosis.
Towards a Health Experience Formulation for Person-centered Integrative Diagnosis. International Journal of Person Centered Medicine	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	
Pritzker S et al., (2012) [41]	**A: Health Scope**	They propose paying attention to holistic aspects and individualized diagnosis formulated with patient participation.
Person-centered medicine at the intersection of East and West. European Journal for Person Centered Healthcare	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
Botbol M, Banzato CEM, Luis Salvador-Carulla L (2012) [42]	**A: Health Scope**	Elaborates on the descriptive means the diagnosis and the emphasis on a shared narrative in a pluralistic descriptive procedures (categories, dimensions, narratives)
Categories, Dimensions, and Narratives for Person-Centered Diagnostic Assessment. The Int' Journal of Person Centered Medicine; June, 196–200	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	
Djorđević, V., Bras, M., Brajković, L (2012) [43]	**A: Health Scope**	It support the importance of the interview for person-centered diagnosis and for bringing closer together individualized genetic medicine and whole person medicine.
Person-centered medical interview. *Croatian Medical Journal*, *53*(4), 310–313.	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	

Table 11.2 (continued)

Authors, publication year Abbreviated paper title, and publication vehicle	Study areas: health scope and fields, diagnosis proposal scope	Key diagnostic proposals
Wallcraft J, Amering M, Steffen S, Salloum IM (2012) [44]	**A: Health Scope**	The importance of collaboration is emphasized for diagnostic evaluation and therapeutic decision-making that lead to effective and accepted treatments and learning to take care of oneself.
Evaluators and assessment process in Person-centred Integrative Diagnosis. The International Journal of Person Centered Medicine Vol 2 Issue 2.	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	
Mezzich JE, Zinchenko Y, Krasnov V, Pervichko E, Kulygina M (2013) [45]	**A: Health Scope**	Proposes the need for implementation of a cross-cultural study of the subjective pattern of disease and its correlation with a particular social situation of personality development under disease conditions.
Person-centered approaches in medicine: clinical tasks, psychological paradigms, and the postnonclassical perspective. Psychology in Russia: State of the Art	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	
Jakovljević M, Ostojić L, (2013) [46]	**A: Health Scope**	It proposes attention to multimorbidity which promotes the effectiveness and efficiency of clinical care, increasing the validity of diagnosis and therapeutic decisions.
Comorbidity and Multimorbidity in Medicine Today: Challenges and Opportunities for Bringing Separated Branches of Medicine Closer to each Other. Medicina Academica Mostariensia,; Vol. 1, No. 1.	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	

(continued)

Table 11.2 (continued)

Authors, publication year	Study areas: health scope and fields, diagnosis proposal scope	Key diagnostic proposals
Abbreviated paper title, and publication vehicle		
Ringstrom G, Sjovall H, Simrén M, Ung EJ. (2013) [47]	**A: Health Scope**	It proposes the exploration of phenomenological experiences and interpretations in the diagnostic evaluation of patients with IBS that lead to a better understanding of the disease, relief of symptoms and fears, and the identification of personal solutions to face such syndromes.
The importance of a person-centered approach in diagnostic workups of patients with irritable bowel syndrome: a qualitative study. Gastroenterol Nurs; 36(6):443–451.	Ill Health	
	B: Health fields	
	Gastroenterology	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	
Muth, C., van den Akker, et al. (2014) [48]	**A: Health Scope**	Following Ariadne's principles, the following are proposed: (a) a comprehensive evaluation of the interaction of the patient's conditions, treatments, constitution and context; (b) attention to the patient's preferences; (c) individualized care
The Ariadne principles: how to handle multimorbidity in primary care consultations. BMC Med.	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	
Espinosa A. (2015) [49]	**A: Health Scope**	It proposes combining the principles of MCP and those of personalized or precision medicine
People-centered medicine and personalized medicine. MediSur, 13 (6), 920–924.	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
Tomasdottir MO, et al. (2015) [50]	**A: Health Scope**	Proposes the use of allostatic load to account for the interrelation between biography and biology and to deal with the importance of what strengthens versus what weakens a human being.
Self-Reported Childhood Difficulties, Adult Multimorbidity and Allostatic Load. A Cross-Sectional Analysis of the Norwegian HUNT Study. PLoS One. Jun 18;10(6):e0130591.	Ill health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	

Table 11.2 (continued)

Authors, publication year Abbreviated paper title, and publication vehicle	Study areas: health scope and fields, diagnosis proposal scope	Key diagnostic proposals
Bahrs O, et al. (2015) [51]	**A: Health Scope**	The use of "review dialogues" is proposed as a form of integrative diagnostic collaborative summary and its application to shared therapeutic decision-making.
Review Dialogues as an Opportunity to Develop a Person-related Overall Diagnosis	Total health	
The International Journal of Person Centered Medicine; Vol 5 Issue 3: 112–119	**B: Health fields**	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	
Mezzich JE. (2016) [52]	**A: Health Scope**	It prioritizes the whole person. This implies an ethical commitment, a contextualized person-centered diagnostic model; emphasis on health experience and values.
Values and context in person-centered diagnosis. Indian J Soc Psychiatry;32:188–95	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	
Kirmayer L.J., Mezzich J.E., Van Staden C.W. (2016) [53]	**A: Health Scope**	It recommends explicit attention to patients' experience and values by understanding the meanings of symptoms and suffering in the social and cultural context.
Health Experience and Values in Person-Centered Assessment and Diagnosis. In: Mezzich J., Botbol M., Christodoulou G., Cloninger C., Salloum I. (eds) Person Centered Psychiatry. Springer.	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	
Berger Zackary D, et al. (2017) [54]	**A: Health Scope**	Proposes that a patient-centered diagnosis is more effective through the interactive dialogue between doctor and patient regarding the needs, preferences and circumstances of the patient.
Patient centred diagnosis: sharing diagnostic decisions with patients in clinical practice BMJ; 359 :j4218	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	

(continued)

Table 11.2 (continued)

Authors, publication year Abbreviated paper title, and publication vehicle	Study areas: health scope and fields, diagnosis proposal scope	Key diagnostic proposals
Prados-Torres, et al.	**A: Health Scope**	Ariadne principles to deal with persons with multimorbidity in primary care.
Multimorbidity in family medicine and the Ariadne principles. A person-centered approach. Atención Primaria Volume 49, Issue 5, May 2017	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
Cuba M, et al. (2017) [55]	**A: Health Scope**	Proposes a concept of health that takes into consideration the fulfillment of the person's goals and a diagnostic process that describes illness, emotional reactions, and context as well as physician-patient collaboration.
Exploring health, disease and illness. Rev. Med. Hered vol. 28 no.2 Lima abr./jun.	Total health	
	B: Health fields	
	GenHealthFields	
	C: DxPropScope	
	1. BroadConcep	
	2. SpCon&Pro	

covered, 27 dealt with general medical conditions and only 2 focused on only one field, i.e., mental health. Concerning the Scope of Diagnostic Proposals, 28 papers involved broad concepts and 22 involved specific proposals or procedures.

11.4.2 Key Proposals for Person-Centered Diagnosis in General Medicine.

The key proposals for person-centered diagnosis in general medicine described synoptically on the third column of Table 11.2 are summarized and organized conceptually in Table 11.3. They are listed in terms of their basic enunciation and the bibliographic references that proposed them. The references mostly come from the literature review presented in Table 11.2, plus in a few cases some important additional references.

Concerning the Overarching Concept and Structure of Diagnosis, one of the fundamental meanings of diagnosis being a *process,* when applied to person-centered diagnosis it involves a collaborative process among all protagonists in the diagnostic enterprise, i.e., health professionals, patient and family. The other fundamental

Table 11.3 Key proposals for person-centered diagnosis obtained for general medicine

Overarching Concept and Structure of Diagnosis.
Collaborative process [20, 41, 43, 44, 54, 55]
Multiaxial formulation [20, 31]
Collaborative narrative diagnostic summary [40, 47, 48, 51, 57]
Nature of Health
Health as enabler of a person's goals [55] and life project [56]
Bio-psycho-social framework of health [37 38, 41]
Environmental as additional health element [38, 58]
Harmonic equilibrium among internal, social and natural worlds in Andean cosmovision [59]
Broad Areas of Health
Ill-health [20, 33]
Positive health [20, 36]
Health Specific Content Variables and Dimensions
Health status [20]
Health contributors [20]
Predisposing, triggering and modulation factors [34]
Homeostasis dysregulation factors [35]
Health experience, culture and values [20, 29, 45, 48, 52, 53]
Experiential aspects [33]
Multimorbidity [46]
Suffering [53]
Emotional reactions to illnesses [55]
Bodily homeostasis [38]
Personal coherence [38]
Personality development [45, 60]
Description/Interpretation/Information Tools
Categorical, dimensional and narrative descriptors [20, 42]
Interpretation/hermeneutic aspects [33, 47, 61]
Information technology [37]
Care Flow/Nursing Assessment
Person-centered nursing assessment: major complaints [32]
Person-centered nursing assessment: situation acuteness [32]
Additional Issues
Cost/effectiveness reported for person-centered diagnosis [39]
Combining person centered diagnosis and precision medicine [49]
Allostatic load integrating biography and biology [50]

meaning of diagnosis being a *formulation,* when applied to person-centered diagnosis it tends to involve a comprehensive or multiaxial formulation (rather than simpler formulations, such as disease labels). An additional key proposal in this section involves a collaborative narrative diagnostic summary which reflects the importance of establishing a common ground for person-centered diagnosis and care [62].

The section on the Nature of Health contains four proposals involving the theoretical components of health or framework to understand health. They have not been considered usually in standard diagnostic systems, but they seem to be quite relevant to person-centered diagnosis.

The section on Broad Areas of Health lists two proposals, ill health and positive health, that a mainstay of current person-centered diagnostic systems, such as the Person-centered Integrative Diagnosis model [24] and its practical applications.

The section on Health Specific Content Variables and Dimensions contains 12 proposals, half of which are included in the above mentioned Person-centered Integrative Diagnosis model and its applications, and half represent new proposals.

The section on Description, Interpretation and Information Tools, includes one proposal referring to the use of categorical, dimensional and narrative descriptors that are part of the Person-centered Integrative Diagnosis model and its applications. The other two, using informational technology and interpretation/hermeneutic approaches, represent innovative proposals. Particularly promising here are hermeneutic proposals because of their potential for enhancing the preparation of collaborative narrative diagnostic summaries [61].

The Care Flow/Nursing Assessment section includes two proposals relevant to the directioning of care (main complaints) or to the determination of its urgency (situation acuteness), often managed by nurses.

11.5 Discussion

It is apparent from reviewing the diagnostic models presented earlier that an increased and more pointed attention has been given to providing an increasingly broad scope to the diagnostic process when considering person-centered diagnosis. This broader scope included the attention to cultural factors and multi-aspects of health by developing multiaxial formulations and highlighting the bio-psycho-social formulation in the diagnostic process. The concept of person-centered diagnosis also includes, in addition to assessing ill-health, an equally important assessment of positive aspects of health and well-being and it places further emphasis on contextual and environmental factors as well as on stressing the importance of subjective experience of health. A key tenet of person-centered diagnosis is its emphasis on a collaborative process, as a partnership among the person presenting for care, health professionals, families and other stake holders, concerning shared decision making within the clinical encounter.

As summarized in Table 11.3, proposed elements for person-centered diagnosis for general medicine included overarching concepts that ranged from the process and structure of diagnosis to the nature and areas of health to be covered to the inclusion of contributors and modulators of health to the concept of homeostasis. While implementation of patient-centered diagnostic procedures were found to have more favorable costs and effectiveness than non-patient-centered ones [39], the format and structure of person-centered diagnosis in general medicine is still to be fully developed. The important work carried out by the World Organization of Family Doctors [63] and the World Health Organization [64] for adapting diagnostic classifications to the realities of primary care could be potentially enhanced through a person-centered care framework. Such advanced models may optimize the therapeutic relationship of persons seeking care with the health care provider and the care system in general and also may be feasible and adaptable to the workflow in diverse settings and across systems and cultures.

The view of the nature of health as an enabling the person to realize her/his life project and goals implicate a broader assessment of health status to include positive aspects of health. It would also require assessments of the individualized determinants of health (bio-psycho-social and environmental-contextual factors) for the person seeking care. A process of partnership and shared understanding and its results expressed in a collaborative narrative indicate the way forward concerning the culmination of the diagnostic process and its articulation with treatment planning.

A highly promising qualitative approach to enhance the preparation of collaborative narrative summaries involves hermeneutics. In effect, one of the key challenges for person-centered interviewing and diagnosis is to organize clinical information of different nature (categories, dimension and narratives) into a coherent and comprehensible account of the illness and wellness history of a patient. It is integrative in nature and requires more than just an exhaustive juxtaposition of all the information that a clinician manages to collect and analyze from the patient. To make a formulation that does justice to and makes clinical sense of the subjective experience of the patient, a clinician cannot simply use objective tools and discourses to fully represent the rich discourse of the patient. It is here where the relevance of hermeneutics comes in. Hermeneutics acknowledges the multi-faceted nature of the bio-psycho-social-cultural-spiritual discourse of patients. Hermeneutics cautions against the ontological and epistemological error of reductionism turning the personal special and unique experience of patients into an impoverished depersonalized and oversimplified discourse. Hermeneutics highlights the irreducibility of different aspects of the multi-faceted discourse of patients and argues for a multilayered personal narrative as the theoretical base and clinical outcome of person-centered interviewing and diagnosis [65]. For hermeneutics, while explanation (objective discourse on cause and effect) and understanding (subjective discourse on significance and meaning) are not reducible to each other, explanation and understanding can interact with each other to achieve an integrative formulation not through merging them into a single discourse but via the dialectic of "explaining more in order to understand better", otherwise known as the therapeutic hermeneutic circle [61]. Hermeneutics in this sense may support the Person-centered Integrative Diagnosis model as a means of enhancing the delineation and organization of a collaborative narrative summary during the diagnosis process. From the hermeneutic perspective, the person-centered interviewing is a patient- and clinician-friendly application of the hermeneutic dialogue between the patient and the clinician, and acts as a basis for person-centered shared decision making.

Modern technology, such electronic health records might facilitate such an individualized assessment of risk and vulnerabilities as well as strengths and resiliencies that would lead to personalized and shared decision making and treatment planning. At the same time, one must be aware of the challenges placed by digital technologies for conducting person-centered interviews and diagnostic processes [66].

11.6 Conclusions

Extensive and productive work has been conducted in the past few decades to develop concepts and procedures for person-centered clinical interviewing and for person-centered diagnosis. Much of the work done was completed under the aegis of the World Psychiatric Association Section on Classification and Diagnostic Assessment, the International College of Person Centered Medicine, and the Latin American Psychiatric Association. Thus, such work although aimed at general health diagnosis, it was particularly relevant to the mental health field and for the use of mental health professionals.

The most recent work presented here is pointedly directed to the identification and articulation of concepts and procedures explicitly aimed at the development of person-centered diagnosis for medicine at large. Many of these proposals have proved quite helpful for person centered diagnosis in broadly based person-centered mental health, and may be also helpful for general medicine. Some other new and innovative proposals appear to be intriguing and promising for the development of future person-centered diagnosis models for general medicine in its various fields and applications.

Acknowledgements and Disclosures The authors report no conflicts of interest in the preparation of this manuscript.

References

1. Cassell E. The person in medicine. Int J Integr Care. 2010;10(Suppl):50–1.
2. Tempier R. Treatment and care of psychosis: the person first. Paper presented at symposium on person centered care, WPA Regional Meeting, Beijing, 1-5 September, 2010.
3. Mercier C, Tempier R, Renaud C. Services communautaires et qualité de la vie: une étude d'impact en région éloignée. Can J Psychiatr. 1992;3:553–63.
4. Mezzich JE, Kirisci L, Salloum IM, Trivedi JK, Kar SK, Adams N, Wallcraft J. Systematic conceptualization of person centered medicine and development and validation of a person-centered care index. Int J Pers Cent Med. 2016;6:219–47.
5. Appleyard J. Introduction to ethical standards for person-centered health research. Int J Pers Cent Med. 2013;3:258–62.
6. Bouësseau M-C. Strengthening research ethics review systems. Int J Pers Cent Med. 2013;3:263–5.

7. Adams N, Grieder DM. Treatment planning for person-centered care. Amsterdam: Elsevier; 2005.
8. Braš M, Dubravac J, Đorđević V, Pjevač N. Perception of communication between doctors and patients - On-line research among doctors in Croatia. Psychiatr Danub. 2019; 31(Suppl 1):79–83.
9. Stewart M, Brown JB, Weston W, McWhinney IR, McWilliam CL, Freeman T. Patient-centered medicine: transforming the clinical method. Cleveland, OH: CRC Press; 2013.
10. Mezzich JE, Berganza CE, von Cranach M, Jorge MR, Kastrup MC, Murthy RC, Okasha A, Pull C, Sartorius N, Skodol AE, Zaudig M. Essentials of the WPA international guidelines for diagnostic assessment (IGDA). Br J Psychiatry. 2003;182(Suppl):45.
11. Mezzich JE, Kleinman A, Fabrega H, Parron D. Culture and psychiatric diagnosis. A DSM-IV perspective. Washington, DC: American Psychiatric Press; 1996.
12. Mezzich JE, Good BJ. On culturally enhancing the DSM-IV multiaxial formulation. In: Widiger TA, Frances AJ, Pincus HA, Ross R, First MB, Davis W, editors. DSM-IV source book (volume 3). Washington, DC: American Psychiatric Press; 1997.
13. World Health Organization. International Statistical Classification of Diseases and Related Health Problems. Washington, DC: World Health Organization; 1992.
14. Berger Zackary D, et al. Patient centred diagnosis: sharing diagnostic decisions with patients in clinical practice. BMJ, 359: j421810th revision (ICD-10). Geneva: Author; 2017.
15. World Health Organization. Multiaxial presentation of ICD-10 for adults. Cambridge: Cambridge University Press; 1997.
16. Orley J, Kuyken W. The WHO quality of life instrument. Geneva: World Health Organization; 1994.
17. Mezzich JE, Cohen NL, Ruipérez MA, Pérez C, Yoon G, Liu J, Mahmud S. The Spanish version of the quality of life index: presentation and validation. J Nerv Ment Dis. 2000;138:301–5.
18. Mezzich JE, Caracci G, Fabrega H, Kirmayer LJ. Cultural formulation guidelines. Transcult Psychiatry. 2009;46:383–405.
19. Mezzich JE, Snaedal J, van Weel C, Heath I. The international network for person-centered medicine: background and first steps. World Med J. 2009;55:104–7.
20. Mezzich JE, Salloum IM. Clinical complexity and person-centered integrative diagnosis. World Psychiatry. 2008;7(1):1–2.
21. Salloum IM, Mezzich JE. Conceptual appraisal of the person-centered integrative diagnosis model. Int J Pers Cent Med. 2011;1:39–42.
22. Asociación Psiquiátrica de América Latina, Sección de Diagnóstico y Clasificación. Guía Latinoa-mericana de Diagnóstico Psiquiátrico, Version revisada (GLADP-VR). Lima: Asociación Psiquiátrica de América Latina; 2012.
23. Asociación Psiquiátrica de América Latina, Sección de Diagnóstico y Clasificación. Guía Latinoa-mericana de Diagnóstico Psiquiátrico. Guadalajara: Asociación Psiquiátrica de América Latina; 2004.
24. Mezzich JE, Salloum IM, Cloninger CR, Salvador-Carulla L, Kirmayer L, Banzato CE, Wallcraft J, Botbol M. Person-centered integrative diagnosis: conceptual bases and structural model. Can J Psychiatr. 2010;55:701–8.
25. Seyer J (2012). Development of the health improvement card developed by the World Health Professions Alliance. Paper presented at the 5th Geneva conference on person-centered medicine. International College of Person Centered Medicine, May 2012.
26. Kirmayer LJ, Thombs BD, Jurcik T, Jarvis GE, Guzder J. Use of an expanded version of the DSM-IV outline for cultural formulation on a cultural consultation service. Psychiatr Serv. 2008;59:683–6.
27. Fulford KWM. Moral theory and medical practice. Cambridge: Cambridge University Press; 1999.
28. Fulford KWM, Christodoulou GN, Stein DJ. Values and ethics: perspectives on psychiatry for the person. Int J Pers Cent Med. 2011;1:131–3.
29. Mezzich JE. Towards a health experience formulation for person-centered integrative diagnosis. Int J Pers Cent Med. 2012;2:188–92.

30. Saavedra JE, Otero A, Brítez J, Velásquez E, Salloum IM, Zevallos S, Luna Y, Paz V, Mezzich JE. Evaluation of the applicability and usefulness of the Latin American guide for psychiatric diagnosis, revised version, in comparison with other international systems among Latin American Psychiatrists. Int J Pers Cent Med. 2017;7:216–24.
31. Lolas F. The psychosomatic approach and the problem of diagnosis. Soc Sci Med. 1985;21(12):1355–61.
32. Ford P, McCormack B. Keeping the person in the centre of nursing. Nurs Stand. 2000;14(46):40–4.
33. Jeffrey HD, Cornelius-White. Maintain and enhance: an integrative view of person-centered and process-differentiated diagnostics. Pers Cent Exp Psychother. 2004;3(4):268–76.
34. Galland L. Patient-centered care: antecedents, triggers, and mediators. Altern Ther Health Med. 2006;12(4):62–70.
35. Hui KK, Hui EK, Johnston MF. The potential of a person-centered approach in caring for patients with cancer: a perspective from the UCLA center for East-West medicine. Integr Cancer Ther. 2006;5(1):56–62.
36. Cloninger CR. The positive health domain in person-centered integrative diagnosis. Int J Integr Care. 2010;Suppl:e026.
37. Klinkman M, van Weel C. Prospects for person-centred diagnosis in general medicine. J Eval Clin Pract. 2010;17(2):365–70.
38. Sturmberg JP, Martin CM, Moes MM. Health at the center of health systems reform: how philosophy can inform policy. Perspect Biol Med. 2010;53(3):341–56.
39. Stewart M, Ryan BL, Bodea C. Is patient-centred care associated with lower diagnostic costs? Health Policy. 2011;6(4):27–31.
40. Adams N. Finding common ground: the role of integrative diagnosis and treatment planning as a pathway to person-centered care. Int J Pers Cent Med. 2012;2(2):173–8.
41. Pritzker S, Katz M, Hui KK. Person-centered medicine at the intersection of east and west. Eur J Pers Cent Health. 2012;1(1):209–15.
42. Botbol M, Banzato CEM, Salvador-Carulla L. Categories, dimensions, and narratives for person-centered diagnostic assessment. Int J Pers Cent Med. 2012;2(2):196–200.
43. Djorđjević V, Bras M, Brajković L. Person-centered medical interview. Croatian Med J. 2012;53(4):310–3.
44. Wallcraft J, Amering M, Steffen S, Salloum IM. Evaluators and assessment process in person-centred integrative diagnosis. Int J Pers Cent Med. 2012;2(2):201–4.
45. Mezzich J, Zinchenko Y, Krasnov V, Pervichko E, Kulygina M. Person-centered approaches in medicine: clinical tasks, psychological paradigms, and the postnonclassical perspective. Psychol Russ State Art. 2013;6(1):2013.
46. Jakovljević M, Ostojić L. Comorbidity and multimorbidity in medicine today: challenges and opportunities for bringing separated branches of medicine closer to each other. Medicina Academica Mostariensia. 2013;1(1):18–28.
47. Ringstrom G, Sjovall H, Simrén M, Ung EJ. The importance of a person-centered approach in diagnostic workups of patients with irritable bowel syndrome: a qualitative study. Gastroenterol Nurs. 2013;36(6):443–51.
48. Muth C, van den Akker M, et al. The Ariadne principles: how to handle multimorbidity in primary care consultations. BMC Med. 2014;12:223.
49. Espinosa A. People-centered medicine and personalized medicine. MediSur. 2015;13(6):920–4.
50. Tomasdottir MO, et al. Self-reported childhood difficulties, adult multimorbidity and allostatic load. A cross-sectional analysis of the Norwegian HUNT study. PLoS One. 2015;10(6):e0130591.
51. Bahrs O, et al. Review dialogues as an opportunity to develop a person-related overall diagnosis. Int J Pers Cent Med. 2015;5(3):112–9.
52. Mezzich JE. Values and context in person-centered diagnosis. Indian J Soc Psychiatry. 2016;32:188–95.

53. Kirmayer LJ, Mezzich JE, Van Staden CW. Health experience and values in person-centered assessment and diagnosis. In: Mezzich J, Botbol M, Christodoulou G, Cloninger C, Salloum I, editors. Person centered psychiatry. Berlin: Springer; 2016. p. 179–99.
54. Berger ZD, Brito JP, Ospina NS, Kannan S, Hinson JS, Hess EP, et al. Patient centred diagnosis: sharing diagnostic decisions with patients in clinical practice. BMJ. 2017;359:j4218.
55. Cuba M, et al. Exploring health, disease and illness. Rev Med Hered. 2017;28(2):Lima abr./jun.
56. Gracia D. Fundamentals of bioethics. Madrid: Eudema; 1989.
57. Prados-Torres, et al. Multimorbidity in family medicine and the Ariadne principles. A person-centered approach. Atención Primaria. 2017;49(5):300–7.
58. Querol M. La vida y la salud como sistemas ecobiopsicosociales. BolOficina Sanitaria Panamericana. 1993;115:557.
59. Salaverry O. Interculturalidad en salud. Rev Per Med Exp y Salud Pública. 2010;27:80–93.
60. Cloninger CR, Svrakic DM, Przybeck TR. A psychobiological model of temperament and character. Arch Gen Psychiatry. 1993;50(12):975–90.
61. Wong MTH. Values, meanings, hermeneutics and mental health. In: Stoyanov D, Fulford B, Stanghellini G, Van Staden W, Wong M, editors. International perspectives in values-based mental health practice: case studies and commentaries. Cham: Springer Nature; 2021. p. 341–439.
62. Botbol M, Adams N, Mezzich JE. Establishing common ground, engagement and empathy. In Mezzich et al Person centered medicine. Basel, Switzerland: Springer; in press.
63. Bentzen N, editor. WONCA international glossary for general/family practice. Fam Pract. 1995;12:267.
64. World Health Organization. International classification of primary care, second edition (ICPC-2). Geneva: Author; 2011.
65. Wong MTH. Ricoeur and the third discourse of the person: from philosophy and neuroscience to psychiatry and theology. London: Lexington Books; 2019.
66. DeBronkart D. From patient centred to people powered: autonomy on the rise. BMJ. 2015;350:h148.

Chapter 12
Collaborative Treatment Planning

Paul Glare and W. James Appleyard

12.1 Introduction

The situation with COVID-19 notwithstanding, many people in the twenty-first century are living with complex, chronic conditions that require multiple considerations to be taken into account when choosing treatments, not simply which is the most effective. Questions arise such as: Is it a single treatment, or does it require multiple administrations? is the outcome permanent or temporary? what if it is effective but toxic? what if there are two options with similar effectiveness, but the side effect profiles are very different? will I have usual treatment or go in a clinical trial? where is it administered? what are the qualifications, experience and outcomes achieved by the treating team there? am I willing to bankrupt my family in the process of pursuing treatment?

Because the results of clinical trials and systematic provide only partial answers to these person-centred questions, this approach has been called "preference-based medicine" [1]. Collaborative treatment planning refers to the practice of preference-based medicine, and describes how the clinician—or interdisciplinary team of clinicians—works with the patient and/or family to achieve a shared treatment decision,

---

P. Glare (✉)
Northern Clinical School, Faculty of Medicine and Health, University of Sydney, Sydney, NSW, Australia

Memorial Sloan-Kettering Cancer Center and Weill Cornell Medical College, New York, NY, USA
e-mail: paul.glare@sydney.edu.au

W. J. Appleyard
Presidency 2013–2017, International College of Person Centered Medicine, New York, NY, USA

Presidency 2003-2004, World Medical Association, Ferney-Voltaire, France

St George's University School of Medicine, Grenada, Grenada

Kent and Canterbury Hospital, Canterbury, UK

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_12

and then documents the decision so that it can be implemented and the outcomes measured.

12.2 A Person Is More Than His or Her Symptoms

Each person lives their life guided by their own vision and dreams for a healthy fulfilling life. Each person is affected by illness, suffering and disability in their own unique way. Each person finds distinct meaning in the experience of illness and the road back to wellness and health.

The conditions that promote well-being and recovery from illness involve a set of common features of health that include hope, empathy and respect for one's self and others. These common characteristics of well-being emerge from a self-transcendent outlook on life with a sense of participation in the boundless unity of all things or inseparable connectedness with nature and other people [2]. Self-transcendent outlooks and values are typical of healthy and creative people in all human cultures. An outlook of separation predisposes a person to feelings of fear, alienation, and individual pride or shame, thereby predisposing to dissatisfaction with life and ill health.

Person-centered care promotes health by providing the experience of an outlook of unity in the therapeutic alliance, which can later be generalized beyond the alliance. An outlook of unity fosters well-being by activation of a synergistic spiral of increasing self-directedness, cooperativeness, and self-transcendence.

The common factors in all treatments include the patient' s characteristics, the therapist' s qualities of respect (i.e., prizing, unconditional positive regard, acceptance, trust), empathic understanding, and genuineness (i.e., realness, authenticity), and the quality of the therapeutic alliance between them (shared goals, emotional engagement and exchange). These common factors are characteristic of all truly healthy interpersonal relationships, and are important for maintenance and recovery of all aspects of well-being, whether physical, mental, or spiritual.

The interpersonal attitudes of respect, genuineness and empathic understanding are crucial for the development of well-being. When physicians rely only on symptom-based diagnosis and treat patients without respectful exchange in dialogue, there are usually high rates of drop-out and non-compliance with treatment prescriptions, as well as high rates of burn-out in the physician and stigma in the patient. Accordingly, effective clinical practice depends on tools that facilitate non-stigmatizing personality assessment, rapid facilitation of a therapeutic alliance and guided development of self-awareness for people to learn how to live well.

A person's illness is more than a checklist of symptoms and the life course of their past medical history needs to be integrated with additional information about personal, social, cultural, and spiritual aspects [3]. Even with a thorough symptom-based diagnosis, most This enables physicians to understand the causes of the illnesses and the unique set of strengths that will allow the person to recover their health.

Individual differences in a person's outlook on life strongly determine their capacity to work, love, and serve others with satisfaction and health. Personality assessment helps a clinician to know who the person is, stimulates the patient to reflect on their strengths and weaknesses in regulating their emotions in accord with their goals and values. Instead of merely generating a pejorative categorical label of personality traits and disorders, both the clinician and patient need to understand how a patient's personality profile is organized and may contribute to his or her health and illness.

Medical treatment should be focused on not only the relief of acute symptoms of illness but on the promotion of health and well-being to be effective in the prevention and management of chronic diseases. Treatments directed at acute symptoms of illness, rather than its causes, result in temporary relief, frequent relapse and recurrence, and no lasting improvement in public health [4]. A fuller understanding of the individual enables care decisions are driven by each individual's preferences, values, and culture.

12.3 How May a Clinician Understand Their Patient?

Shared understanding and active patient participation therefore are essential in the development of the treatment plan. The process of moving from mere information to a shared understanding of the individual's circumstances and needs is at the heart of what it means to be person-centered. Effective clinical solutions that are endorsed and supported by the patient can only come from this process. This collaborative development of a treatment plan assures that the core principles of person-centered care are integrated into everyday clinical practice [5].

The starting point, but also the most difficult and most neglected type of understanding, is to try and grasp the patient's own experience and understanding of their illness and treatment needs. This is really where common ground is to be found. Without it, successful healing and treatment is difficult if not impossible. This is not easy to accomplish and takes time, trust, effort and a true commitment to the values and principles of person-centered care. In this way, the formulation or integrative narrative serves as an essential bridge between data gathering in the assessment and the creation of a treatment plan that is truly person-centered.

Health care professionals need to try to understand—and respect—patient preferences. At times, this can be something as simple as wanting the liquid form of a medicine as compared to a tablet or a reluctance to use drugs that could become habit forming or the preference for a lifestyle change and diet regimen before considering, for example, statin pharmacotherapy for elevated lipid levels. The need for choice and options is critical and should be offered whenever possible. At other times, there are subtle risk/benefit equations that enter into patients' decisions about treatment that shape how patients respond to a clinician's treatment plan. A good example is the patient with atrial fibrillation and elevated risk of a stroke who declines warfarin, an indicated anticoagulant treatment and instead opts for a

Table 12.1 Domains of the Person-centered Integrative Diagnostic Model [3]

Illness	Well being
• Disorders and disabilities	• Adaptive functioning and physical, mental, and social well-being
• Nature of suffering	• Self-awareness, resilience, fulfilment
• Biological, psychological and social risk factors	• Biological, psychological and social promoters of health

somewhat less potent and less effective alternative, aspirin, because of the fear of occupational exposure to injuries resulting in severe bleeding.

The Person-Centered Integrative Diagnostic Model provides a very useful conceptual model and structure for how this kind of understanding can be achieved and organized as shown on Table 12.1.

The integrative narrative can substantially contribute to a more humanistic person-centered diagnosis that can lead, in turn, to the creation of efficacious plans and effective treatment that promote each person's individual wellness goals. This perspective and insight is found in the formulation or integrative synthesis. Typically recorded in narrative form, this helps both provider and patient reach agreement on the circumstances related to his/her condition, the strengths and resources available to engage the individual in his efforts to overcome his illness and achieve his goal(s), along with an identification of the challenges or barriers that must be addressed and resolved. It is essential that these barriers/challenges be identified and understood in the context of the patient's illness and life experience. The objectives or short-term goals in the treatment plan should build on the person's strengths and be designed to help patients overcome or ameliorate those challenges and barriers, so that they can realize their wellness vision and goals. For this process to be meaningful and effective, it must be built on common ground and a shared understanding of the patient's circumstances, perspectives, preferences and potential to achieve stated goals.

12.4 Communication Skills for Undertaking Collaborative Treatment Planning

The narrative approach comes naturally to some clinicians, but others need guidance in how to approach it. One method that has been developed is the "Choice Talk-Options Talk-Decision Talk" framework [6], which goes as follows:

Step 1: Choice Talk. This conversation lays out the choice that needs to be made and the options that are available, e.g. treatment vs. no treatment; immediate treatment vs. 'watching and waiting'; pharmacotherapy vs. a procedural technique; surgery vs. radiotherapy. Some may be dismissed out of hand by the patient ("I don't like needles"; "do whatever is needed to eradicate the cancer") or provider (e.g. not available in this country; not for your diagnosis; too young/too old; not well enough; prognosis too short/long).

Step 2: Option Talk. From the list of viable options, the health care provider provides more information on the evidence base for each option, and the pros and cons as might apply to the patient. For example, in the case of surgery vs. radiotherapy for localized prostate cancer, there may be a greater chance (75% vs. 50%) of erectile function recovering at 2 years but twice the risk (20% vs. 10%) of cancer recurrence at 10 years with radiotherapy. Variability in the qualifications, experience and outcomes achieved by the providers of the different treatments at the place of care may also be relevant.

Step 3: Decision Talk. The clinician empathically elicits the patient's values and preferences for their treatment and engages them in a discussion that supports them in making their choice.

The three steps would be expected to occur in order, although the third stage (Decision) may require reiteration of some parts of the Choices and Options talk. A decision may be able to be made on the spot or may require a longer period for deliberation.

A well-documented example of shared decision making was Angelina Jolie's highly publicized choice to opt for a prophylactic double mastectomy after testing positive for the BRCA1 mutation. While, one can only speculate how Ms. Jolie and her surgeons actually made this decision, one can reconstruct how the Choice/Options/Decision-Talk approach might have facilitated her treatment choice, based on her story as it was documented in *Time* magazine (see Box 12.1) [7].

Box 12.1 How the Choice/Options/Talk Model may have facilitated Angelina Jolie's decision to undergo surgery

CHOICE TALK: Yes, Ms. Jolie, the choices are prophylactic surgery or regular screening. There are no effective drug treatments.

OPTIONS TALK: There is a 90% chance you will get breast cancer or ovarian cancer**.**

Extensive surgery will drastically reduce the risk but not eliminate it.

If found early with screening, 5-year survival after breast cancer treatment is almost 100%, and >90% for ovarian cancer.

Screening is good for breast cancer but not simple for ovarian cancer.

Screening has no side effects. Surgery side effects include body image and pain.

DECISION TALK: If your goal is a sense of relief by minimizing your cancer risk by doing whatever it takes then you may want to choose prophylactic surgery.

If you wish to avoid surgery, choose screening even though the risks are slightly higher

Other factors like your celebrity status and your children may be relevant.

12.5 The Role of the Treatment Plan

Having come to a shared decision, a treatment plan is a written record of shared decisions organized into a standard format of a medical record [8]. A treatment plan should be an organic "living" document that is, in effect, a social contract between physicians, their teams and the individual person under their care that elaborates clear expectations and outcomes from such care as well as details about the variety of strategies employed to achieve them.

The importance of empathy as fundamental to effective therapeutic healing relationships [9]. Empathy refers to the ability to understand and share the feelings of another and is the foundation for establishing common ground. While common ground cannot be achieved without an empathic understanding, it implies something even more significant: the overt process of establishing a therapeutic alliance between patient and clinician that is based on that shared understanding.

A clinical consultation includes an interview with the patient to gather information about his/her concerns and a narrative history concerning the onset of the problem/s, the patient's experience and past experiences with health, illness and treatment. This is followed by physical examination and assessment—including a mental status examination, that usually leads to a summary diagnosis based upon one's professional understanding of the presentation and history, the reported and observable symptoms, collateral information from laboratory and other studies Understanding the psychosocial context in which the patient experiences their symptoms or distress is also important. We know that there are multiple ways in which social and environmental factors impact health, wellness and healing. This should also include recognition of the patient's strengths and assets that can be engaged in the treatment process; motivation and the capacity for self-care are often under-appreciated, but critical factors This approach establishes the creation of a profile of the individual upon which a treatment plan can be built. Patients need and want to understand the doctor's thinking, the rationale for treatment and the expected outcome and to agree with and accept the doctor's rationale in order for a treatment.

In any treatment it is necessary for practitioner and patient to have a shared understanding of the cause of the problems, the impact it has on the individual and how it is viewed and experienced before meaningful treatment decisions can be made. This is especially true when working with people across different cultures. There are multiple examples of how culturally based understandings of illness and suffering shape people's help-seeking behavior and acceptance of treatment. For example, in many Latin American countries/cultures, disease is understood to result from spirit possession and this perspective must be incorporated into any treatment plan if it is likely to be accepted and implemented by a patient and family.

There are many different, but complementary, approaches or methods for achieving common ground. They are all similar in their emphasis on the importance of creating a formulation or integrated synthesis of the clinical and personal data about the patient that support the diagnosis and serve as a bridge between assessment and the creation of a treatment plan. Each approach also focuses on the value of a written narrative that captures the essence of the understanding and the importance of dialog between the patient and the provider that is the foundation of common ground. Disagreements must be acknowledged and reconciled in the process; without this, the therapeutic alliance central to healing relationships is absent and a meaningful treatment plan based on shared decision- making cannot be achieved.

Treatment plans can be simple or elaborate, depending on the setting and circumstances. In some clinical arenas they are succinct, may be more implicit than explicit and not, *per se*, given much attention. All the same, treatment plans are at the heart of any care process and are critical in guiding treatment decisions, as well as having an important role in patient engagement and treatment success. Treatment plans should be built upon and reflect both shared understanding and decision-making between the patient and the lead physician.

Treatment plans can be viewed as a "social contract" between one party known as the patient and another party referred to as the provider or as in many instances, the treatment team. This contract or compact is organized around a logic model that incorporates three basic elements that are common to any planning process. Typically, there is a large, over-arching "big-picture" goal that describes the overall purpose or intention of the plan. Ideally, the goal incorporates the patient's vision and hope for wellness and a satisfying life consistent with their roles, responsibilities and expectations. Goals are frequently rather non-specific and ideally are expressed and recorded in the patient's own words. The next logical element in the plan is typically the identification of objectives or short- term interim goals to be accomplished in the course of treatment that help the person to achieve and realize his larger goal. Objectives should be measurable and time framed and they describe the very specific and meaningful changes that need to occur. Lastly, a plan specifies the interventions, action steps and/or treatment activities that the provider and patient together agree upon as a strategy to help the individual achieve the specified objectives, overcome barriers and challenges and reach the larger goal.

12.6 Formulating the Treatment Plan

There are three basic elements to a formal treatment plan:

1. Goals;
2. Objectives
3. Interventions, services, or treatments

Plans may be simple or complex, depending on the severity of the individual's needs and the complexity of their condition. The plan is often described as a 'road map' guiding both provider and patient/consumer in their journey to recovery and health. The plan is created by moving through a set of sequential steps that should begin with access and engagement, followed by assessment. The next important step is an integration and synthesis of assessment data into an understanding of the individual's circumstances, the illness, causative factors and the subsequent formulation of suggestion for strategies for relief.

Supporting and promoting person-centered care and shared decision-making is enhanced by sharing the understanding within the patient/physician relationship. Shared understanding is indeed the foundation of shared decision-making. Care cannot be person-centered if the physician and patient have highly divergent understandings of the nature of the problems and the overall strategies to restore health and wellness. Without that understanding, care is driven by something other than a person-centered approach. It is necessary as part of this process that goals are specified and barriers to attaining these goals as a result of the illness are identified. Objectives are specific intermediate steps taken to resolve barriers and pave the way to goal attainment. Interventions or strategies include the application of treatments, supports and self-directed efforts to achieve the objective and make progress towards the goal In person-centered care and planning, the goal should capture the patient's or consumer's vision of health, wellness and a satisfying life. It is often useful to have that expressed and recorded in the person's own words.

Goals within the person-centered approach are highly individualized and not specific to the condition or diagnosis. In contrast, the goal in illness-centered care is often about amelioration of the condition with a focus on the acute symptoms or distress.

Objectives should describe the short-term or intermediate steps necessary to resolve barriers and promote goal attainment. If the individual's goal is independent living, but if he lacks the adequate ability to perform routine activities of daily living (ADLs), objectives might describe the mastery of skills like hygiene, medication self-management and food preparation.

Services, treatments, or interventions are the specific therapeutic steps taken to achieve objectives. They may range from medications for symptom relief to further tests for diagnostic clarification to specific therapies for reducing impairments and enhancing self-management and healing. It should be clear as to why a specific intervention is offered/applied and how it will help the individual to fulfil the objective.

The rigor, discipline and logic of treatment planning is one way to promote shared decision-making and in doing so assure person-centered care and promote recovery. Good proper treatment planning is at the heart of person-centered practice. Providers may need to reconsider their roles and relationship with patients/consumers and develop new skills in collaboration and planning to assure that care is person-centered and recovery-oriented.

Without understanding, the plan and the treatments/interventions may simply make no sense. Problems with sustained adherence to treatment/medication regimens and recommendations is something observed across the range of physical and mental illness and the reasons for poor adherence are as varied as individuals and their circumstances. In some instances, the cost or availability of the medicine(s) might be a factor, while in others the complexity of too many medications and too many doses may cause confusion or overwhelm the patient and interfere with compliance. In other instances, side effects or other problems with the medicines may be the cause. Each of these reasons begs its own response. We need to understand an individual's unique reasons for not adhering to treatment so we can help them to participate in shared decisions.

12.7 Shared Decision Making/Collaborative Treatment Plans vs. Consent

The concept of truly shared decision making implies that the patient agrees to the treatment being administered. However, a distinction has been made between shared decision making and informed consent [10]: while they both concern the promotion of patient autonomy, shared decision-making is a medical ethics approach while informed consent is a legal process. These authors propose a two-dimensional construct with Choice on one axis and Risk on the other. Using the examples provided by Whitney et al., Fig. 12.1 illustrates that some medical decisions have only one option and are low risk, while at the opposite end of the spectrum are decisions with more than one option that require a formal discussion of the pros and cons of each option, for which the risk of iatrogenic harm are high making written informed consent necessary.

Whitney et al. include conventional cancer treatment in their typology, but an emerging issue is deciding and agreeing about participation in clinical trials [11], which are common in patients with advanced cancer or other serious illnesses. These patients and their caregivers are involved in a number of emotional and urgent decisions, such as whether to participate in clinical research that could potentially involve risks without personal benefit. For example, patients undergoing stem cell transplantation may be presented with information for many different clinical studies at one time, each with lengthy consent documentation. This can result in an overwhelming and stressful amount of information in patients facing choosing and consenting to a treatment that already has a high physical and psychological burden [11].

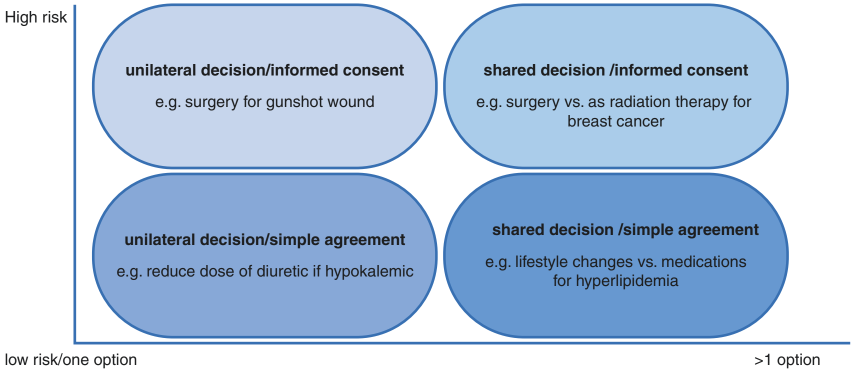


Fig. 12.1 Decision plane for shared decision making vs. consent, according to certainty of choice and risk of harm, adapted from Whitney et al. [10]

12.8 Collaborative Clinical Team

"A team is a small number of people with complementary skills who are committed to a common purpose, set of performance goals, and approach for which they hold themselves mutually accountable". Clinical teams need to be built up according to the needs and preferences of the patient with a lead clinician, and other medical colleagues with Nursing, Therapy Social Work Spiritual and Cultural support. The team should embed continuity of care so that the patient is "known" and long-term trusting relationships can be established and provide tailored, patient-centered care through shared understanding of an agreed treatment plan which relies on recognizing and addressing the wants and needs of the individual patient by working within the individual's psychosocial context, available financial and support resources, ability to self-manage, and barriers to self-care.

12.9 Beyond the Basics: Practical Aspects of Undertaking Collaborative Treatment Planning

Even when physicians are committed to practicing collaborative treatment planning, they need to be aware that there are many psychological confounders which can impact on the decision-making process and they have to be very careful to avoid them. **The whole situation needs to be discussed, not just selected aspects of it.** When people face complex decisions they tend to take to take a mental short cut and oversimplify it, which can be a mistake in health decision making. For example, deciding to pursue life prolonging treatment in a seriously ill person may have serious consequences if survival is the only outcome that is evaluated, especially if the chances of prolonging life are low [12]; quality of life, place of care, cost of care and mode of death all need to be weighed. But this begs the question whether a health care professional has a duty to present every single aspect and option, even if they think it is inappropriate? For example are they obliged to prognosticate, or discuss the cost of a treatment? **Patients may not act fully autonomously when participating in collaborative treatment planning.** People's behavior can prevent them fully participating in collaborative treatment planning. Most people will agree with what's proposed because they want to be liked, including by their doctor. They want to be good, expecting their generosity to be reciprocated. They believe what they are told, especially by someone in authority. They also want to be consistent in their decisions so are unlikely to change their mind. **There are many cognitive biases that influence peoples make choices.** These apply in all realms of life, including health care decision making. Health examples could include believing that one will be the 1-in-100 who responds to an experimental treatment (optimism bias), being over-influenced by what's been recently reported in the media or on social media (availability bias), or only recalling cases supporting one's opinion (confirmation bias). **How the health care professional frames the decision affects the choice.** People react differently to how numbers depending on how they are framed. A person is more likely to choose a treatment with 1% chance of succeeding than a 99% chance of failing. Health care professional need to be aware of this phenomenon and in particular to avoid using framing to manipulate patient's decision. A classic example of framing was published in the *New England Journal of Medicine* nearly half a century ago [13]. It concerned people's preferences for surgery (labelled Treatment A) or radiation therapy (labelled Treatment B) for the treatment of cancer Treatment A causes some deaths at the time of treatment but has a better long-term outcome. Treatment B causes no deaths at the time of treatment but has a worse long-term outcome. The proportions and outcomes were framed in various ways that were always numerically identical (i.e. 10% succeed vs. 90% fail). The study found that preferences flipped from Treatment A to Treatment B depending on how the data were presented. Short-term outcome was presented as 10% chance of dying after Treatment A (in which case B is preferred) to 90% chance of surviving after Treatment A (prefer A). Long term outcome was described as survival (prefer A) vs. cumulative mortality (prefer B). Treatment A was also preferred when it was revealed to be surgery and Treatment B was revealed to be radiation therapy. Other studies have shown that people's preferences change when equivalent numerical data are presented in different ways [14]. Some examples include giving a fraction vs. a percentage (e.g. one-in-five vs. 20%); a percentage (e.g. 20%) vs. a category (e.g. common, possible, unlikely); aggregated results (median 15 months) vs. disaggregated results (6 months: 80%, 1 year: 60%; 2 years 30%; 5 years 10%); average case vs. best case vs. worse case; reduction of risk from 100% to 80% vs. reduction from 20% to 0%; relative risk reduction vs. absolute risk reduction (Reduction from 96% to 94% framed as a 33% relative risk reduction vs. a 2% absolute risk reduction).

12.10 Barriers and Challenges to Practising Collaborative Treatment Planning

National healthcare systems have begun explicitly integrating shared decison-making into their policies, and even invested and legislated in its favor. Yet few healthcare professionals are adopting it. Many health care professional mistakenly believe they already engage their patients in shared decison-making, probably arising from not really understanding what shared decison-making is or how to do it. Physicians might not even recognize the need for a decision [15]. For example, a systematic review of shared decison-making using the Observing Patient Involvement in Decision Making (OPTION) scale found low levels of patient-involving behaviors by clinicians [16]. There are a number of excuses given for this poor uptake, but none are supported by data [17]. Pressure of time is the commonest reason given by those acknowledging there are barriers to shared decison-making, but studies indicate no consistent increase in consultation duration occurs when shared decison-making is implemented. Clinicians also hold strong views on the patient characteristics of those who do, don't, can, can't participate in collaborative treatment planning. It may be true that some patient groups may be more or less interested in collaborative treatment planning according to factors such as age, gender, marital status, culture/acculturation, religion, education, health literacy. Disease- and other clinical factors may also be relevant, such as stage of cancer, but the point is that health care professional routinely underestimate the proportion of their patients who wish to participate in collaborative treatment planning. For example, a survey of 78 Canadian patients with advanced cancer indicated that only two-thirds wanted to participate in shared decison-making, however their health care professionals under-estimated this proportion, correctly predicting patient preference in less than 50% cases [18].

12.11 Conclusion

The values of person-centered care are often endorsed by many clinicians as they resonate with personal beliefs about how consistently to achieve humanistic, empathic and efficacious responses to illness and suffering. However, the practical steps of translating those values and principles into everyday practice can be elusive. The application of conceptual models such as the Person-Centered Integrative Diagnosis, through the creation of narrative formulations, can significantly contribute to ensuring that care is, in fact, person-centered. Synthesizing the data collected in assessment into insight and understanding that can help to establish shared understanding and common ground, is essential. Frameworks such as Choice/Options/Decision Talk may be helpful here. Translating that understanding into effective, individualized and culturally sensitive/informed treatment plans is at the heart of person-centered care. Without a formulation or integrative narrative diagnosis as a bridge between diagnosis and care, it is difficult, if not impossible, to be truly person-centered as part of routine clinical practice.

References

1. Quill TE, Holloway RG. Evidence, preferences, recommendations—finding the right balance in patient care. N Engl J Med. 2012;366(18):1653–5.
2. Cloninger C, Cloninger K. Person-centred therapeutics. Int J Pers Cent Med. 2011;1(1):43–52.
3. Mezzich JE, Salloum IM, Cloninger CR, Salvador-Carulla L, Kirmayer LJ, Banzato CE, Wallcraft J, Botbol M. Person-centred integrative diagnosis: conceptual bases and structural model. Can J Psychiatr. 2010;55(11):701–8.
4. Osterberg L, Blaschke T. Adherence to medication. N Engl J Med. 2005;353(5):487–97.
5. Coulter A, Collins A. Making shared decision-making a reality. No decision about me, without me. London: King's Fund; 2011.
6. Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P, Cording E, Tomson D, Dodd C, Rollnick S, Edwards A, Barry M. Shared decision making: a model for clinical practice. J Gen Intern Med. 2012;27(10):1361–7.
7. Kluger J, Park A. The Angelina effect. Time. 2013;181(20):28–33.
8. Adams N. Finding common ground: the role of integrative diagnosis and treatment planning as a pathway to person-centered care. Int J Pers Cent Med. 2012;2(2):173–8.

9. Mercer SW, Reynolds WJ. Empathy and quality of care. Br J Gen Pract. 2002;52(Suppl):S9–12.
10. Whitney SN, McGuire AL, McCullough LB. A typology of shared decision making, informed consent, and simple consent. Ann Intern Med. 2004;140(1):54–9.
11. Raj M, Choi SW, Gurtekin TS, Platt J. Improving the informed consent process in hematopoietic cell transplantation: patient, caregiver, and provider perspectives. Biol Blood Marrow Transplant. 2018;24(1):156–62.
12. Verma AA, Razak F, Detsky AS. Understanding choice: why physicians should learn prospect theory. JAMA. 2014;311(6):571–2.
13. McNeil BJ, Pauker SG, Sox HC Jr, Tversky A. On the elicitation of preferences for alternative therapies. N Engl J Med. 1982;306(21):1259–62.
14. Glare P, Fridman I, Ashton-James CE. Choose your words wisely: the impact of message framing on patients' responses to treatment advice. Int Rev Neurobiol. 2018;139:159–90.
15. Legare F, Witteman HO. Shared decision making: examining key elements and barriers to adoption into routine clinical practice. Health Aff (Millwood). 2013;32(2):276–84.
16. Couet N, Desroches S, Robitaille H, Vaillancourt H, Leblanc A, Turcotte S, Elwyn G, Legare F. Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument. Health Expect. 2015;18(4):542–61.
17. Hoffmann TC, Legare F, Simmons MB, McNamara K, McCaffery K, Trevena LJ, Hudson B, Glasziou PP, Del Mar CB. Shared decision making: what do clinicians need to know and why should they bother? Med J Aust. 2014;201(1):35–9.
18. Bruera E, Sweeney C, Calder K, Palmer L, Benisch-Tolley S. Patient preferences versus physician perceptions of treatment decisions in cancer care. J Clin Oncol. 2001;19(11):2883–5.

Chapter 13
Education and Counselling for Person-Centered Care

Alberto Perales, W. James Appleyard, Juan E. Mezzich, and Eduardo Ticona

---

A. Perales (✉)
Institute of Ethics in Health, School of Medicine, San Marcos National University, Lima, Peru

W. J. Appleyard
Presidency 2013–2017, International College of Person Centered Medicine,
New York, NY, USA

Presidency 2003–2004, World Medical Association, Ferney-Voltaire, France

St George's University School of Medicine, Grenada, Grenada

Kent and Canterbury Hospital, Canterbury, UK

J. E. Mezzich
Presidency 2009–2013, International College of Person-Centered Medicine,
New York, NY, USA

Presidency 2005–2008, World Psychiatric Association, Geneva, Switzerland

Division of Psychiatric Epidemiology and International Center for Mental Health, Icahn School of Medicine at Mount Sinai, New York, NY, USA

Hipolito Unanue Professor of Person Centered Medicine, San Fernando School of Medicine, San Marcos National University, Lima, Peru

Professor of Epidemiology, Graduate School of Public Health and Professor of Psychiatry, School of Medicine, University of Pittsburgh, Pennsylvania, PA, USA

Department of Psychiatry and Behavioral Sciences, Stanford University School of Medicine, Stanford, CA, USA

E. Ticona
"Dos de Mayo" National Hospital, San Marcos University (UNMSM), Lima, Peru

Infectious and Tropical Diseases, San Marcos National University, Lima, Peru

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_13

13.1 Introduction

13.1.1 Basic Definitions

Education can be thought of as the transmission of a society's *ethos* (habits, tradition, morals and values), and accumulated knowledge to guide their members in internalizing its culture, shaping their behavior towards responsible citizenship, and directing them into their eventual role in society (https://www.britannica.com/topic/education).

Person-centered Health Education means to instruct and guide a sick person to learn how to become a better partner to collaborate with his/her doctor in a joint effort to overcome his/her illness, palliate suffering and take responsibility on his own care.

Person-Centered Health Counselling is a dialectic interaction of opinions between two persons, one in need of being helped on account of health problems, the patient, and the other, responsible and well trained in medical sciences and human values, the doctor. Both will help each other through deliberation from which judgements are made and advice given for an agreed direction of thought and action. Counselling starts with the identification of the 'wellbeing problems' that have been presented, whether it be in any, all or some of the areas of health, social relationships, psychological, emotional or reaction to cultural beliefs or current social mores as Cloninger and Cloninger [1] stated.

Mezzich et al. [2, 3] identified eight PCM's key features: ethical commitment, cultural awareness and responsiveness, holistic framework, relational focus, individualized care, common ground for collaborative diagnosis and treatment, people-centered integrated health services, and person-centered education and research. From those eight distinctive elements, Education and Counselling in Person-centered Medicine, base their interventions on the first six.

As Kumagai [4] states, "At its core, medicine is a type of applied humanism, that is, the application of science in recognition of human values and in the service of human needs". And humanism in medicine is, according to Branch et al. [5] "the physician's attitudes and actions that demonstrate interest in, and respect for, the patient and that address the patient's concerns and values." .

13.1.2 Disease and the Subjective Reaction to Disease (Psychological or Spiritual "Aching" or "Distress")

While *disease* is a pathological condition that impairs normal body functions and has measurable signs and symptoms, we should highlight an important characteristic of human illness: the subjective psychological and spiritual suffering that it causes in the patient and also in the family. This has been recognized in the anthropological literature as "*distress" referring* to the idiosyncratic manifestations or personal subjective reactions to an illness process. The important point here is that this reaction nurtures itself not only from the objective physical ailment but also from the psychological and cultural interpretation of what the illness means to a particular individual or cultural group as Seguin [6] and Delgado [7] asserted. Personal reactions in this sense would be of infinite variety.

In Russian medicine, a similar concept was developed by Vygotsky, namely *the patient's subjective pattern of disease*, covering a whole set of the patient's subjective ideas about his/her disease, cited by Mezzich et al. [8]. These authors describe that "The term was introduced into the scientific vocabulary in 1935 by the Russian clinician Roman Luria, the father of Alexander Luria, who was the founder of neuropsychology…He defined the term as follows: The subjective pattern of disease is all that the patient experiences and suffers, the whole set of his/her sensations, not only local painful ones, but referring to the general state of health, the introspection, the notion of disease and its causes—the interior universe of the patient, which embraces intricate combinations of perception and sensation, emotions, affects, conflicts, mental experience and traumas". Later on, clinical-psychological studies carried out by Russian researchers revealed that the subjective pattern of disease is a complex structure, comprising at least four levels: (1) Sensations. (2) Emotional, including the emotional reaction to diverse symptoms, to disease as a whole and its consequences. (3) Cognitive, which includes the patient's awareness of the disease, its conception, causes, and after-effects. (4) Motivational-personality, which is affected by the attitude of patients to their diseases and to imminent changes in their way of life.

13.2 Education and Counselling in PCM Clinical Practice

Two of the core components of the duties of physicians as doctors are to educate those who seek their professional services as patients, and to counsel them so that they are able to improve and sustain their wellbeing. This can only be fully achieved within a professional relationship of service to an individual patient, whom the physician recognises as a *person* and where the clinical relationship is based on trust [9]. Confidence in such a relationship grows from the knowledge and skills that the physician is able to apply within a trusted ethical framework. Following the Hippocratic tradition, the World Medical Association re-established physicians' ethical 'contract' with individuals and communities after World War II with its Declaration of Geneva and its subsequent associated Statements [10, 11]. The duty of care to the individual with respect for the autonomy of each patient is central.

In this clinical practice perspective, Education and Counselling in Person-centered Medicine mean to establish a doctor-patient trusting therapeutic alliance that would allow, step by step, to inform and train the latter in a new cooperative health role, switching his or her attitude from a passive one onto an active partnership to share—as much as the clinical condition would permit with his or her needs—and clearly identify the responsibility for their health care between the professional and their patient. This patient's doctor 'alliance' is the foundation for a physician's own education as patients form a major part of a doctors continuing education throughout their undergraduate, post graduate and lifelong learning in the clinic, within hospital practice and in the community. As *Sir William Osler wrote: 'for the junior student in medicine and surgery, it is a safe rule to have no teaching without a patient for a text, and the best teaching is that taught by the patient himself'* [12].

Patients share their experience face to face with students and doctors and allow access to their paper based or electronic record for a detailed case review. Indeed, experienced patients may become involved in teaching and/or evaluating students and as equal partner in student education, evaluation and curriculum development.

When meeting a patient during a consultation, a good Person-centered medical practitioner would need to make two equally important diagnoses: First, to elucidate the disease causing the health problem; and second, to clarify and understand the *subjective pattern of disease* (*distress*) causing the person's suffering. For example, in two patients from different cultural background, disease diagnosis could be the same, (myocardial infarction, for instance), leading to likely receive similar pharmacologic therapy; while, the *subjective pattern of disease* (*distress*) diagnosis might probably be different: one patient could react with mild anxiety, fearing premature death but trusting that his or her young age would help overcome the problem; while the other might be depressed and severely anxious, not only on account of his or her possible life's ending but, for being in charge of grandchildren after a son's death. These different human needs should lead to diverse educational and counselling approaches.

In this respect, Mezzich et al. [2, 3] have recently pointed out that person centered medicine should go beyond the individualization of care and respect for patients' rights, as it has higher and wider aspirations. These include the recognition of the individual subjectivity of the whole person of the patient beyond what characterizes his or her illness or the status or role of patient. The inner world of a patient in his particular situation of suffering and dependence caused by illness needs to be unfolded. These subjective dimensions are accessed through what the patient and his/her careers say in words or show in acting, as long as these words or acts can trigger in the professionals enough empathy to approach the patient's subjective feelings to which these expressions are related. The shared expression of empathy has in turn a positive effect on the physician and a reason for Doctors to receive positive feelings from contact with their patients.

It has become clear that current models of health care are not fit for the future and that they are unsustainable in both economic and humanistic terms. There is a pressing need, therefore, articulated increasingly by patients themselves, to move away from impersonal, fragmented and decontextualized systems of healthcare towards personalised, integrated and contextualised models of clinical practice [13].

13.2.1 Profile of the Patient as a Person

A proper profile of each person needs to be obtained during the initial and any follow-up consultation. This enables a growing understanding of the individual patient upon which a developing education and counselling programme can be based, as stated by Miles and Mezzich [13].

A person-centered integrative diagnosis aims puts into practice the vision of person-centered medicine affirming the whole person of the patient in context as the center of clinical care and health promotion at the individual and community levels. It integrates three main domains each of which addresses both ill health and positive aspects of health.

The first domain is the assessment of health status (ill health and positive aspects of health or well-being). The second domain includes contributors to health, both risk factors and protective factors. The third domain includes health experience and values.

Patients seeking medical help should be greeted initially respectfully by their formal name according to their age and sex. The physician must demonstrate his or her attributes of listening, empathy and compassion in a non-judgemental way.

A personal portrait may be constructed using the following outline:

- Full name, age and sex
- A list of medical and related problems, including a summary of the main presenting symptoms and signs.
- Educational achievements
- Employment
- The family structures
- The social environment such as urban/country housing
- Local culture
- Spirituality
- Religion
- Communications

Additional elements particularly with regard to growth and development need to be incorporated concerning children's needs [14].

With regard to the communication environment, there is a variety of sources for health-related information that is available to individuals and some that may have been targeted at them. These include:

- Family and friends
- Newspapers
- Magazines
- Popular Internet sites
- Specialist Internet sites
- Charities
- Support networks
- Health professionals
- Complementary health providers

It is clearly important to assess and respect the relative importance and impact of these influences. Bearing in mind the emerging picture, realistic *educational aims* need to be established in partnership with the individual patient. There may be some immediate steps to be taken and other objectives planned over a period of time, but always in context.

Once each problem has been identified, a greater shared understanding will be gained through education and then a goal set from what the individual wants to happen. Motivation is necessary to create the will to make the necessary changes, particularly in lifestyle. The possible options available to reach the goal need to be explored with their relative risks and their advantages and disadvantages in each of the key areas of the individual's 'profile'.

What ‘fits’ and ‘feels best’ may emerge. Steps can then be designed to see exactly what is necessary to achieve the best resolution of each of the outstanding problems within the general context of the individual. Once set on this agreed path through shared decision making, progress needs to be recognised and celebrated to encourage each person on their unique journey in improving their health and wellbeing.

13.3 The General Health Educational Process

The health educational process evolves with an *explanation* of the problems brought by the patient and their likely causes to enable their *understanding*. An action plan can then be developed to include any necessary investigations, medical or surgical interventions and the risks involved. Through this process greater confidence will develop to *empower* the individual on their therapeutic journey, enabling greater self-management and self-care.

According to Colom and Vieta [15] health education (they name it, psycho-education) aims to teach patients how to understand and deal with their diseases in the best way, to tolerate how to live with it, and to prevent its negative consequences. Besides, the patient would better comprehend the logic of their treatments and the importance of therapeutic adherence to prevent worsening or relapses.

A health education program, based on scientific evidence, is of absolute need in medical chronic diseases, particularly, in mental disorders.

Health professionals should comprehend that this part of their job is not only because of beneficence but to fulfill patient’s human rights, their rights to be well informed to take their best decisions on their own behalf. A good program should not only deal with illness but also with life style trying to identify those bad habits that favor the disease in order to be changed by others to favor health and wellbeing.

Colom and Vieta [15] point out the benefits of health education for the patient’s integral treatment:

- Improving and reinforcing the therapeutic alliance
- Favoring pharmacologic compliance
- Supporting patient’s autonomy to comprehend and demand whatever he/she feels necessary or convenient
- Understanding how to work as a principal actor of the health team in his/her case.
- Overcoming the verticality of doctor-patient relationship switching to an horizontal one not only with the doctor but also with any member of the health team
- Changing attitude from a passive and demanding one to a collaborative and responsible one.

Frequently, informing the patient about the disease is not a cause of anxiety. On the contrary, this quite often calms down his worries and fears, empowering him or her to face the real health situation…when the patient *knows* what the doctor *knows* about his illness, he would have an opportunity for better collaboration, correcting or improving the health problem information with his own data, and to discover his habits and life style that favor the illness as well as to learn how to counteract them.

Disease and illness always generate a feeling of solitude and suffering in human beings. Emotional support from family and health team's members are of basic importance

In all this process family and health team's support are important elements to overcome the solitude and suffering produced by the disease and the illness.

13.3.1 Illustratively Understanding the Patient in His Disease Process to Obtain His Collaboration

The person is the most valuable being in our society and for physicians, such persons become an existential reason in situation of health or illness.

Medical vocation leads physicians to understand human illness, not only from a scientific perspective but also to account for the patient's psychological suffering. Illness proves how fragile and vulnerable we all are [16]. On becoming ill human beings will come to physicians seeking for help, trusting that they will get them back to health. Actually, the help they look for is of a comprehensive nature, searching not only for physical recovery but also to regain their self-confidence, autonomy, abilities to relate to others, so that they re-integrate themselves into society.

Medicine is a profession that sometimes cures, many times cares but always comforts. Physicians may be experts in scientific medicine, but don't always know how to reach the depth of the patient's feelings to help them in his psychological, emotional and spiritual needs.

This is why medical doctors need to prepare themselves to reach the patient's feelings accepting his autonomy and promoting the recovery of his abilities [17]. If physicians are able to understand the patient's psyche, his/her emotions and his/her spirituality, they will be in a better position to suggest alternatives and better guidance.

Even if the patient understands illness and the importance of following a proper treatment, doctors always need to understand their "cultural world" and network, otherwise they may run the risk of contributing to a poor patient's motivation for treatment.

Even in two patients belonging to the same cultural context, and sharing the same diagnosis, one can notice some differences in their illness due to several factors, such as age or family situation. For instance, if one of them is a health professional in comparison to one who is not. A religious patient would show different characteristics from another who is not. This issue would become more complex if the patient and the doctor come from different cultural backgrounds.

Medical care in health services today, for various reasons, is usually limited to just a short clinical interview and a given prescription. From a legal or health insurance point of view this form of health service may be considered correct although quite distant from a proper professional one. Person Centered Medicine adds values and proposes that the processes, diagnosis and therapy should be shared with the professional team, the patient and his family. Consequently, this will ensure the correct collaboration of the patient and family to achieve the best clinical results as a fundamental variable [18, 19].

Frequently, when a case is not going well, doctors usually assume the patient is not complying with the therapeutic recommendations, the problem tending to be thought of as due to the patient themselves [20]. Actually, most often than not, the patient has not been offered the opportunity to understand why are they ill, what their illness is due to, and how the medication given is going to help them. Probably, the impact of the medical office setting, and the omnipotent presence of the doctor may furnish enough motivation to get him into an initial compliance, but as the patient moves away from the office, after few days their personal conflicts would dominate the scene, causing a negative impact on their motivation to comply with the medical treatment. As a conclusion, during the medical interview at outpatient clinics, both the doctor and the patient may participate in a 'dialogue of the deaf', reducing the percentage of patients that will comply with their treatments correctly. As a consequence, only few of them will regain health, although they have supposedly received a correct medical care.

On the other hand, chronic diseases often cause psychological problems due to their long duration, which more often than not interfere with a normal family and social interaction. These kinds of patients have hard time complying with their treatments, especially when they are aware of the slow or negative progress in its evolution [21]. Besides, in Peru, chronic diseases such as tuberculosis or HIV infection, have different connotations. TBC is stigmatized by both the affected person and the people around him. It usually affects people of low socioeconomic class. The treatment cost worsens the financial situation on account of that the family emotional situation is further affected with risk of mental health secondary problems such as Depression, Anxiety Disorders or family violence. If the physician fails to manage both, the clinical and social situation, the risk that the patient wouldn't comply the treatment increases.

The patient's autonomy becomes an important issue during the illness process. Physicians must respect it and to build together the healing environment, in order to reach the end of the process, with full reintegration of the person in his society (affective circle and/or work activities). On the contrary, with patients that have finished their treatment under unfavorable conditions, and have been left with some sequelae, they need encouragement to accept their new reality and search for a new role in society to assume his activities and continue his life.

13.3.2 Illustrative Patient's Collaboration on His Own Diagnosis and Treatment Formulation

13.3.2.1 On His Diagnosis

In spite of the patient's and doctor's interest to do so, it is not always possible to achieve a diagnosis in the first interview. Most often, we need to request some further examination and investigations to confirm or eliminate some diagnostic hypothesis.

During this diagnostic period, the patient could become impatient and decide to change their doctor to get an immediate response to their ailments. Many times, he or she doesn't show up to the second visit; sometimes on account of working difficulties interfering, or at other times, because they may have adapted to live with their symptoms or have gone on self-medication.

This is why, it is convenient to explain to a patient in the first interview, that the making a diagnosis is a process, which begins with a medical evaluation, continues with auxiliary examinations and a thorough analysis of the findings. In complex situations, other colleagues' opinions may be needed through inter-consultations. A precise diagnosis is the way to recovery. To succeed in this important task time must be offered to the patient, explaining, in the best way possible, what is happening and how he or she can help in this endeavor. We must always remember that a medical diagnosis is a valuable task depending mainly on two actors: The Patient and the Doctor.

13.3.2.2 On His Therapy

The best way to help the patient to become a "better partner" is, (*i*) To reinforce their disease knowledge, explaining to them the appropriate medical information in as simple as possible way, and probing how much they have understood. (*ii*) To make them comprehend that illness is a process which affects human beings mainly on account of our vulnerabilities. That it is not due to god's punishment or bad luck. (*iii*) That they need to take good care of themselves and follow closely the therapeutic indications to help in their recovery. (*iv*) That tuberculosis is an evolving process which has to be cured or controlled, otherwise its advance will seriously interfere with their activities and eventually kill them. In some cases, its evolution is so slow that its progression may not be apparent to the patient, during a good period of time, without symptoms, only to see, after being diagnosed it is probably a bit late, (*v*) The patient's habits need to be checked, since some or many of them predispose to the disease. After identification of risky habits even accepting how hard it is, attempts should be made to change them knowing it is the basis to achieve good progress, (*vi*) It is necessary to reinforce therapy motivation explaining the need to adhere to an agreed therapy. Once more, the described process takes such amount of time and personal dedication that many doctors would not be able to meet or do not want to.

Undoubtedly "*v* and *vi* items", are those the patient needs to comply with. By now this may prove to be very difficult.

According to the illness under treatment, a patient's life style may be an important variable in its causality, so doctors must try to greatly influence them; for example, improving eating habits, leaving smoking. But in other cases, there may not be much time to act upon them, or get a change in a short time, as the illness demands. An example of this is the consumption of drugs or alcohol in a patient with tuberculosis or HIV/AIDS. In these cases, the help of other specialists will be needed

Taking medicines for a long time is not an easy matter either, especially in chronic diseases. As an example, the patient may need them they must alter their way of life, adapt their habitual schedules, and tolerate the medication's adverse effects. Symptoms that seem relatively minor such as constipation, some sleep disorder, or decreased libido, are important to any person who knows that just stopping taking the medication these side effects would disappear. Needless to say, the difficulties of adherence are greater with more severe adverse events that affect significantly daily life.

Adverse events are more frequent in older people, in whom physicians need to perform a careful evaluation of the most appropriate and convenient doses. Some patients of this age group leave the office after their first visit understandably worried about how their bodies would react to the given medication, and will be tempted initially to modify the prescription. This is why the patient should be taught in advance over their possible early reactions to the treatment, reassured about the short period of adaptation to it and end their first clinical interview convinced that the doctor has prescribed the most appropriate medicine, and that, they can contact his/her if needed. Psychological support over the telephone is many times enough to handle the problem. However, once more, the doctor needs time to fulfill this task.

In general, adverse effects, that impact physically and psychologically, are important factors to understand the non-compliance or non-adherence of patients to treatment. Unfortunately, many doctors tend to give vertical orders instead of horizontal ones respecting patient's autonomy. Besides, within the context of health programs, most often than not, the health team tries to impose the established therapeutic protocol on people insisting on compliance with the therapeutic scheme. Many times these difficulties have been resolved by adopting a kind and understanding attitude and explaining the reasons and advantages of following the protocol. This sort of cases illustrates very well what a healthy person-centered approach is. It is not the fault of the patient or health personnel; it is the fault of our health system.

Poverty is another important factor to be considered. Patients could be quite conscious of their disease situation and consequences, but they are the breadwinners of their family and depend on the daily income they generate to cover the family. They would claim lack of time to meet their hospital visits or that their time possibilities can't match the hospital attention schedule to follow his therapy. Here a doctor's individual action is of minimal impact. A multidisciplinary team approach, specially trained to evaluate social and psychological conditions is needed, one that would allow generation of individual strategies of management. In the case of tuberculosis, a public health problem, the patient should be offered the possibility of institutional isolation in suitable places to guarantee feeding conditions, healthiness, adequate treatment and non-transmissibility prevention of the infectious agent to the community. It is recommended that this treatment be on voluntary basis, however, in exceptional cases it could be through legal provisions [22].

13.4 Practical Implications for the Implementation of Person-Centered Care

Empowering the patient and getting his/her collaboration to optimize the results of treatment requires not only instruction about his disease but, specifically, motivation to work in therapeutic alliance with the doctor in true teamwork.

However, there is a difference between *person-centered doctors* and other "medical practitioners". The first one, in addition to scientific and professional competence, is also a thorough person who experiences a call for solidarity based on service vocation when facing a human being.

To make this possibility real, the medical student must watch his/her own human development on becoming a person; searching to be a responsible and fully moral human being.

Quite often, medical education does not include among its objectives the achievement of such human development in its students, leaving it free to spontaneous growth. From this perspective, the medical school is often unaware that many students begin their medical studies suffering of various problems, both in their own personal development and in their mental health [23]. Furthermore, the medical institution does not warn them about such needs or guide them to overcome them. In this way, and this is regrettable, such problems are usually solved randomly due to fortuitous circumstances, missing a precious opportunity for a helpful intervention during the period of university studies. If intervening in time, difficulties in human relations with patients when practicing the profession could be avoided. Person-centered medicine can only be properly practiced by physicians who, in their moral development, have reached the level of **persons**.

During COVID-19 pandemia, examples of two moral levels of medical practice have been observed: heroism and death in the fulfillment of their duty of care, on the one hand; and cases that are located in the opposite negative extreme. This observation seems to verify the thesis that *"no one can give what they do not have"* (if you are not a person, you can't treat others as persons). In other words a group that in addition to its knowledge relies on its medical vocation to exercise a scientifically correct and ethically humanized professional practice, centered on the person; and, another group that, through a technological and impersonal medical practice, applies its knowledge without human commitment.

13.4.1 How to Exercise in Practice a Medical Act Centered on the Person

Michel Balint [24] postulated that the best medicine a patient can receive corresponds to the personality and personal manner of his own treating physician.

Gregorio Marañón [25], the wise Spanish doctor, declared that: *"One is only a worthily doctor with the idea, stuck in the heart, that we work with imperfect instruments and with insecurely useful remedies; but with the certain awareness that even where knowledge cannot reach, love always does"*

And, Carlos Alberto Seguin [26] coined the concept of *Therapeutic Eros*, defining it as: *"a disinterested, non-possessive, non-imperative love, free of sexual implications, that unites the doctor with the patient in a beneficial and flourishing quality"*. To which one may add that the physician acts out of moral responsibility, to assist others, at the cost of various personal risks even in his/her own life.

The royal way to empower the patient, and achieve an alliance with the doctor to work as a team, is the human encounter that constitutes the Person-Centered Medical Act, not exclusively related to the disease. In such a situation, the doctor, through the unconditional love that he/she experiences for his patient, manages to become a significant other who will accompany him and guide him/her in the patient's fight, not only with illness but against the various causes of suffering.

In concrete practice, we must repeat, the person-centered medical act is, above all, an intimate and personal dialogue; a human encounter between two beings: one, affected in health and suffering from an ailment, and the other, professionally trained to take care of that person.

In that first meeting, the doctor should offer a cordial and respectful greeting, creating an atmosphere of human warmth and confidentiality. Knowing how to listen is the art made praxis in this encounter. Focusing attention on the patient's complaints is essential, asking pertinent questions to fully understand the patient's illness and disease and also the influence of their socio-economic and cultural environment. The doctor should always maintain a positive and optimistic tone, ending the encounter by summarizing to the patient what is understood as well as explaining the diagnostic and therapeutic work plan that requires the collaborative effort of both. The farewell will be affectionate, specifying the date of the next meeting, and looking directly into the eyes of the patient, transmit reinforcing hope.

13.5 Conclusions

Both health and disease are existential situations that involve the whole being. In any of them, human beings react as a totality.

Science, technology and ethics must always be united. The advance of knowledge reaches its fullest value when it broadens the moral horizons, that is, when it is directed to achieve the fullness of human experience.

PCM argues for a professional practice based on scientific research and technology but, at the same time, conscious that we are treating human beings and not fixing broken machines.

In such a conceptual framework, clinical care should be oriented to assessing and adequately managing three specific dimensions of any patient's health problem: (a) the biological one, the body and its physical illness, (b) the subjective pattern of disease (psychological and spiritual "aching") with its fears, concerns and, expectations; and (c) the socio-cultural-spiritual one, with all its "concepts and mythology of disease", values and faiths established in any culture.

To control disease and succeed in rescuing health, involves a joint effort among doctor, patient ,and family. On that endeavor, we must assume the responsibility of educating and counselling our patients, teaching them how to assume an active, collaborative and responsible role, contributing positively on the fight for their health. In other words, to educate and counsel them to become better partners for health.

Acknowledgements and Disclosures The authors report no conflicts of interest in the preparation of this manuscript.

References

1. Cloninger CE, Cloninger KM. Person centered therapeutics. Int J Pers Cent Med. 2011;1(1):43–5.
2. Mezzich JE, Kirisci L, Salloum IM, Trivedi JK, Kar SK, Adams N, Wallcraft J. Systematic conceptualization of person centered medicine and development and validation of a person-centered care index. Int J Pers Cent Med. 2016;6:219–47.
3. Mezzich JE, Appleyard J, Botbol M, Ghebrehiwet T, Groves J, Salloum IM, van Dulmen S. EDITORIAL INTRODUCTION. Communication and relationships in person centered medicine. Int J Pers Cent Med. 2016;6(1):1–6.
4. Kumagai AK. Conceptual framework for the use of illness narratives in medical education. Acad Med. 2008;83:653–8.
5. Branch WT Jr, Kern D, Haidet P, et al. The patient-physician relationship. Teaching the human dimensions of care in clinical settings. JAMA. 2001;286:1067–74.
6. Seguin CA. La enfermedad, el enfermo y el médico. Madrid: Ediciones Pirámide, S.A; 1982.
7. Delgado H. El Médico, la Medicina y el Alma. Lima: Ediciones Universidad Peruana Cayetano Heredia; 1992.
8. Mezzich JE, Zinchenko YP, Krasnov VN, Pervichko EI, Kulygina MA. Person-centered approaches in medicine: clinical tasks, psychological paradigms, and the postnonclassical perspective. Psychol Russ State Art. 2013;6(1):95–109. https://doi.org/10.11621/pir.2013.0109. http://psychologyinrussia.com.
9. International Association of Medical Colleges. The essence of medical professionalism. 2004. www.iaomc.org/ec.htm.
10. WMA International Code of Medical Ethics. 2006. www.wma.net/publications.
11. WMA Declaration of Geneva 1948 Revised. 2006. www.wma.net/publications.
12. Osler W. Aequinamitas with other addresses. Philadelphia: Blakiston's Son & Co.; 1922. In: "Without a patient for a text": medical education in the age of COVID. Posted by steveserver on May 15, 2020. https://medicalhealthhumanities.com/2020/05/15/without-a-patient-for-a-text-medical-education-in-the-age-of-covid/. Accessed 15 Mar 2021.
13. Miles A, Mezzich JE. The care of the patient and the soul of the clinic: person-centered medicine as an emergent model of modern clinical practice. Int J Pers Cent Med. 2011;1(2):207–22.
14. Appleyard WJ. A personal approach to person centered paediatric care. J Eval Clin Pract. 2011;17(2):376–8.
15. Colom F, Vieta E. Manual de psicoeducación para el trastorno bipolar. Barcelona: Ars Medica; 2004.
16. Bisbee Cynthia C. Patient education in psychiatric illness. Orthomol Psychiatry. 1979;8(4):239–47.
17. Perales A, Mendoza A, Sánchez E. Vocación médica; necesidad de su estudio científico. Ann Fac Med. 2013;74(2):133–8.
18. Mendoza A. La relación médico paciente: consideraciones bioéticas. Rev Peru Ginecol y Obstet. 2017;63(4):555–64.
19. Perales A. Medicina Centrada en la Persona: del Concepto a la Acción. Rev Peru Med Exp Salud Publica. 2016;33(4):605–6.
20. Fuentes MSC, Albino ZR. El Método Clínico Centrado en la Persona y su Aplicación Primaria de Salud. Rev Peru Med Exp Salud Publica. 2016;33(4):780–4.

21. Tavares NUL, Bertoldi AD, Mengue SS, Arrais PSD, Luiza VL, Oliveira MA, et al. Factors associated with low adherence to medicine treatment for chronic diseases in brazil. Rev Saude Publica. 2016;50:10s.
22. Ticona E, Vásquez R. Manejo Institucionalizado Del Paciente Con Tuberculosis. Rev Peru Med Exp Salud Publica. 2009;26(3):358–63.
23. Perales A, Izaguirre M, Sánchez E, Barahona L, Martina M, Amemiya I, et al. Salud mental en estudiantes de pregrado de la Facultad de Medicina de la Universidad Nacional Mayor de San Marcos. An Fac Med. 2019;80(4):443–50. https://doi.org/10.15381/anales.v80i4.17142.
24. Balint M. The doctor, his patient and the illness. London: Pitman Medical Publishing; 1957.
25. Gregorio M. Prólogo a la Antología de trabajos científicos de A. García Tapia. Madrid; 1945. Citado por Pedro Lain Entralgo. Marañón y la relación entre el médico y el enfermo. Centro de Investigaciones de Historia de la Medicina de la Universidad de Chile. 1962. p. 23.
26. Seguin CA. De la Psiquiatría y la vocación psiquiátrica. Cap.1. en Perales A, Zambrano M, Vásquez-Caicedo G, Mendoza A, editors. Manual de Psiquiatría “Humberto Rotondo”. Lima: Universidad Nacional Mayor de San Marcos, Facultad de Medicina; 1991.

Chapter 14
Narrative Medicine

Laurence J. Kirmayer, Ana Gómez-Carrillo, Ekaterina Sukhanova, and Eduardo Garrido

14.1 Introduction

Narrative medicine is a recent innovation in clinical training, research, and practice that recognizes the human capacity to tell stories as central to health care. People are storytellers, and patients' stories are key to understanding their health care problems, predicaments and concerns and to negotiating effective treatment. As self-interpreting beings, the ways we narrate our lives are crucial determinants of our own illness experience and behavior as well as the responses of others. Patients present their symptoms and suffering through stories. Physicians too use the vehicle of narrative to organize their thinking, engage in clinical conversations with patients and colleagues, provide explanations, and frame interventions. Narrative reasoning is central to clinical practice and stories are the primary way that meaning is attached to affliction by both patients and physicians [1, 2].

The narrative turn in medicine has been spurred by concerns that biomedicine gives insufficient attention to human subjectivity, treating the person's relationship to their body much as an auto mechanic might treat the owner of a car. Patients' accounts of their illness may then be heard only in terms of the diagnostic task of recognizing symptoms and signs of disease, ignoring the personal meanings and social contexts of illness that are crucial to understand and respond effectively to

---

L. J. Kirmayer (✉) · A. Gómez-Carrillo
Division of Social and Transcultural Psychiatry, McGill University, Montreal, QC, Canada
e-mail: Laurence.kirmayer@mcgill.ca; ana.gomez-carrillo@mcgill.ca

E. Sukhanova
University Associate Dean for Academic Affairs, City University of New York,
New York, NY, USA

E. Garrido
Center for Primary Medicine, Universidad Tecnologica de los Andes,
Abancay, Apurimac, Peru

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_14

health problems. Attention to patients' stories provides insights into their experience and lifeworld. Focusing on the process of narration allows us to recognize patients as actively engaged in understanding and coping with their afflictions through meaning-making. This recognition can lead to new ways of listening in the clinical encounter and to new interventions that mobilize narrative resources to support patients' coping and resilience [2]. A growing body of work on humanities in medicine suggests the power of literature, including illness narratives, as well as fiction and poetry, to promote clinical understanding and greater empathy for patients' illness experience among health trainees and practitioners [3, 4]. Educators and practitioners of narrative medicine aim to mobilize the study of narrative as a tool for clinical care as well as research and training [2, 5, 6]. In this chapter, we outline these innovations and draw out their relevance to person-centered medicine.

14.2 What Is Narrative?

A narrative is a story, most often conveyed in words, of something that happened or could happen [7]. Narratives are basic forms of communication used to convey information, but they also serve to organize experience, thought and action. When communicated to others, narratives evoke, create or convey meaning by locating experiences and events both within the framework of the story, which invokes particular scenes or events, and in relation to the larger world, which provides a tacit backdrop to the story. This larger social world provides crucial background information for making sense of the story and imbues what is said—and not said—with particular significance. Narratives portray a scenario, setting or situation and a causal trajectory, sequence or other temporal order, with past origins and future projections of what may happen. Our experience of the world is thus mediated by narratives—both those we acquire through cultural learning over the course of development and those we construct for ourselves in everyday efforts to communicate.

Narratives are ubiquitous in human life and central to how we come to know ourselves, plan our actions, and explain ourselves to each other. Indeed, philosophers and psychologists have argued that narrative is central to our sense of self [8–11]. We weave our experience into an autobiographical account and this, in turn, shapes our memories, goals, and expectations. Narratives are also crucial in the experience of health and illness, framing symptoms and giving them meaning, guiding coping, help-seeking, and the response to interventions. In clinical settings, narratives serve as the basis for giving an account of our current concerns and our personal and medical history as well as the vehicle through which we convey treatment plans and interventions; narrative is both *discourse* and *praxis*, ways of talking and of taking action [12].

Narratives are learned through social practices of conveying information and experience, explaining perspectives, organizing memory, justifying actions, positioning oneself, and influencing others [13]. Narrative capacities reflect cognitive and emotional abilities to structure experience in ways that allow diverse styles of reasoning involving temporal, biographical, causal, and thematic structures [14]. Narratives also allow the individual to reframe or contextualize their experience, exercise control of behavior, imagine others' points-of-view, consider new possibilities, and enable the distinctive human capacities for meta-cognition and self-reflection. Further, narrative practices are sociocultural practices: they engage others in cooperative forms of communication, dialogue, and discourse that further extend individual capacities. Narrative content grounds cognition and experience in developmental histories and local worlds of meaning as well as generating new possibilities for thought and action through the "what if" of imagination. Understanding these developmental, social and pragmatic functions of narrative can inform our deliberate use of narrative methods in medicine [15].

14.3 The Relevance of Narrative to Person-Centred Medicine

Narrative medicine is currently used as an umbrella term for a number of approaches that aim to counteract the deficiencies of a strictly biomedical model by borrowing from the humanities and the social sciences to consider the implications for clinical practice of the human capacity for storytelling. As defined by Rita Charon and her colleagues at Columbia University, whose research and advocacy provided one of the initial theoretical frameworks for this emerging field, narrative medicine is "medicine practiced with the narrative competence to recognize, absorb, interpret, and be moved by the stories of illness" ([16], p. vii). A committee of international experts in 2014 offered a further characterization of narrative medicine as "a fundamental tool to acquire, comprehend and integrate the different points of view of all the participants having a role in the illness experience" ([17], p. 8).

Listening to the patient is central to patient-centered medicine [18]. The realization that the patient-clinician encounter is a bidirectional interaction is implicit in George Engel's [19] biopsychosocial approach, which emphasized a framework for an integrative medicine that recognized the importance of patients' experience, behavior, beliefs, and social context. Person-centered medicine aims to realize this vision with new tools and frameworks. Yet with economic pressures, the length of primary care consultations in high income countries is estimated to range from a median of 5 min to a high of 22 min (in Sweden); studies in the U.S.A. and Canada arrive at an estimate of 16–20 min [20]. The result of time constraints may be suboptimal medical care that neglects important aspects of the patient's situation and fails to create an effective clinical alliance. Recognizing the value of patients' stories and developing narrative skills can equip clinicians to push back against these constraints and insist on the time needed to establish and maintain an empathetic connection and elicit vital aspects of patients' health condition and concerns.

Patient autonomy became a central concern in the second half of the twentieth century, while similar social forces gave rise to the learner-centered movement in education, and the importance of a collaborative clinician-patient relationship gained mainstream acceptance. This went along with greater recognition of the importance of subjectivity in medical care [21]. It was in this context that attention to stories emerged as a focus in medical education. However, the emphasis on autonomy reframed the clinical encounter as akin to a customer-provider relationship, undermining the deeper relational foundation of a medical ethics of care [22–24]. Narrative medicine holds the promise of a more thoroughgoing engagement with patients as persons situated in a lifeworld.

The movements to respect patient autonomy and subjectivity coincided with the revision of standards by the Liaison Committee for Medical Education (LCME) of the Association of American Medical Colleges (AAMC), the accrediting agency for U.S. and Canadian medical education programs, to recommend the inclusion of ethical, behavioral and socioeconomic topics relevant to medicine [25], opening the door to greater attention to humanities and social science in medicine.

Narrative medicine can contribute to many of the goals central to person-centered medicine identified by Mezzich et al. [26], particularly in regard to its ethical commitments, holistic framework, cultural awareness and responsiveness, and relational and communication focus. Narrative medicine provides a toolkit for medical education and practice, which can expand the skills of clinicians. Narrative approaches can facilitate patient empowerment, strengthen the clinical relationship, and improve all aspects of care, including assessment, treatment, and rehabilitation.

The 2016 Madrid Declaration on Person-Centered Medical Education and the Goals of Healthcare proposed a number of future directions for the development of this field, asserting the value of traditional humanities in a holistically conceived medical education and calling for further research on the methodologies of incorporating such approaches in medical training with the goal of furthering the objectives of person-centered medicine [27].

14.4 Social Science Approaches to Illness Narratives

The turn to narrative in medicine was also motivated by earlier work in social sciences. The psychiatrist and anthropologist Arthur Kleinman built on the conceptual distinction between "illness" and "disease" [28], to show how attention to patients' illness narratives provided an essential complement to the clinician's models of disease [29, 30]. Social psychologist Eliot Mishler [31, 32] examined the ways in which narrative accounts of the lifeworld emerged or were blocked in clinical encounters. Sociologist Arthur Frank [33] wrote about his own illness experience and the role of narrative in coping with symptoms and mortality, giving meaning to suffering, and instilling hope. This and much other work revealed patients as people actively seeking and elaborating the meaning of symptoms and suffering in an effort to understand and address their health concerns [34]. Acute illness causes discomfort, distress and uncertainty or immediate threat that requires appropriate action. Chronic illness poses questions about how to live with symptoms and disability. In both cases, narrative framing guides individuals' responses as well as the ways they convey their experience and concerns to others. Illness narratives may be malleable, rewritten as a result of the evolution of the disease process, life-experience, and the process of narration itself.

Symptom and illness experience have their origins in physiological processes of the body and the interoceptive mechanisms of the brain and peripheral nervous system. But all sensations are modulated by cognitive schemas, attributions and interpretations shaped by narrative processes of framing and communication by the patient and others in their familial and social world (Fig. 14.1). These narratives reflect individual development and previous symptom and illness experience, as well as cultural models. Narratives about symptoms and illness are always constructed and interpreted in relation to other available stories and narrative templates. For example, in describing a symptom like headaches, patients may refer to their own or others' past experiences, information gleaned from TV or social media, and accounts from biomedical or other healing systems.

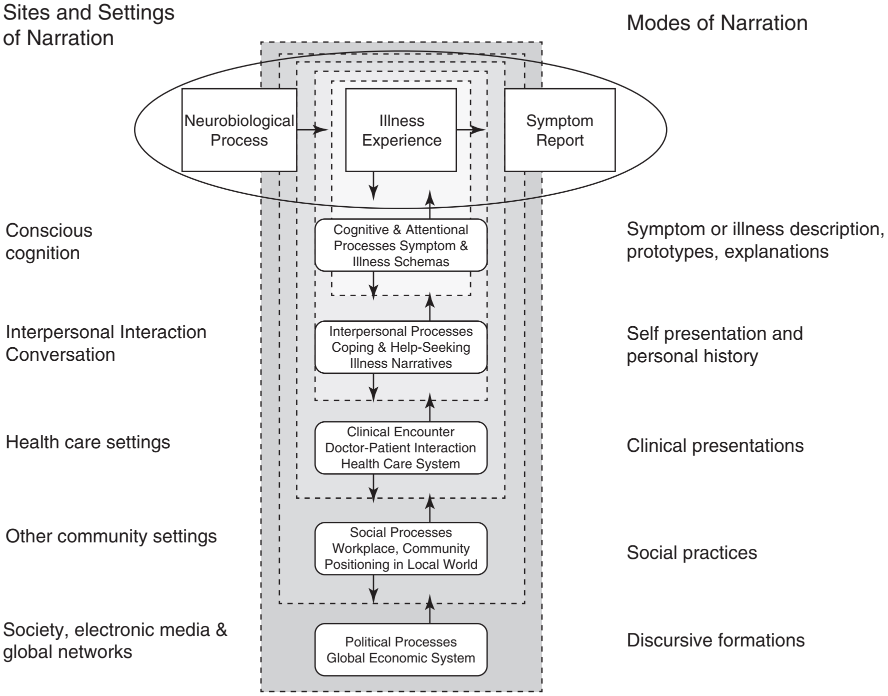


Fig. 14.1 The narrative mediation of illness experience
Illness experience is not simply a reflection of underlying disease processes, bur results from a complex web of events, attitudes, beliefs, actions and interpretations. While the biomedical model of disease focusses on the correspondence between symptoms and signs and underlying pathophysiology, assuming there is a one-to-one correspondence, what is distressing about symptoms and what leads to dysfunction may include cognitive and interpersonal processes that are mediated by narratives. (Adapted from: Kirmayer, L. J. (2008). Culture and the metaphoric mediation of pain. *Transcultural Psychiatry, 45*(2), 318–338 [35])

The dynamic interaction between clinician and patient narratives constitutes a space of potential meanings in which the patient's experience is negotiated. However, there are great asymmetries in power in the doctor-patient relationship that shape the process of narration and that may silence the patient and the voice of the lifeworld. While some of this asymmetry is necessary and intrinsic to the doctor's role as expert [36], total domination of the course of the interview by a narrow technical agenda can lead clinicians to miss crucial information and to fail to engage in the kinds of conversational exchanges essential to building trust and a collaborative relationship important for ethical and effective treatment. Clinical conversations that give patients freedom to position themselves in the discourse rather than having to submit to the dominant medical narrative can allow the person to organize their experience, disclose aspects of their lifeworld, and introduce their most urgent and intimate concerns with profound consequences for diagnostic assessment and treatment options.

The ways that symptoms and suffering are narrated are not only important to communicate distress and guide help-seeking, they can also influence the process of symptom perception and coping, amplifying or dampening the intensity of symptoms, and the emotional response to illness [37, 38]. A substantial body of work suggests that disclosing emotional distress and trauma experiences through narrative can have beneficial effects on health and well-being including physiological function [39–41]. However, it appears that it is not simply open expression or disclosure but the organizing effects of narrative on cognition that mediate these positive effects [42]. Hence, narrative constructions of experience are the explicit focus of clinical interventions in health psychology and psychotherapy, which aim to help the patient (and their family) interpret symptoms and affliction in ways that are not simply biomedically accurate but that reduce anxiety or catastrophizing and promote coping and resilience. Even when doctor-patient communication does not focus explicitly on narrative as intervention, the production and negotiation of alternative narrative accounts is inevitably in play and contributes to illness behavior and clinical outcomes.

14.5 The Limits of Narrative

Narratives are ways of organizing and presenting experience or point of view or interpretation, but they may not always reflect or determine individuals' actual experience and behavior. We can produce narratives as rationalizations or justifications, following prescribed forms of self-presentation, reason-giving, and justification. We may dissimulate or even lie to ourselves, subscribing to a narrative that is at best a half-truth but that portrays us in ways that we like or find advantageous.

Narratives are produced in response to particular contexts and for specific purposes. Although there are general expectations for how we converse that assume we take the other's position into account and provide the necessary background information to make ourselves intelligible [43], the constraints of the clinical interview may prevent crucial information needed to understand the patient's story, leading to misinterpretation and misunderstanding.

Narrative medicine recognizes and respects the person's story as central to their experience and to an ethical and effective clinical encounter. But people vary widely in their ability and propensity to articulate their experience through narrative. Indeed, some critics have claimed that narrative is not important to their sense of self or identity [44]. Certainly, there are aspects of the self that do not reside in stories or autobiographical accounts but in our embodied experiences, habits, routines and social positioning. Moreover, on situations of acute distress, it may be especially difficult to give a detailed or coherent story of the origins or context of our suffering. While patients with chronic or persistent conditions may develop a coherent narrative, it may be formulaic and distant from the complexities of their life situation and lived experience.

For all of these reasons, it is important to focus on narratives as situated and pragmatic efforts at self-organization, presentation and communication and explore their meaning and significance in context. Further, we need to look beyond narrative to see the more fragmentary, metaphoric expressions that capture essential aspects of experience that may not yet be elaborated into a story [45]. Expanding the focus of narrative medicine on stories to consider the broader process of "poiesis" through which metaphors structure symptom experience and behavior can be an important corrective to over-valuing narratives [46].

14.6 Narrative in the Clinical Encounter

Narrative is used by patients not only to tell the history of their present illness and their past personal and medical history, but also to convey life circumstances, predicaments and concerns. Illness narratives influence how symptoms and diseases are experienced and dealt with. The process of narration itself can reshape illness experience as well as the individual's sense of self and personhood [47–49]. Clinical assessment and treatment therefore require understanding and apprehending illness narratives both to grasp patients' experience and to understand how their interpretations are shaping their response.

Constructing an illness narrative serves to domesticate symptoms; the narrative provides a bridge between the unexpected, unusual and disruptive effects and the expected, the usual, or "normal functioning." When symptoms cannot be readily controlled, explained or normalized, they provoke a more extended search for meaning and mastery. The failure to develop a meaningful and reassuring narrative may mark the onset of illness and prompt help-seeking.

To treat the whole person, the clinicians must recognize within the patient's account not only what is relevant to biomedical diagnosis but, equally important, the materials for co-constructing a coherent narrative that organizes the patients' experience to promote agency, adaptation, and recovery. As Fuks et al. [50] note, part of the suffering of illness results from "the absence of a meaningful narrative explanation, an unfulfilled need for a story that makes sense over time" (p. 307). It follows that "the goal of the physician working from a narrative framework is to relieve the mystery of the broken story and its attendant suffering by helping the patient craft a new or amended narrative that can explicate the symptom or sign, provide a plausible causal chain, and begin to demystify the future for both interlocutors" (p. 308).

Narrative meaning is not simply elicited or uncovered by the clinician's inquiry; it is always co-constructed with the patient. The sources of this co-construction include the ideas of patient and clinician but also the larger discursive frameworks and resources available in social context, including family, community, mass media, and other networks and institutions. Meaning is contingent on the field in which it emerges. This includes what Foucault [51] calls the *discursive formation* surrounding a particular utterance, which depends on social and cultural institutions and practices, and, in the clinical context, the symptom and illness explanations, disease models, potential treatments, expected course and outcome. The narrative that emerges reveals what Mikhail Bakhtin [52] called *heteroglossia*, the multiple voices and contexts embedded in every exchange, which provide potential new meanings. In the clinical interview, heteroglossia is reflected in the patient's metaphors, professionals' language, and the emotional significance of images and explanations that the doctor and patient bring to the conversation [46, 53].

Clinicians influence the illness narrative as listeners with their own perspective and life-story, as agenda setters with a mandate and responsibility to provide appropriate medical care, and as authorities in the institutional context in which narrative emerges. Clinicians have both direct and indirect influence on how patients produce and perceive their story [47]. Both clinicians' and patients adjust their narratives in anticipation of and response to the other's account. Clinicians are expected to explain the illness and prescribe effective treatment. Patients are expected to describe their problem in ways that fit diagnostic templates and to clearly report the changes they experience in response to treatment. At the same time, patients may try to be interesting, to capture the doctor's attention, and doctors try to be authoritative to demonstrate their expertise, inspire confidence, and ensure treatment adherence [54]. These stances may help or hinder the process of mutual understanding and co-construction of a healing story. In the process, crucial information may remain unelicited or ignored and patients may feel unheard. In turn, clinicians may be frustrated when their recommendations are not taken up by patients.

A fundamental outcome of a shared narrative is an explanation for symptoms and affliction that is meaningful and useful for both patient and clinician. Constructing a credible explanation for symptoms and illness is one of the basic forms of help provided by biomedicine. Diagnosis is part of a medical narrative that gives meaning and order to the strange and unsettling symptoms of illness, reducing the patient's sense of uncertainty and fear. To accomplish this function of ordering experience, narratives must be jointly developed by patient and clinician and accepted by others in the patient's local world. Even when potentially helpful narratives are discovered by the patient or others in their life, the clinician can play an important role of ratification and legitimation, lending authority to the new account.

If illness narratives are co-constructed, then meaning is created collaboratively through the narrative competencies of patient and physician. “Indeed, if healing is, at least in part, the mending of a broken tale, then care is hindered when the patient’s metaphors have been silenced. Further, if congruence of conceptual models of illness is needed for a strong clinical bond, then the patient’s metaphors have to be not only heard, but also understood and shared. A particular challenge is the unearthing of private or idiosyncratic metaphors that require a serious degree of clinical listening and patience to be comprehended” ([50], p. 304).

14.7 Narrative Methods in Clinical Practice

Although narrative is a part of everyday communication, learning to listen closely to stories to facilitate empathy, derive clinically relevant information, and devise narrative interventions requires specific frameworks. In simple terms, any method that seeks to elicit, engage, understand and intervene through the stories told or imagined by patients or clinicians as part of clinical practice can be viewed as a narrative method**.** The use of knowledge gained through stories to guide clinical interventions requires active listening skill to elicit narratives. Stories emerge not only by one person narrating and another listening attentively but also in the back-and-forth of conversation. In either case, the listener uses background information to create a ‘mental model’ of events as the story unfolds. This process involves filling in the unsaid or implicit through inferences, which depend on a fund of shared knowledge about the body, life experience and social contexts. When this knowledge is not shared, as may occur when patient and clinician have had very different life experiences or come from different cultural backgrounds, the inferential process may be difficult and prone to error, misinterpretation, and misunderstanding.

Narrative methods can be applied to clinical practice in three broad ways: (1) to elicit and understand patients’ accounts of symptoms, illness, and suffering; (2) to more effectively formulate and convey the clinicians’ explanations; and (3) to devise interventions explicitly based on narrative processes.

Table 14.1 lists some methods for eliciting patient illness narratives. These provide ways to inquire into patients’ experience and concerns and allow the space for narrative elaboration. They can be entirely open-ended or structured to explore specific domains of interest or modes of narration. Several of the tools use visual representations of a temporal grid or trajectory which can help to engage the patient in a process of constructing and reflecting on their life history and which may allow some distance, facilitating the discussion of sensitive issues. In addition, the way in which the grid anchors narratives in accounts of life events can reveal important patterns, sequences or turning points. Although conceptually there is a difference between eliciting narratives and intervening through narratives, the process of narrative elicitation constitutes a form of intervention in itself.

Kleinman et al. [30] introduced a simple set of 8 questions that can be used to explore key features of the patients understanding of the illness. When time allows, the clinician can use these as a basis to elicit a more comprehensive illness narrative, with questions and responses that clarify and deepen the account.

The McGill Illness Narrative Interview is a semi-structured protocol for eliciting in-depth narratives centered on specific symptoms or illness experiences [59].

Table 14.1 Methods for eliciting patient narratives

Tool	Method/approach	Domains/content/focus	Applications	Reference
Patient's Explanatory Model Questions	8 flexible, open-ended questions developed for general medical use	Perceived causes of problem, reasons for onset, mechanism, impact, expected treatment, course and outcome	Clinical Assessment Training Research	Kleinman et al. [30]
Life chart Life history grid Self-discovery tapestry	Visual tools for mapping key life-events	Serve as prompt for eliciting life narratives around significant life events, showing temporal patterns, and fostering discussion	Clinical Assessment Intervention Training Research	Anderson and Brown [55] Feldman and Howie [56] Meltzer et al. [57]
Explanatory model interview catalogue (EMIC)	Semi-structured interview, open-ended questions	In-depth exploration of illness explanatory models	Research	Weiss [58]
McGill illness narrative interview (MINI)	Semi-structured interview, symptom focused, open-ended questions Developed as research tool for eliciting symptom experience, illness narratives, and help-seeking	Initial symptom experience (temporal narrative); symptom or illness prototypes from self, others or media; explanatory models (diagnostic labels, causal explanations, expectations for outcome)	Research Training Can be used for qualitative and quantitative data analysis Used in training of medical residents	Groleau et al. [59]
Barts Explanatory Model Inventory (BEMI)	Structured interview	Focus exploration of illness explanation covering illness identity, causes, timeline, consequences, cure/control	Clinical Assessment Research	Rüdell et al. [60]
Clinical ethnographic interview (CEI)	Semi-structured interview supplemented with social network map, body image map, and timeline of illness experience	Components of DSM-IV cultural formulation and social/cultural context of illness	Clinical Assessment Training Research	Arnault and Shimabukuro [61]

Table 14.1 (continued)

Tool	Method/approach	Domains/content/focus	Applications	Reference
Cultural Formulation Interview (DSM-5 CFI)	Semi-structured interview, 16 open-ended questions	Problem definition; causal explanations; social stressors and supports; cultural identity; coping and help-seeking; expectations for care Supplementary modules on explanatory models, level of functioning, social network, psychosocial stressors, spirituality and religion, migration, developmental experiences; care giver experience	Clinical Assessment Training Developed to facilitate assessment of culturally relevant information in psychiatric diagnostic interviews	Lewis-Fernández et al. [62]

Originally developed as a research tool for studies of help-seeking and health care utilization, the MINI has been adapted for clinical training in family medicine, internal medicine, and psychiatry to help trainees gain awareness of the patient's perspective and the social contexts of illness [63–65].

Elements of Kleinman's explanatory model questions and the MINI were incorporated in the DSM-5 Cultural Formulation Interview, a brief semi-structured interview for eliciting patients' illness models [66]. The CFI is based on the DSM-5 Outline for Cultural Formulation, which includes clinically relevant aspects of the person's cultural identity, illness explanations, social stressors and supports, and expectations for care. The core CFI has 16-items and can be administered in about 20 min. A parallel version can be used with family members or other key informants who can provide added contextual information. Supplementary modules are available to guide inquiry into specific domains or life contexts [62]. Although developed for psychiatric diagnostic assessment, the CFI is widely applicable to medical practice [67].

While the information elicited through these methods can be used to guide diagnostic assessment, narrative medicine aims for a broader view of patients' experience. Narrative practices are undergirded by several key concepts:

- **Narrative knowledge** refers to the meaning and significance of stories elaborated through cognitive, symbolic and affective processes. In clinical practice, the ability to use narrative knowledge allows clinicians to translate general knowledge of disease into explanations specific to individual patients in their lifeworld.
- **Narrative understanding** is the process of developing insight into how events—real or imagined—relate to patients' experience, including the multiple perspectives and attitudes available and influences both internal and external to the narrative. As Hutto [68] writes "To understand narratively is to grasp the significance of what goes on in a particular episode of inter-connected happenings. […] We gain a narrative understanding of what someone has done and why if we are

provided with a coherent and revealing account that provides details of how a specific series of events unfolded and what those involved in such goings-on thought and felt about them" (p. 2).

- **Narrative humility**, a term coined by DasGupta [69], describes the attitude of narratively competent clinicians who accept patients as teachers and recognize themselves as lifelong learners who know how "to listen to, and surrender to, the other" (p. 1391). Central to this notion, which is similar to cultural humility [70], is the ability to take a non-judgmental stance towards the sufferer's account while remaining aware of one's biases and positionality in the encounter. This includes the recognition of the limitations of narrative and other means of mutual understanding, which requires that one remain open to the other and to rethinking and revising one's position.
- **Narrative therapeutics** refers to the explicit use of narrative as an intervention. This includes the recognition that the attentiveness of a skilled clinician who can listen to a patient's narrative in a sympathetic manner can itself provide healing through helping the patient derive meaning from the clinical encounter which also helps decrease the fear, anxiety and uncertainty that often obstruct healing [50].

Narrative therapeutics can go beyond the beneficial effects of empathic listening and meaning-making to enable patients to acquire new ways of coping and adapting. Table 14.2 lists some forms of intervention that make deliberate use of narrative. The

Table 14.2 Narrative therapeutics

Intervention	Approach	Applications	Reference
Narrative therapy	Employs narrative empathy and inquiry to identify pathogenic narratives and work to replace with stories that are more salutogenic	Common mental disorders, eating disorders, trauma-related disorders	White and Epston [71]
		Combined with Motivational Interviewing for treatment of substance use disorders in primary care	Oshman and Combs [72]
Focused narrative intervention	Use of tailored narrative intervention to address specific health problem	Treatment of depression in palliative care	Lloyd-Williams et al. [73]
	miLivingStory Telephone-based life narrative review	Depression in patients with advanced cancer	Wise et al. [74]
Narrative informed medical family therapy	Integrative of narrative theory approach with Medical Family Therapy	Chronic illness	Williams-Reade et al. [75]
		Medically unexplained symptoms	Rajaei and Jensen [76]
Bibliotherapy	Therapeutic use of fiction or poetry	Addressing issues of chronic illness, identity, stigma and loss	Peterkin and Grewal [77]
Narrative intervention in public health	Use of narrative methods to develop health communication to promote behavioral change	Health promotion	Perrier and Martin Ginis [78]

therapeutic uses of narratives include fostering reflection on the prevailing models and discourses that frame the patient's problem and its implications, offering alternative accounts, encouraging the development of explanations that modify or supplant patients' accounts through processes of reframing or reattribution, or prescribing explicit exercises to generate and enact new narratives in interaction with others.

14.8 Narrative and the Clinical Alliance

The practice of narrative medicine employing close listening and negotiation of shared meaning and understanding can contribute to a strong patient-clinician alliance and increase treatment adherence. The clinical alliance is central to the practice of medicine. In addition to its ethical importance, research on the patient-doctor relationship has demonstrated that the quality of the patient-doctor relationship influences both patient satisfaction and clinical outcomes [18, 79]. A strong clinical alliance increases trust and confidence in the healer and positive expectations, which result in hope, treatment adherence, and enhanced placebo response to interventions.

Developing a shared narrative starts with active listening by the clinician which can make patients feel heard and understood. Charon et al. [80] refer to this dimension of narrative medicine as *clinical attention*. Active listening allows the patient to be present to the clinician who can then *represent* them in their own thinking about the nature of the illness and in formulating a response. This response then furthers a process of relatedness or *affiliation* that is central to the helping relationship. The combination of these three dimensions—attention, representation and affiliation—allows the patient gain trust, feel reassured and actively participate in the healing process.

In a meta-analysis of 48 studies, Arbuthnott and Sharpe [81] found that a positive physician-patient relationship contributes to treatment adherence. In psychiatry and especially in psychotherapy, the clinical alliance is recognized as crucial, but it remains relevant for any change in health behaviour or adoption of new regimens and routines necessary to treat, manage or prevent most disorders.

How people understand an illness shapes their treatment expectations and response. The more that patient and clinician manage to align their conceptual models of illness and disease, the greater coherence and synchronicity emerges in their interactions, which in turn, may enhance mutual understanding and trust through positive feedback. For patients, this synchrony may translate into confidence in the clinician's healing abilities, as well as an experience of being listened to that reinforces their sense of agency and self-efficacy, all of which can contribute to positive clinical outcomes.

14.9 Narrative Interventions

There is a narrative dimension to all clinical interactions and one consequence of describing one's predicament to a clinician is to embed it in a story. This embedding confers specific meaning to experiences. In turn, clinicians may ratify, challenge or disrupt patients' narratives and offer alternatives [82]. Mattingly [83] has discussed how clinicians can situate patients' stories within a larger narrative frame in a process of therapeutic emplotment.

Narrative is a key element of most forms of psychological intervention in behavioral medicine and psychotherapy. For example, many forms of cognitive therapy assume that narratives reveal core beliefs and assumptions that can be pathogenic. Having an account of one's illness or life circumstances that evokes anxiety, avoidant behaviour or other maladaptive coping responses can amplify symptoms and impair well-being and functioning. Helping patients alter their illness narratives can lead to symptom reduction and improve well-being and functional status [84].

Narrative interventions may aim to change pathogenic narratives by constructing alternative accounts whether in conversation, imagination, writing or other forms of symbolic enactment. Specific methods include bibliotherapy, journal or diary keeping, letter-writing, collaborative note-taking, and storytelling. Arts-based methods can be used to facilitate narration or allow a form of nonverbal narrative ordering of experience. Narrative therapy, as developed by White and Epston [71] employs these methods to identify pathogenic narratives and actively work to replace these with stories that are more salutogenic. The key elements include: exploring and 'deconstructing' the patient's illness narratives; externalizing the problem by understanding its larger social structural and discursive origins; identifying the impact of the illness and its narrative construals on the patient and others in their family; and, ultimately, rewriting or reauthoring illness and self-narratives to support more adaptive responses. These interventions simultaneously address individuals' self-understanding, their ways of engaging the world, and their adaptation to illness. Narrative therapy can be integrated with other psychosocial and behavioral interventions, like Motivational Interviewing to treat substance use disorders [72] or Medical Family Therapy [75].

14.10 The Ethics of Narrative and Narrative Ethics

The study of narrative has also been recognized as essential in medical ethics. Ethical dilemmas are framed in terms of "what if" narratives and exploring the construction of these accounts provides ways to understand patients' predicaments and imagine alternatives [85, 86]. People frame their illness and the moral quandaries and choices that arise in treatment in terms of particular stories involving self, relationships and the meanings of sickness and recovery. To the extent that clinical accounts ignore patients' stories as essential data in framing therapeutic options and decision making, they may contribute to epistemic injustice, in which the patient is disqualified as a knower and knowledge maker.

One of the lessons of narrative theory and research for bioethics is the multiplicity, heteroglossia and indeterminacy of illness narratives. While overly fixed or rigid stories may be part of the patients' predicament, stories also provide ways to contain the threat and chaos presented by affliction. Illness narratives shift with the context of retelling and evolve with repeated retelling in ways that reveal new layers of meaning and afford new possibilities for adaptation [84, 87].

Close listening provides a path to empathy, but this requires understanding the building blocks of patients' accounts, which are based in their distinctive lifeworlds, social contexts, and cultural systems of meaning [88]. Clarifying the meaning of ethical dilemmas thus requires attention to social and cultural background knowledge and context.

The valorization of narrative creates its own ethical dilemmas [89, 90]. The focus on narrative privileges patients' ability to give coherent accounts of their concerns. Yet many individuals may be reluctant to share their stories with clinicians, lack facility with storytelling, or experience their symptoms and suffering in ways that are chaotic or inchoate and do not lend themselves to a smooth and coherent account. This difficulty with narrative itself may reveal important dimensions of their embodied experience and predicament, but it may also impair patients' ability to elicit attention and understanding from care providers [46]. Narrative forms may also differ across cultures resulting in stories that may be difficult to follow or unsatisfying for clinicians who expect a more familiar or conventionally structured account. Attention to more fragmentary or unusual modes of expression is crucial to building an effective alliance with the full range of patients [46, 89, 90].

14.11 Teaching and Learning Narrative Medicine

Most work on narrative methods has focused on training, which eventually influences clinical practice. To enable practitioners to acquire narrative competency as a basic framework and set of skills for diagnosis, treatment and care, it needs to be made integral to medical education and professional development [91]. Some studies have suggested that medical students show a decrease in empathy over the course of their training, specifically, at the time they begin clinical clerkships: as students develop the skills required to take a standardized clinical history, they may become less capable of encouraging and utilizing patients' narratives [92, 93]. Narrative medicine training may counteract this negative effect of medical education [94]. Although skills such as cultural competence have gained recognition as part of accreditation standards, most curricula continue to provide limited training in narrative approaches to clinical interaction, assessment, formulation, and intervention. Several small-scale surveys point to improved student outcomes following curricular integration of humanities and social sciences in medicine, including anthropology, sociology, psychology, history, philosophy, and literary studies, but more research and evaluation is needed to demonstrate the impact of such practices and support wider acceptance [95].

In the past two decades, medical schools across the globe have started experimenting with curricular options that provide opportunities for students to explore the cultural meanings and values underpinning concepts of health and illness in diverse populations [96]. Institutions embracing the concept of medical humanities within the framework of person-centered care tend to be more open to the use of narrative medicine as a tool to foster skills such as close reading, active listening, interviewing skills, critical analysis of narratives, and self-reflection to identify explicit and implicit biases. There is a wide range of approaches to integrating humanities in medicine which illustrate the potential for narrative medicine [97].

For example, the Technical University of Munich, Germany, offers a 2-year program in *Lettered Medicine & Lettered Medical Education* that is designed as an enrichment curriculum for medical students but is also open to practicing physicians. The program combines medical humanities coursework and seminars with elements of narrative medicine techniques. The focus is on improving effectiveness in clinical settings as well as helping clinicians engage with the humanities in ways that can prevent burnout and provide greater professional fulfillment. The Icahn School of Medicine at Mount Sinai School of Medicine of New York requires an *Art of Listening* course for all first-year freshmen and offers other optional interdisciplinary courses linking medicine to art, humanities and philosophy. The University of Basel, Switzerland, includes medical humanities as a core subject, requires a yearlong project in psychosocial medicine in the third year of its medical education program, and emphasizes the development of physician-patient communicative skills, particularly in the last 2 years of the program.

Recently, increased attention has been given to raising medical students' awareness of structural determinants of health and equipping them with a critical lens to address the legacies of discrimination and to encourage active engagement in advocacy for a more equitable and efficient healthcare delivery [98]. This has been particularly evident in the U.S., where the lack of universal healthcare coverage drastically exacerbates other social inequities, resulting in major disparities in health outcomes. Columbia University, where the concept of narrative medicine was developed, offers a free-standing Masters in Narrative Medicine, open to both clinical and non-clinical students interested in conducting research in the field. The CUNY School of Medicine (CSOM), one of the most diverse medical schools in North America, focuses on educating primary care physicians to work with diverse, largely underserved populations and promote healthier communities. At CSOM, the commitment to narrative medicine follows from the school's mission which is anchored in an understanding of social determinants of health. CSOM's innovative curriculum includes a required course in narrative medicine, taken during Year One of the BS/MD program, that aims to develop narrative competences through reading, reflective writing and discussion. An additional elective in narrative medicine as well as numerous extracurricular opportunities to engage with arts and humanities are available, including workshops that use both visual and narrative art to discuss the impact of factors such as environment, socioeconomic status, race and gender, education and nutrition on health and illness.

14.12 Conclusions and Implications for Person-Centered Care

We are storied beings: narrative is at the heart of human experience in health and illness. Narrative medicine aims to equip clinicians to skillfully receive and respond to the stories through which patients convey their concerns. This is complicated by the realization that narratives are not simply preconceived and packaged gifts passed along to an open-minded listener, but co-constructions, created in response to particular contexts, with the active participation of the listener or interlocutor as well as others who may not be present in the clinical encounter. The stories of patients as well as those produced by clinicians have multiple authors, reflecting the voices of family, friends, colleagues as well as popular accounts circulated in the community and through social media. Moreover, we do not write or tell stories simply to express what we already know but to discover (construct or invent) a position. Hence, narrative exchange is always a process of creative discovery. Even when old stories are being rehearsed, the way they are told conveys new information about the person's current situation.

Narrative medicine provides new ways of approaching clinical practice and resources for training and for research that can inform person-centered medicine. Narrative studies provide insights into the nature of the self and the process of resilience and adaption. Narrative medicine provides pedagogical methods for deepening clinical empathy and understanding of patients as persons situated in a lifeworld, as well as cultivating practitioners' ability to listen and communicate effectively. Learning to listen to narratives is a crucial clinical skill for exploring patient experience, and reflecting on and reconstructing narratives are important therapeutic interventions.

Narrative is also a path to understanding the social world that gives rise to health inequities and resources for coping, resilience and healing. Stories can convey the patient's predicament and provide both the motive force and rhetorical tools for advocacy. Recognizing the patient as person requires engaging with their narrative, whether this is expressed in words or actions. The dialogical mechanisms inherent in a narrative approach can help counteract some of the implicit biases and stigma in healthcare delivery. This can support the process of identifying and addressing structural inequities in clinical care and of forging the solidarity needed for effective advocacy. For all of these reasons, narrative medicine provides a central pillar of any vision of person-centered medicine.

Acknowledgements and Disclosures The authors do not report conflicts of interest in regard to this manuscript.

References

1. Brody H. Stories of sickness. Oxford University Press; 2002.
2. Greenhalgh T, Hurwitz B, editors. Narrative based medicine: dialogue and discourse in clinical practice. London: BMJ Books; 1999.

3. Bleakley A. Medical humanities and medical education: how the medical humanities can shape better doctors. Routledge; 2015.
4. Charon R. Narrative medicine: a model for empathy, reflection, profession, and trust. J Am Med Assoc. 2001;286(15):1897–902.
5. Charon R. What to do with stories: the sciences of narrative medicine. Can Fam Physician. 2007;53(8):1265–7.
6. Hurwitz B, Greenhalgh T, Skultans V, (Eds.). Narrative research in health and illness. Wiley; 2008.
7. Bal M. Narratology: introduction to the theory of narrative. 4th ed. University of Toronto Press; 2017.
8. Bruner JS. Acts of meaning. Harvard University Press; 1990.
9. Bruner JS. Making stories: law, literature, life. Harvard University Press; 2003.
10. Schechtman M. The constitution of selves. Cornell University Press; 2018.
11. Taylor C. The language animal. Harvard University Press; 2016.
12. Holmgren L, Fuks A, Boudreau D, Sparks T, Kreiswirth M. Terminology and praxis: clarifying the scope of narrative in medicine. Lit Med. 2011;29(2):246–73.
13. Hutto DD. Folk psychological narratives: the sociocultural basis of understanding reasons. MIT Press; 2012.
14. Turner M. The literary mind: the origins of thought and language. Oxford University Press; 1996.
15. Hutto DD, Brancazio NM, Aubourg J. Narrative practices in medicine and therapy: philosophical reflections. Style. 2017;51(3):300–17.
16. Charon R. Narrative medicine: honoring the stories of illness. Oxford University Press; 2008.
17. Fioretti C, Mazzocco K, Riva S, Oliveri S, Masiero M, Pravettoni G. Research studies on patients' illness experience using the Narrative Medicine approach: a systematic review. BMJ Open. 2016;6(7):e011220.
18. Stewart M, Brown JB, Weston W, McWhinney IR, McWilliam CL, Freeman T. Patient-centered medicine: transforming the clinical method. CRC Press; 2013.
19. Engel GL. The need for a new medical model: a challenge for biomedicine. Science. 1977;196(4286):129–36.
20. Irving G, Neves AL, Dambha-Miller H, Oishi A, Tagashira H, Verho A, Holden J. International variations in primary care physician consultation time: a systematic review of 67 countries. BMJ Open. 2017;7(10):e017902.
21. Sullivan M. The new subjective medicine: taking the patient's point of view on health care and health. Soc Sci Med. 2003;56(7):1595–604.
22. Kleinman A. The soul of care: the moral education of a husband and a doctor. Penguin; 2019.
23. Saad TC. The history of autonomy in medicine from antiquity to principlism. Med Health Care Philos. 2018;21(1):125–37.
24. Tauber AI. Sick autonomy. Perspect Biol Med. 2003;46(4):484–95.
25. Jonsen AR. Leadership in meeting ethical challenges. Acad Med. 1987;62(2):95–9.
26. Mezzich JE, Kirisci L, Salloum I, Trivedi J, Kar SK, Adams N, Wallcraft J. Systematic conceptualization of person centered medicine and development and validation of a person-centered care index. Int J Pers Cent Med. 2016;6(4):219–47.
27. International College of Person-Centered Medicine. Madrid declaration on person centered medical education and the goals of healthcare. Int J Pers Cent Med. 2017;7:80–1.
28. Eisenberg L. Disease and illness distinctions between professional and popular ideas of sickness. Cult Med Psychiatry. 1977;1(1):9–23.
29. Kleinman A. The illness narratives: suffering, healing, and the human condition. New York: Basic Books; 1988.
30. Kleinman A, Eisenberg L, Good B. Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. Ann Intern Med. 1978;88(2):251–8.
31. Clark JA, Mishler EG. Attending to patients' stories: reframing the clinical task. Sociol Health Illn. 1992;14(3):344–72.
32. Mishler EG. The discourse of medicine: dialectics of medical interviews. Greenwood Publishing Group; 1984.

33. Frank AW. The wounded storyteller: body, illness and ethics. Chicago: University of Chicago Press; 1995.
34. Mattingly C, Garro LC, editors. Narrative and the cultural construction of illness and healing. University of California Press; 2000.
35. Kirmayer LJ. Culture and the metaphoric mediation of pain. Transcult Psychiatry. 2008;45(2):318–38.
36. Pilnick A, Dingwall R. On the remarkable persistence of asymmetry in doctor/patient interaction: a critical review. Soc Sci Med. 2011;72(8):1374–82.
37. Ainley V, Maister L, Brokfeld J, Farmer H, Tsakiris M. More of myself: manipulating interoceptive awareness by heightened attention to bodily and narrative aspects of the self. Conscious Cogn. 2013;22(4):1231–8.
38. Kirmayer LJ, Sartorius N. Cultural models and somatic syndromes. Psychosom Med. 2007;69(9):832–40.
39. Cepeda MS, Chapman CR, Miranda N, Sanchez R, Rodriguez CH, Restrepo AE, et al. Emotional disclosure through patient narrative may improve pain and well-being: results of a randomized controlled trial in patients with cancer pain. J Pain Symptom Manag. 2008;35(6):623–31.
40. Pennebaker JW. Telling stories: the health benefits of narrative. Lit Med. 2000;19(1):3–18.
41. Pennebaker JW, Smyth JM. Opening up by writing it down: how expressive writing improves health and eases emotional pain. New York: Guilford Publications; 2016.
42. Pennebaker JW. Expressive writing in psychological science. Perspect Psychol Sci. 2018;13(2):226–9.
43. Sperber D, Wilson D. Relevance: communication and cognition. Cambridge, MA: Harvard University Press; 1986.
44. Strawson G. The unstoried life. In: Altobrando A, Niikawa T, Stone R, editors. The realizations of the self. Cham: Palgrave Macmillan; 2018. p. 113–33.
45. Kirmayer LJ. The body's insistence on meaning: Metaphor as presentation and representation in illness experience. Med Anthropol Q. 1992;6(4):323–46.
46. Kirmayer LJ. Broken narratives: Clinical encounters and the poetics of illness experience. In: Mattingly C, Garro L, editors. Narrative and the cultural construction of illness and healing. Berkeley: University of California Press; 2000. p. 153–80.
47. Hydén LC. Illness and narrative. Sociol Health Illn. 1997;19(1):48–69.
48. Polkinghorne DE. Narrative and self-concept. J Narrat Life Hist. 1991;1(2–3):135–53.
49. Williams G. The genesis of chronic illness: narrative reconstruction. Sociol Health Illn. 1984;6(2):175–200.
50. Fuks A, Kreiswirth M, Boudreau D, Sparks T. Narratives, metaphors, and the clinical relationship. Genre: Forms of Discourse and Culture. 2011;44(3):301–13.
51. Foucault M. The archeology of knowledge. New York: Pantheon Books; 1972.
52. Bakhtin MM. The dialogic imagination: four essays. University of Texas Press; 2010.
53. Bleakley A. Thinking with metaphors in medicine: the state of the art. Taylor & Francis; 2017.
54. Beckman HB, Frankel RM. The effect of physician behavior on the collection of data. Ann Intern Med. 1984;101(5):692–6.
55. Anderson JE, Brown RA. Life history grid for adolescents. Soc Work. 1980:321–3.
56. Feldman S, Howie L. Looking back, looking forward: reflections on using a life history review tool with older people. J Appl Gerontol. 2009;28(5):621–37.
57. Meltzer PJ, Abbott P, Spradling P. Teaching gerontology using the Self-Discovery Tapestry: an innovative instrument. Gerontol Geriatr Educ. 2003;23(2):49–63.
58. Weiss M. Explanatory Model Interview Catalogue (EMIC): framework for comparative study of illness. Transcult Psychiatry. 1997;34(2):235–63.
59. Groleau D, Young A, Kirmayer LJ. The McGill Illness Narrative Interview (MINI): an interview schedule to elicit meanings and modes of reasoning related to illness experience. Transcult Psychiatry. 2006;43(4):671–91.
60. Rüdell K, Bhui K, Priebe S. Concept, development and application of a new mixed method assessment of cultural variations in illness perceptions: Barts Explanatory Model Inventory. J Health Psychol. 2009;14(2):336–47.

61. Arnault DS, Shimabukuro S. The clinical ethnographic interview: a user-friendly guide to the cultural formulation of distress and help seeking. Transcult Psychiatry. 2012;49(2):302–22.
62. Lewis-Fernández R, Aggarwal N, Hinton L, Hinton D, Kirmayer LJ, editors. Handbook for the DSM-5 cultural formulation. Washington: APPI Press; 2015.
63. Bastos DF, Cunha AJLAD, Souza AND. The experience of family medicine interns conducting McGill Illness Narrative Interview with non-compliant chronic patients. Rev Bras Educ Med. 2018;42(3):178–88.
64. Covelli V, Figini L, Santagelo A, Memini F, Bonforte G. A narrative medicine pilot study using the McGill Illness Narrative Interview (MINI) with patients suffering from nephropathy and on dialysis. J Soc Sci Humanit. 2019;2(3):62–5.
65. Groleau D, D'Souza NA, Bélanger E. Integrating the illness meaning and experience of patients: the McGill illness narrative interview schedule as a PCM clinical communication tool. Int J Pers Cent Med. 2013;3(2):140–6.
66. Lewis-Fernández R, Aggarwal NK, Bäärnhielm S, Rohlof H, Kirmayer LJ, Weiss MG, et al. Culture and psychiatric evaluation: operationalizing cultural formulation for DSM-5. Psychiatry. 2014;77(2):130–54.
67. Lewis-Fernández R, Aggarwal NK, Kirmayer LJ. The cultural formulation interview: progress to date and future directions. Transcult Psychiatry. 2020;57(4):487–96.
68. Hutto DD. Narrative understanding. In: Carroll N, Gibson J, editors. The Routledge companion to philosophy of literature. New York: Routledge; 2016. p. 281–301.
69. DasGupta S. Between stillness and story: lessons of children's illness narratives. Pediatrics. 2007;119(6):e1384–91.
70. Tervalon M, Murray-Garcia J. Cultural humility versus cultural competence: a critical distinction in defining physician training outcomes in multicultural education. J Health Care Poor Underserved. 1998;9(2):117–25.
71. White M, Epston D. Narrative means to therapeutic ends. W.W. Norton & Company; 1990.
72. Oshman LD, Combs GN. Integrating motivational interviewing and narrative therapy to teach behavior change to family medicine resident physicians. Int J Psychiatry Med. 2016;51(4):367–78.
73. Lloyd-Williams M, Shiels C, Ellis J, Abba K, Gaynor E, Wilson K, Dowrick C. Pilot randomised controlled trial of focused narrative intervention for moderate to severe depression in palliative care patients: DISCERN trial. Palliat Med. 2018;32(1):206–15.
74. Wise M, Marchand LR, Roberts LJ, Chih MY. Suffering in advanced cancer: a randomized control trial of a narrative intervention. J Palliat Med. 2018;21(2):200–7.
75. Williams-Reade J, Freitas C, Lawson L. Narrative-informed medical family therapy: using narrative therapy practices in brief medical encounters. Fam Syst Health. 2014;32(4):416.
76. Rajaei A, Jensen JF. Empowering patients in integrated behavioral health-care settings: a narrative approach to medical family therapy. Fam J. 2020;28(1):48–55.
77. Peterkin A, Grewal S. Bibliotherapy: the therapeutic use of fiction and poetry in mental health. Int J Pers Cent Med. 2018;7(3):175–81.
78. Perrier MJ, Martin Ginis KA. Changing health-promoting behaviours through narrative interventions: a systematic review. J Health Psychol. 2018;23(11):1499–517.
79. Riedl D, Schüßler G. The influence of doctor-patient communication on health outcomes: a systematic review. Z Psychosom Med Psychother. 2017;63(2):131–50.
80. Charon R, Dasgupta S, Hermann N, Irvine C, Colon ER, Spencer D, Spiegel M, editors. The principles and practice of narrative medicine. Oxford University Press; 2017.
81. Arbuthnott A, Sharpe D. The effect of physician–patient collaboration on patient adherence in non-psychiatric medicine. Patient Educ Couns. 2009;77(1):60–7.
82. Lewis B. Narrative psychiatry: how stories can shape clinical practice. JHU Press; 2011.
83. Mattingly C. Healing dramas and clinical plots: the narrative structure of experience. Cambridge University Press; 1998.
84. Hamkins S. The art of narrative psychiatry: stories of strength and meaning. Oxford University Press; 2013.

85. Jones AH. Literature and medicine: narrative ethics. Lancet. 1997;349(9060):1243–6.
86. Nelson HL. Stories and their limits: narrative approaches to bioethics. Routledge; 2014.
87. Groleau D, Kirmayer LJ. Sociosomatic theory in Vietnamese immigrants' narratives of distress. Anthropol Med. 2004;11(2):117–33.
88. Kirmayer LJ. Empathy and alterity in psychiatry. In: Kirmayer LJ, Lemelson R, Cummings C, editors. Re-visioning psychiatry: cultural phenomenology, critical neuroscience, and global mental health. New York: Cambridge University Press; 2015. p. 141–67.
89. Woods A. The limits of narrative: provocations for the medical humanities. Med Humanit. 2011;37(2):73–8.
90. Woods A. Beyond the wounded storyteller: rethinking narrativity, illness and embodied self-experience. In: Carel H, Cooper R, editors. Health, illness and disease: philosophical essays. Routledge; 2014. p. 125–40.
91. Milota MM, van Thiel GJMW, van Delden JJM. Narrative medicine as a medical education tool: a systematic review. Med Teach. 2019;41(7):802–10.
92. Bell SK, Krupat E, Fazio SB, Roberts DH, Schwartzstein RM. Longitudinal pedagogy: a successful response to the fragmentation of the third-year medical student clerkship experience. Acad Med. 2008;83(5):467–75.
93. Ferreira-Valente A, Monteiro JS, Barbosa RM, Salgueira A, Costa P, Costa MJ. Clarifying changes in student empathy throughout medical school: a scoping review. Adv Health Sci Educ. 2017;22(5):1293–313.
94. Schneider G, Gillis M, von Harscher H. Developing empathy through narrative, medicine. In: Foster AE, Yaseen ZS, editors. Teaching empathy in healthcare: building a new core competency. Springer; 2019. p. 165–78.
95. Barber S, Moreno-Leguizamon CJ. Can narrative medicine education contribute to the delivery of compassionate care? A review of the literature. Med Humanit. 2017;43(3):199–203.
96. Remein CD, Childs E, Pasco JC, Trinquart L, Flynn DB, Wingerter SL, et al. Content and outcomes of narrative medicine programmes: a systematic review of the literature through 2019. BMJ Open. 2020;10(1):e031568.
97. Pfeiffer S, Chen Y, Tsai D. Progress integrating medical humanities into medical education: a global overview. Curr Opin Psychiatry. 2016;29(5):298–301.
98. Metzl JM, Petty J, Olowojoba OV. Using a structural competency framework to teach structural racism in pre-health education. Soc Sci Med. 2018;199:189–201.

Chapter 15
Digital Technology for Person-Centered Care

Paul Glare, Liliana Laranjo da Silva, Levent Kirisci, and Claire Ashton-James

15.1 Introduction: Why Is a Chapter on Digital Technology Important in a Book on Person-Centered Medicine?

Even before the COVID-19 pandemic, health care systems were facing multiple challenges. These included patients not receiving the care they wanted or needed, clinician burnout, and unsustainable costs [1]. Technology is starting to disrupt health care, although not as yet to the same degree as seen in other industries [2]. The convergence of digital technologies with healthcare is called digital health. The goal of digital health is to make health care more effective and efficient through the use of information and communication technologies [3] to overcome some of the problems

---

P. Glare (✉)
Northern Clinical School, Faculty of Medicine and Health, University of Sydney,
Sydney, NSW, Australia

Memorial Sloan-Kettering Cancer Center and Weill Cornell Medical College,
New York, NY, USA
e-mail: paul.glare@sydney.edu.au

L. Laranjo da Silva
Westmead Applied Research Centre, Faculty of Medicine and Health, University of Sydney,
Sydney, NSW, Australia

Australian Institute of Health Innovation, Centre for Health Informatics, Macquarie
University, Sydney, NSW, Australia
e-mail: liliana.laranjo@sydney.edu.au

L. Kirisci
Department of Pharmaceutical Sciences, University of Pittsburgh, Pittsburgh, PA, USA
e-mail: levent@pitt.edu

C. Ashton-James
Pain Management Research Institute, Faculty of Medicine and Health, University of Sydney,
Sydney, NSW, Australia
e-mail: claire.ashton-james@sydney.edu.au

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_15

listed above. Digital health is relevant to person-centred medicine because it has the potential to make the practice of medicine more — or less — person-centred [3, 4].

The relatively slow uptake of digital health can be attributed to a number of challenges and concerns [5]. These include disparities in access and engagement with digital technologies—the so-called “digital divide”—[6] concerns about data security and the privacy of sensitive health information, a lack of evidence for the effectiveness of digitally-delivered healthcare relative to in-person care, safety concerns and implications for the healthcare workforce [7]. At least some of these concerns may be allayed if digital technologies are understood as tools to support or improve person-centred care rather than vehicles to eliminate human care or for standardising care without regard for individual patient preferences and perspectives.

This chapter seeks to contribute to understanding of the interface of digital health technology and person-centred medicine. It describes the scope of digital health technology, the opportunities for improving the practice of person-centred medicine, and the challenges that remained to be solved.

15.2 Scope of Digital Health Technology

An end-goal of digital health technology is to create an interconnected health system that utilizes computational technologies, smart devices, computational analysis techniques, and communication media to aid healthcare professionals and patients to manage illnesses and health risks, as well as promote health and wellbeing [3]. These technologies include the hardware, software and services required to enable telemedicine, health information technology, web-based analysis, email, mobile phones and applications, text messages, social networking, wearable devices, and clinic-based or remote monitoring sensors [8]. Genomics, and personal genetic information are sometimes included [4], because of the technological aspects of genome-wide screening and because the digitized information can be stored on a cell phone for ease of access. There are many stakeholders with an interest in the development of digital health [9], including clinicians, scientists/researchers from various disciplines (e.g. healthcare, engineering, social sciences, public health, health economics and data management), administrators, entrepreneurs, as well as patients and their families.

15.2.1 List of Domains in Digital Health

- The use of technology to prevent, diagnose or treat diseases, and monitor patient outcomes, including rehabilitation or long-term care. Examples include assistive rehabilitation robotics for people with disabilities aiding their independence to perform daily tasks [10], unobtrusive monitoring sensors and wearable devices [3, 4].

- Clinical decision support, aiding clinicians at the point of care, including diagnosis, analysis and interpretation of patient-related data, such as improving cancer diagnosis in primary care [11].
- Computational simulations, modelling and machine learning approaches which can predict health-related outcomes [12].
- E-health, including telemedicine, which delivers health information and services to enable data collection, storage, transmission, and retrieval for clinical, educational and administrative purposes [13].
- Mobile health (or mHealth) can be defined as "the use of mobile telecommunication technologies for the delivery of health care and in support of wellness" [14], including both mobile phone technologies (e.g. text-messaging, mobile applications) and wireless devices (e.g. wearables, tracking devices).
- Health systems engineering applications of digital health technology in health care, such as knowledge discovery, decision making, optimization, human factors engineering, quality engineering, and information technology and communication [15].

Human-computer-environment interactions are important in digital health. Human-computer interaction principles tend to be based around user-centred, experience-centred or activity-centred designs. Virtual reality, video gaming rehabilitation (integrating commercial videogames with physical rehabilitation programs), and serious games (non-commercial video games that have no entertainment value) provide a social and interactive experience for healthcare students and patient education [16]. Speech and hearing systems for natural language processing, speech recognition techniques, and medical devices can aid in speech and hearing (e.g. cochlear implants). Telehealth, telemedicine, telecare, tele-coaching and telerehabilitation provide various forms of patient care remotely at a distance.

One useful framework for grouping these disparate technologies is to think of what is being digitized: medical devices, patients, or the clinic/hospital [3].

15.2.1.1 The Digitized Medical Device

Advances in consumer mobile technologies have resulted in a range of platforms to promote health and deliver healthcare. In general, the patient transfers their data via the Internet for interpretation of the data by a human provider or via automated algorithms, and the data is returned to the patient and provider for clinical decisions [3]. Several such mHealth technologies have been approved for use by EU and US regulatory authorities. These include:

- Wireless, wearable devices such as Fitbit (www.fitbit.com) which can monitor patients where they are, even remotely. Not only does this include physical activity tracking like the number of steps taken or the number of stairs climbed, but also bodily measurements like weight, vital signs, blood pressure levels and sleep stage, but also other relevant data such as geographical location, air quality and dietary calorie intake. Even the time spent on a mobile phone can be used to monitor a person's everyday behaviours to paint a picture of their current mental health [17].

- Sensors built into smartphones can be used to perform diagnostic functions. This can include using the built-in camera to screen skin lesions for malignancy [18], or for the patient to attach a wearable device to self-record a 6-lead EKG [19], or perform an ultrasound [20].
- Sensors can also be built into medications to assist not only with medication adherence [21], but also for remotely activating their delivery [4].
- Social media and online social networks can be used to effectively promote health behaviour change [22]. In particular, existing online social networks like Facebook present several advantages for the implementation of health interventions [23]. They have extensive reach—millions of regular users worldwide—potentially alleviating problems of retention and lack of engagement with interventions. Also, they can efficiently disseminate interventions and recruit participants, and they can leverage participants' existing social networks.
- Conversational agents (i.e. chatbots) such as Apple's Siri or Alexa are increasingly being used to support patient self-management and to deliver mental health interventions [24, 25]. For instance, "Woebot" is a chatbot freely-available via Facebook messenger, that delivers cognitive behavioural therapy to users, having been shown to significantly decrease depression symptoms, in a randomised controlled trial [26].

15.2.1.2 The Digitized Clinic/Hospital/Healthcare System

Computers have been increasingly used in medicine since the 1960s [27]. There are now unprecedented opportunities to generate health data electronically, analyse them and integrate them into clinical workflows [3].

- Data generated by devices and fed back to the provider and the patient become clinical information that in turn may influence clinical decision making. For one example, mobile EKG monitoring has been shown to help in the management of patients with atrial fibrillation [28].
- Such information can also contribute to the repository of medical knowledge and be utilized to develop diagnostic, therapeutic and prognostic algorithms generated using machine learning/artificial intelligence that are anticipated to soon surpass the accuracy of clinicians [29], and improve outcomes including in remote and resource-limited areas. For example, remote monitoring and algorithms have enabled the creation of the eICU that can be run by primary care workers [30].
- The cost-effectiveness of digital health interventions has begun to be demonstrated. In a systematic review of 14 studies of outcomes in cardiovascular disease, use of digital health technology was shown to achieve higher quality-adjusted life years (QALYs) with cost savings in 43% (6/14) studies [31]. In the other

57% (8/14) of studies, it had a higher cost but with an acceptable incremental cost-effectiveness ratio. Furthermore, a digital health care model for primary care has been shown to be less costly than traditional in-office primary care in Sweden [32].

15.2.1.3 The Digitized Patient

People who are willing and able to engage with technology have the ability to take an increasingly active role in their self-management and healthcare if they become ill. The term ‘e-patients’ has been coined to describe “empowered, engaged, equipped, and enabled” patients who are able to use modern electronic tools to actively participate in care, and to be heard by other patients, physicians, and policy makers [33]. Ways in which patients become digitized include:

- Using telemedicine and other forms of telehealth so that they can have their care at a time and place that is optimal for them.
- Communicating with their providers by using secure *What’s App*-type systems.
- Using devices to improve their outcomes. For example, smokers are twice as likely to quit smoking if they receive SMS text messages (20% relapse rate) as those who only use nicotine replacement therapies (40% relapse rate) [34].
- Consenting to participate in, and allow access to, a portable health record. Several countries now support these initiatives, including Canada (Canada Health Infoway, www.infoway-inforoute.ca) and Australia (*My Health Record*, Australian Digital Health Agency, www.myhealthrecord.gov.au). In addition, providing patients access to electronic health records has the potential to improve health outcomes in chronic conditions like type 2 diabetes, as well as contribute to patient safety [35].
- By accessing health apps. A recent survey in Australia found 40% of the population uses smartphones to access health apps (https://www.abs.gov.au/ausstats/abs@.nsf/mf/8146.0), supporting lifestyle change and taking leadership in their health.
  - For example, Fitbit Premium (www.fitbit.com) offers a digital health program which provides the user with AI-guided, personalized advice, based on data it receives.
  - Patients can also use devices for more precise fertility testing (e.g. Natalist, www.natalist.com), including mail order of fertility products to use at home as directed by the app.
  - “Every Mind Matters” is an NHS-sponsored app to treat the mood problems and insomnia that affect 85% of the UK population (https://www.nhs.uk/oneyou/every-mind-matters/).

– Finally, Facebook has released a “Let’s Talk” Stories filter on Facebook Messenger to help people have important conversations around mental health. Developed with input from the World Health Organization (WHO), the filter acts as an invitation for friends who might be struggling to reach out for support through Messenger (https://newsroom.fb.com/news/2019/10/lets-talk-about-mental-health/)

15.3 Opportunities for Using Digital Technology in Person-Centered Medicine

Opportunities for using digital technology in person-centered medicine include more individualized assessment, shared decision making and collaborative treatment planning, and supporting health behavior change and participation in self-management.

The examples cited in the previous section indicates that there is a 3-way interaction between the patient, the provider and the device. Digital health technology may therefore also be categorized according to where it lies across the self-management continuum (see Fig. 15.1). This categorization is especially useful for understanding the digital health technology solutions to the challenge of chronic disease, which is so prevalent in the twenty-first century. More examples across the continuum are shown in Table 15.1.

As the figure illustrates, digital technologies play different roles across the continuum of care, according to the acuity of the disease and the patient’s preferences. At one extreme of the continuum (‘provider’), the intensivist will use an array of digital technologies in the Intensive Care Unit (ICU) to facilitate the care of the critically ill patient in the ICU who plays little role in self-management, except perhaps for a digitally stored advance care plan. At the other extreme (‘person’), a fit individual may use a wellness app on their phone to support the maintenance of

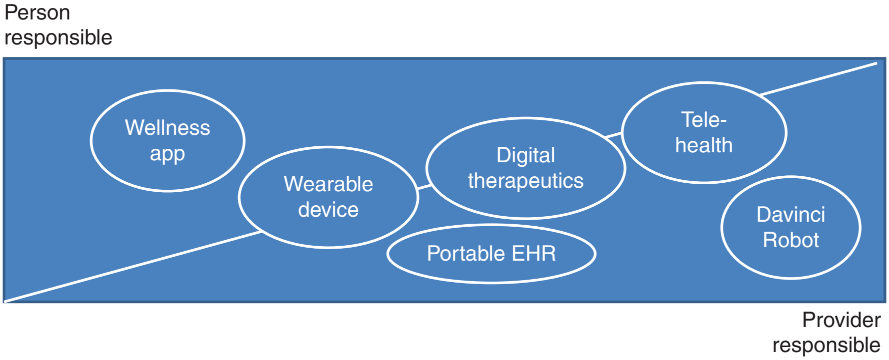


Fig. 15.1 Place of representative digital health technologies across the self-management continuum

Table 15.1 Place of various digital health technologies across the self-management continuum

Provider responsible
• Electronic medical record • CT scan • Machine learning/AI-aided diagnosis • Da Vinci surgical robot
Shared (increasing consumer responsibility)
• 'Virtual' clinical trials: Thread. • Telemedicine • Digital therapeutics with clinician coaching • SMS text messaging: one-way or two-way • portable Health Record • Smart pill dispenser • Wearables such Fitbit • Serious gaming, virtual reality, digital therapeutics with avatar coach
Person responsible
• Wellness apps e.g. Peloton (www.onepeloton.com), Headspace (www.headspace.com) • Digital health program delivery at the consumer level. Examples include Fitbit Premium, which includes AI-guided advice based on data; Natalist at-home ovulation testing (natalist.com) that includes mail order products to use at home with app; Every Mind Matters (which includes a toolkit of digital resources to help mood and sleep, offered free by the NHS) • Private messaging between friends on Facebook to aid mental health

a healthy lifestyle to prevent illness without any consultation with a clinician [36]. In the middle lies the approximately 40% of the population which is living with a chronic illness. Better outcomes are achieved by these people when they become actively involved in their care [37, 38]. Digital technology can support activation by providing the kind of tools shown in the centre of the figure.

Digital technology enables convenient and easy access to health interventions, facilitating tailoring to individuals and groups, real-time delivery, and dissemination to remote and larger audiences, using fewer resources. For instance, the growing availability of mobile phones and their ability to reach individuals continuously in their natural environment has led to the expansion of the field of "ecological momentary assessment", the collection of participants' data in real-time and "ecological momentary interventions" (the ability to trigger the delivery of interventions based on real-time data and on "just-in-time" assessments) [39, 40]. Personalised and context-sensitive interventions are now becoming possible, using ecological momentary assessment to collect self-reported data in response to prompts, combined with the passive recording of information (e.g. messages sent, application usage) and the use of embedded sensors (e.g., accelerometers, video cameras, microphones, light sensors) to collect data and make inferences about the environment (e.g. location, time, weather, activity). The combination of all these sources of data and their analysis via machine learning algorithms enables the delivery of a personalised intervention with a higher potential for long-term engagement.

Digital health interventions are particularly promising in health behaviour change. Mobile applications can be easily designed to deliver different combinations of behaviour change techniques, depending on the health behaviour being targeted. A behaviour change technique is an “observable, replicable and irreducible component” of a behaviour change intervention [41]. Techniques such as self-monitoring of behaviour, feedback, and goal-setting are associated with higher effectiveness of diet and physical activity interventions [42], and are commonly delivered in mobile applications of commercial activity trackers (e.g. Fitbit). Other behaviour change techniques, like social support and social comparison, can be delivered via integration with existing online social networks (e.g. Facebook) or built-in within the app (e.g. Fitbit allows users to add friends, enabling social support and friendly competitions).

Interventions involving digital technologies have shown effectiveness in chronic disease such as COPD, diabetes, heart disease and mental health [43]. Technologies such as electronic health records and telemedicine need to ensure that person-related information provided by the patient is collected as efficiently for decision-making as disease-related data are generated by the clinician and laboratory [44].

15.4 Challenges to Utilizing Digital Health Technology in Person-Centered Medicine, and Strategies to Overcome Them

Despite all the potential benefits of greater utilization of digital technology to improve person centered medicine, at the same time there are numerous challenges to its use, both for the person using the technology and for the clinician caring for them.

15.4.1 Challenges Faced by the Person

- Access: the “digital divide”—due to age, geography, education (including computer skills) and income—is real and continues to define access to and uses of online resources. In Australia, approximately 90% of the Australian under 54 use the Internet, vs. only 60% over 65 (http://theconversation.com/australias-digital-divide-is-not-going-away-91834). Because the digital divide mirrors the segment of the population which is underserved now, simply increasing connectivity to the Internet is not the only solution. Utilizing simpler modalities like SMS texting and appropriate training in use of more sophisticated devices is needed
- Engagement: improving access alone does not ensure digital health will enhance shared care. While most studies of eHealth show that clinical outcomes are improved, only a few have looked at whether eHealth increases engagement. A review of this literature found 11 studies and it was concluded that they tend to focus on only some dimensions of engagement (cognitive, emotional or behavioural) and a more holistic approach is needed. In addition, engagement with

digital health interventions also tends to decline through time, a phenomenon that has been labelled “the law of attrition” [45].

- Privacy and security concerns: While a person’s health care data is probably of less interest to hackers than their Social Security number, credit card information or bank account details, privacy and security remain a major concern for digital health. The sensitivity of a privacy breach will depend on the type of data being stolen (e.g. electronic health record data is likely to be more sensitive than data uploaded from a wearable sensor). Hacking that causes malfunction of a device is also a potential problem and will also be more serious than a privacy breach for certain devices. For example, faulty data from a wearable device that is being monitored for clinical decision making could be very dangerous, even life threatening. And while “identity theft” captures the most media attention, clinicians and the health care system also need to find the right balance in terms of exchanging personal data for treatment: how much data are needed to make decisions? How can we ensure clinicians have enough data without exceeding what they need and compromising the person’s privacy?

15.4.2 Challenges Faced by Their Clinician

Even when a clinician understands digital technologies and the potential benefits of their use, there are still barriers to them embracing and adopting new technologies:

- Stress caused by changes to workflows: In the USA, the introduction of mandatory electronic health record use to comply with the Affordable Care Act has been shown to have aggravated pre-existing high levels of stress and burnout in physicians. In one study, burnout prevalence was considerably higher among physicians who used electronic health records, with 27.2% of that group reporting one or more burnout symptoms, compared with 13.6% of physicians who did not use an electronic health record. Spending time working on an electronic health record poses a direct challenge to connecting with patients and it may be perceived as not improving patient care. It is also stressful for the clinician if the time is not reimbursed, or they are spending a lot of time on it at home. New technologies may also be used to help alleviate clinician documentation burden and associated burnout. A new type of clinical assistant now being developed—the digital scribe—can take advantage of advances in speech recognition, natural language processing and artificial intelligence, to automate the clinical documentation task and potentially improve doctor-patient communication and person-centred care during consultations [46, 47].
- Speed of innovation. The innovation process for digital health is an iterative cycle for technological solutions that can be classified into five main activity processes from the identification of the healthcare problem, research, digital solution, and evaluating the solution, to implementation in working clinical practices. Digital health may incorporate methods and tools adopted by software engineering, such

as design thinking and agile software development. These commonly follow a user-centred approach to design, which are evaluated by subject-matter experts in their daily life using real-world data. In 2019, the FDA published a *Digital Health Innovation Action Plan* that would reduce inefficiencies for physicians to cut overhead costs, improve access, increase quality of service, and make medicine more easily adapted for each person. Topics within the innovation plan are wireless devices, telemedicine, software, and cybersecurity, among others.

- Clinicians, on the other hand, may be hesitant to adopt new tools into practice due to the difficulty of vetting the wide range of digital products being introduced with each passing day. This is in the context of many physicians having a negative attitude about the benefits of digital technologies, due to usage-related stress. The speed of development means that there is little evidence base for the new technologies: by the time a high quality RCT is undertaken and published (3–5 years), the technology being evaluated may well be obsolete. Regulatory approval of the device (by FDA or Fair Trade Commission) is one solution but creates bureaucratic disincentives for the developer. The creation of digital health "formularies" that catalogue the digital health tools that have been deemed to be high-quality is another solution (https://www.mobihealthnews.com/news/north-america/express-scripts-launch-stand-alone-digital-health-formulary-2020).
- Loss of power and control: Most physicians are not trained in shared decision making, so are likely to find it stressful. If the patient is armed with (mis-)information they found on the Internet and output from medical devices, this can add to the physician's stress. Physicians should not misunderstand shared decision-making as diminishing their role to merely the provider of information and options. Rather they need to understand their role as the enablers of "enhanced patient autonomy" which, according to Quill, encourages patients and physicians to actively exchange ideas, explicitly negotiate differences, and share power and influence to serve the patient's best interests [48]. As a result, the physician's recommendations aim to promote "an intense collaboration" with the patient so that the patients can then autonomously make choices that are informed by both the medical facts and the physician's experience. Nowadays, those facts include the data obtained from digital technologies.
- The broad scope of digital health technologies makes it hard to regulate: in the USA for example, the "Cures Act" which was enacted to accelerate medical product development and bring new innovations and advances to patients who need them faster and more efficiently, requires more than 1200 words to define what a medical device is (21st Century Cures Act Sec. 3060. Clarifying Medical Software Regulation). Similarly, the Food and Drug Administration's (FDA) understanding of whether software is a medical device continues to evolve https://www.fda.gov/medical-devices/digital-health. To add to the confusion, digital health includes various activities that may or may not overlap with each other, e.g. Healthcare Information Technology, Health Information Management Systems, eHealth, mHealth, uHealth. Certainly, individuals vary in their uptake of new technologies, but terms like "prescription-only digital therapeutics", "data migration", "digitally enabled workforce", "user interface", "functional-

ity", "interoperability" and "cybersecurity" will turn off many—especially those who are seeking to reconnect with lost values in health care.

15.5 Conclusion

The mass production and widespread use of computers, digital cellular phones, and the Internet has the potential to improve health care and make it more person-centered. The goal of digital health is to provide more effective and efficient health care through the use of information and communication technologies [3]. However, to date, technology-driven change has impacted less on health care than it has on other industries. This can be explained by several obstacles including disparities in access and engagement with digital technologies, concerns about privacy and security of sensitive health information, limited evidence for effectiveness and concerns about safety (e.g. using mental health apps) and concerns about robots replacing clinicians. If these obstacles can be overcome, digital health can make heath care more person centered (of, with, for and by the person) through more individualized assessment, enhanced sharing of decision making and collaborative treatment planning, and by supporting health behavior change and greater participation in self-management.

Acknowledgements and Disclosures No conflicts of interest are reported with any of the products mentioned. Drs. Glare and Ashton-James have philanthropic grants from several private foundations to study text messaging to support opioid tapering.

References

1. Steinhubl SR, Topol EJ. Digital medicine, on its way to being just plain medicine. NPJ Digit Med. 2018;1:20175.
2. Anonymous. A digital (r)evolution: introducing The Lancet Digital Health. Lancet Digit Health. 2019;1(1):e1.
3. Bhavnani SP, Narula J, Sengupta PP. Mobile technology and the digitization of healthcare. Eur Heart J. 2016;37(18):1428–38.
4. Topol EJ. Transforming medicine via digital innovation. Sci Transl Med. 2010;2(16):16cm14.
5. Huckvale K, Wang CJ, Majeed A, Car J. Digital health at fifteen: more human (more needed). BMC Med. 2019;17(1):62.
6. Martin T. Assessing mHealth: opportunities and barriers to patient engagement. J Health Care Poor Underserved. 2012;23(3):935–41.
7. Gelhaus P. I, Medical Robot. On the differences between a virtuous doctor and a good robot. Int J Per Cent Med. 2011;1(2):301–6.
8. Widmer RJ, Collins NM, Collins CS, West CP, Lerman LO, Lerman A. Digital health interventions for the prevention of cardiovascular disease: a systematic review and meta-analysis. Mayo Clin Proc. 2015;90(4):469–80.
9. O'Donoghue J, Herbert J. Data management within mHealth environments: patient sensors,mobile devices, and databases. ACM J Data Inform Qual. 2012;4(1):20.

10. Brose SW, Weber DJ, Salatin BA, Grindle GG, Wang H, Vazquez JJ, Cooper RA. The role of assistive robotics in the lives of persons with disability. Am J Phys Med Rehabil. 2010;89(6):509–21.
11. Usher-Smith J, Emery J, Hamilton W, Griffin SJ, Walter FM. Risk prediction tools for cancer in primary care. Br J Cancer. 2015;113(12):1645–50.
12. Handelman GS, Kok HK, Chandra RV, Razavi AH, Lee MJ, Asadi H. eDoctor: machine learning and the future of medicine. J Intern Med. 2018;284(6):603–19.
13. Saner H. eHealth: from unfulfilled promises to large-scale application. Eur J Prev Cardiol. 2016;23(2 suppl):3–4.
14. Steinhubl SR, Muse ED, Topol EJ. Can mobile health technologies transform health care? JAMA. 2013;310(22):2395–6.
15. Carayon P, Wetterneck TB, Rivera-Rodriguez AJ, Hundt AS, Hoonakker P, Holden R, Gurses AP. Human factors systems approach to healthcare quality and patient safety. Appl Ergon. 2014;45(1):14–25.
16. Bonnechere B, Jansen B, Omelina L, Van Sint Jan S. The use of commercial video games in rehabilitation: a systematic review. Int J Rehabil Res. 2016;39(4):277–90.
17. Boonstra TW, Nicholas J, Wong QJ, Shaw F, Townsend S, Christensen H. Using mobile phone sensor technology for mental health research: integrated analysis to identify hidden challenges and potential solutions. J Med Internet Res. 2018;20(7):e10131.
18. Chuchu N, Takwoingi Y, Dinnes J, Matin RN, Bassett O, Moreau JF, Bayliss SE, Davenport C, Godfrey K, O'Connell S, Jain A, Walter FM, Deeks JJ, Williams HC, G. Cochrane Skin Cancer Diagnostic Test Accuracy. Smartphone applications for triaging adults with skin lesions that are suspicious for melanoma. Cochrane Database Syst Rev. 2018;12:CD013192.
19. Bennett R, French A. Rise of the smart device ECG and what it means for the general cardiologist. Heart. 2019;105(22):1763–4.
20. Gerardo CD, Cretu E, Rohling R. Fabrication and testing of polymer-based capacitive micromachined ultrasound transducers for medical imaging. Microsyst Nanoeng. 2018;4:19.
21. Hafezi H, Robertson TL, Moon GD, Au-Yeung KY, Zdeblick MJ, Savage GM. An ingestible sensor for measuring medication adherence. IEEE Trans Biomed Eng. 2015;62(1):99–109.
22. Laranjo L, Arguel A, Neves AL, Gallagher AM, Kaplan R, Mortimer N, Mendes GA, Lau AY. The influence of social networking sites on health behavior change: a systematic review and meta-analysis. J Am Med Inform Assoc. 2015;22(1):243–56.
23. Cobb NK, Graham AL. Health behavior interventions in the age of facebook. Am J Prev Med. 2012;43(5):571–2.
24. Laranjo L, Dunn AG, Tong HL, Kocaballi AB, Chen J, Bashir R, Surian D, Gallego B, Magrabi F, Lau AYS, Coiera E. Conversational agents in healthcare: a systematic review. J Am Med Inform Assoc. 2018;25(9):1248–58.
25. Kocaballi AB, Quiroz JC, Rezazadegan D, Berkovsky S, Magrabi F, Coiera E, Laranjo L. Responses of conversational agents to health and lifestyle prompts: investigation of appropriateness and presentation structures. J Med Internet Res. 2020;22(2):e15823.
26. Fitzpatrick KK, Darcy A, Vierhile M. Delivering cognitive behavior therapy to young adults with symptoms of depression and anxiety using a fully automated conversational agent (Woebot): a randomized controlled trial. JMIR Ment Health. 2017;4(2):e19.
27. Greene JA, Lea AS. Digital futures past—the long arc of big data in medicine. N Engl J Med. 2019;381(5):480–5.
28. Hickey KT, Biviano AB, Garan H, Sciacca RR, Riga T, Warren K, Frulla AP, Hauser NR, Wang DY, Whang W. Evaluating the utility of mHealth ECG heart monitoring for the detection and management of atrial fibrillation in clinical practice. J Atr Fibrillation. 2017;9(5):1546.
29. Obermeyer Z, Emanuel EJ. Predicting the future—big data, machine learning, and clinical medicine. N Engl J Med. 2016;375(13):1216–9.
30. Tian M, Ajay VS, Dunzhu D, Hameed SS, Li X, Liu Z, Li C, Chen H, Cho K, Li R, Zhao X, Jindal D, Rawal I, Ali MK, Peterson ED, Ji J, Amarchand R, Krishnan A, Tandon N, Xu LQ, Wu Y, Prabhakaran D, Yan LL. A cluster-randomized, controlled trial of a simplified multifac-

eted management program for individuals at high cardiovascular risk (SimCard Trial) in rural Tibet, China, and Haryana, India. Circulation. 2015;132(9):815–24.

31. Jiang X, Ming WK, You JH. The cost-effectiveness of digital health interventions on the management of cardiovascular diseases: systematic review. J Med Internet Res. 2019;21(6):e13166.
32. Ekman B. Cost analysis of a digital health care model in Sweden. Pharmacoecon Open. 2018;2(3):347–54.
33. deBronkart D. From patient centred to people powered: autonomy on the rise. BMJ. 2015;350:h148.
34. Scott-Sheldon LA, Jennings EG, Thind H, Rosen RK, Salmoirago-Blotcher E, Bock BC. Text messaging-based interventions for smoking cessation: a systematic review and meta-analysis. JMIR Mhealth Uhealth. 2016;4(2):e49.
35. Neves AL, Freise L, Laranjo L, Carter AW, Darzi A, Mayer E. Impact of providing patients access to electronic health records on quality and safety of care: a systematic review and meta-analysis. BMJ Qual Saf. 2020;29(12):1019–32.
36. Webb TL, Joseph J, Yardley L, Michie S. Using the internet to promote health behavior change: a systematic review and meta-analysis of the impact of theoretical basis, use of behavior change techniques, and mode of delivery on efficacy. J Med Internet Res. 2010;12(1):e4.
37. Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. Health Aff (Millwood). 2013;32(2):207–14.
38. Veroff D, Marr A, Wennberg DE. Enhanced support for shared decision making reduced costs of care for patients with preference-sensitive conditions. Health Aff (Millwood). 2013;32(2):285–93.
39. Heron KE, Smyth JM. Ecological momentary interventions: incorporating mobile technology into psychosocial and health behaviour treatments. Br J Health Psychol. 2010;15(Pt 1):1–39.
40. Nahum-Shani I, Smith SN, Spring BJ, Collins LM, Witkiewitz K, Tewari A, Murphy SA. Just-in-time adaptive interventions (JITAIs) in mobile health: key components and design principles for ongoing health behavior support. Ann Behav Med. 2018;52(6):446–62.
41. Michie S, Richardson M, Johnston M, Abraham C, Francis J, Hardeman W, Eccles MP, Cane J, Wood CE. The behavior change technique taxonomy (v1) of 93 hierarchically clustered techniques: building an international consensus for the reporting of behavior change interventions. Ann Behav Med. 2013;46(1):81–95.
42. Greaves CJ, Sheppard KE, Abraham C, Hardeman W, Roden M, Evans PH, Schwarz P, I. S. Group. Systematic review of reviews of intervention components associated with increased effectiveness in dietary and physical activity interventions. BMC Public Health. 2011;11:119.
43. Kvedar JC, Fogel AL, Elenko E, Zohar D. Digital medicine's march on chronic disease. Nat Biotechnol. 2016;34(3):239–46.
44. Miles A. Person-centered medicine—at the intersection of science, ethics and humanism. Int J Pers Cent Med. 2012;2(3):329–33.
45. Eysenbach G. The law of attrition. J Med Internet Res. 2005;7(1):e11.
46. Coiera E, Kocaballi B, Halamka J, Laranjo L. The digital scribe. NPJ Digit Med. 2018;1:58.
47. Quiroz JC, Laranjo L, Kocaballi AB, Berkovsky S, Rezazadegan D, Coiera E. Challenges of developing a digital scribe to reduce clinical documentation burden. NPJ Digit Med. 2019;2:114.
48. Quill TE, Brody H. Physician recommendations and patient autonomy: finding a balance between physician power and patient choice. Ann Intern Med. 1996;125(9):763–9.

Chapter 16
Person-Centered Rehabilitation

Marianne Farkas, Juerg Kesselring, and Mary D. Slavin

16.1 Introduction

16.1.1 Person-Centered Care in Rehabilitation

While two traditions, i.e. physical medicine and rehabilitation, emerged as mainstream medical practice during the first half of the twentieth century as approaches to treating veterans with disabling conditions, the roots of what came to be called "rehabilitation" can be traced back to much earlier traditions. For example, Galen described rehabilitative treatments for injured soldiers in the second century BCE, while in the twelfth century, Maimonides emphasized Talmudic principles of medicine as a holistic approach that included diet, exercise and preventative medicine [1]. The World Health Organization [2] defines rehabilitation as "a set of interventions needed when a person is experiencing or is likely to experience limitations in everyday functioning due to aging or a health condition, including chronic diseases or disorders, injuries or traumas". While general medicine typically views health and function in relation to disease processes and thus focuses primarily on the management and stabilization of pathologic conditions, rehabilitation emphasizes the improvement of health and function across multiple domains, (e.g. sensory, physical movement, as well as having relationships or keeping a job [2]. Rehabilitation,

---

M. Farkas (✉)
Rehabilitation Research and Training Center, Center for Psychiatric Rehabilitation, Boston University, Boston, MA, USA
e-mail: mfarkas@bu.edu

J. Kesselring
Department of Neurology and Neurorehabilitation, Rehabilitation Centre, Valens, Switzerland

M. D. Slavin
Health Outcomes Unit, Health Law, Policy and Management, Boston University School of Public Health, Boston, MA, USA
e-mail: mslavin@bu.edu

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_16

in other words, focuses on the complex interactions among multiple personal and environmental variables, including social factors, occupation, living situation, activities of daily living that impact health and function and optimize quality of life [1–3].

Given the aim of rehabilitation, the active engagement of persons served is the cornerstone of its services or interventions. Person-centered care (PCC) includes an approach to the planning and delivery of services across settings and time, centered around collaborative partnerships among individuals, their families and providers, that is responsive to an individual's priorities, needs, and values [4–6]. The focus and goals of Person-Centered Care are not only consistent with rehabilitation service delivery, but have been endorsed by professional organizations and health institutions, as a model for rehabilitation [7]. Advances in rehabilitation in these areas of PCC is exemplified by three of its major developments: (1) use of shared decision making; (2) increasing prominence of patient reported outcome measures (PROMs); and (3) adoption of research methodologies that include perspectives of persons served.

Shared Decision Making (SDM) Both the structure of services (e.g. supportive culture) and care processes are affected by the integration of shared decision making. It is an interactive process in which people, regardless of their disability, are supported by clinicians to consider options and to achieve informed preferences. Research has demonstrated the importance of connection, continuity and calibration of the relationship to set the conditions for PCC [8]. A strong therapeutic alliance is the basis of SDM, while evidence strongly suggests that informed preferences clearly improves motivation [9]. SDM has been shown to improve patient-centered care [10] and is an integral component of goal setting in rehabilitation [11]. However, it has been demonstrated to be lacking in practice. A systematic review [12] revealed that service recipients are still not routinely involved in goal-setting due to a lack of education of clinicians and patients about using SDM.

Patient/Person-Reported Outcome Measures Rehabilitation interventions target a broad range of social, emotional, medical, and vocational domains [1] and can be assessed with patient-reported outcomes measures (PROMs) [13] an assessment congruent with PCC. Assessments from the service recipient's perspective change the way that people think about their conditions and the way that clinicians view their professional roles and relationships with the person [14]. PROMs have become a critical component of rehabilitation practice and reflect a person's own opinion of their condition and abilities. Aggregated PROM data is used to document and benchmark the quality of rehabilitation services provided. When administered longitudinally over an episode of rehabilitative care, PROMs can also be used to set goals, track change over time and document the response to rehabilitation interventions.

Person-Centered Care: Research Initiatives New initiatives that engage the stakeholders as an integral component of the research team, mirror a significant increase in publications on the effects of using person centered approaches [15]. These have strengthened the focus on stakeholder inclusion, established through the Participatory Action Research model commonly used in rehabilitation research [16]. For example, in the US, the Patient-Centered Outcomes Research Institute (PCORI) which aims to improve healthcare delivery and outcomes, routinely involves stakeholders, along with researchers, to evaluate funding applications and participate in overseeing PCORI activities [17].

The complex nature of rehabilitation, requires multidisciplinary teams (e.g. physiatrists, therapists, psychologists, nurses, physical and occupational therapists) with the knowledge and skills needed to provide clinical interventions addressing a broad range of services, including the ability to diagnose and assess impairments; understand activity and participation restrictions and develop and manage treatment plans that addresses multiple concerns [18] to deliver interventions focused on improving function and participation and actively using person centered principles to deliver its practice. Subsequent sections of this chapter describe the implementation of person-centered practices in two specific areas of rehabilitation: psychiatric rehabilitation and neurological rehabilitation.

16.2 Psychiatric Rehabilitation

The mental health field has accepted psychiatric rehabilitation as one of the preferred methods for helping individuals with serious psychiatric disabilities [11, 19].

The broad disabilities associated with mental illnesses cannot be addressed with a single focused intervention alone and thus, psychiatric rehabilitation is not just a series of unique interventions or program models, but rather a field. It has a defined set of values, techniques, program practices and relevant outcomes (e.g., [20, 21]) “Psychosocial” rehabilitation or “Psychiatric rehabilitation” as a field and a service within a comprehensive mental health system, is delivered with the overall purpose of contributing to an individual’s recovery [22] and since its inception has incorporated “person centeredness” as a fundamental principle [21]. While the actual development of person-centered psychiatric rehabilitation may have differed somewhat across different countries, most understand its philosophy, values and overall techniques similarly [23]. Person centered psychiatric rehabilitation (PCPR) is the process of basing the provider-person relationship on the individual’s vision of their own recovery and promoting their capacity to reach their rehabilitation goals within that vision. As in all rehabilitation, PCPR requires a multidisciplinary team able to address whatever domains (living, learning, working, social) reflect the person in mental health recovery’s vision of a meaningful life [24].

16.3 For Whom Is Person Centered Psychiatric Rehabilitation (PCPR) Designed?

First and foremost, Person Centered Psychiatric Rehabilitation (PCPR) was designed to serve *people with* psychiatric disabilities. Using the term “people with…”, also known as “Person First” language focuses PCPR on helping individuals with many characteristics, talents, strengths and interests-and who also have serious mental illnesses, regain valued roles in society. PCPR traditionally serves primarily individuals with serious psychiatric disability. Whether the target population is defined using medical, rehabilitation, mental health, or empirically-derived criteria, all definitions coalesce around the description of a disability that persist over a period of time (usually 2 or more years), with resulting functional impairment, that substantially limits one or more major life activities [25]. Within the group with these characteristics, are many sub-groups: people across different points in the life span, people with co-occurring conditions (e.g. substance abuse and mental illnesses), people who are homeless, and those from a wide range of cultural and ethnic backgrounds. As such, those who can use PCPR services cross diagnostic and demographic categories.

16.4 Recovery and Person-Centered Psychiatric Rehabilitation

The context for individuals with serious mental illnesses has changed considerably over the past 40 years. At present, the idea that people with serious mental illnesses can recover is well accepted (e.g., [26, 27]), even for those in forensic settings [28]. Longitudinal studies carried out between 1972 and 1987 in different countries, had remarkably similar outcomes. One half to two thirds of people with serious mental illnesses, (predominantly schizophrenia), showed marked improvement in terms of variables ranging from symptom reduction to no current signs and symptoms of any mental illness, no current use of medication, working, relating well to family and being integrated into their community [29]. These early findings were confirmed by a later W.H.O longitudinal study. While the results showed heterogeneity of outcomes, the authors concluded that a significant proportion of those diagnosed with psychoses showed favorable long term outcomes consistent with those of the earlier studies [30, 31].

Typically, therefore, recovery outcomes have included multidimensional variables ranging from an increase in physical health and wellbeing to gaining or regaining valued social roles, as well as reducing symptoms [32]. In addition to objective outcomes such as increased success functioning in a range of life roles (worker, student, wife, softball team member, etc.), equally important are subjective outcomes such as an increased sense of self-worth and empowerment and it is these types of outcomes that are most central to a person's recovery from mental illness. The most cited definition of recovery concludes that recovery is "…a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness" [33].

In the current emphasis on recovery-oriented services, implementing the process of PCPR has achieved greater prominence because PCPR's outcomes go beyond simply supporting adaptation or survival in the community. PCPR can and does promote a vision of recovery or the achievement of a meaningful life [22, 34], through its emphasis on gaining or regaining valued roles. The process of PCPR is designed to help people *be successful and satisfied in the living, working, learning, and social environments of their choice* [20, 35]. Rehabilitation operates at the intersection between the individual, an individual's personal network and the wider social context [36]. Rehabilitation, of any kind (i.e., physical, psychiatric, social, etc.) is ecological ("person-environment fit") and specifically targets improving role performance. The term "psychiatric rehabilitation" reflects the focus of this field on *people with psychiatric disabilities* and *their improved abilities within their specific preferred role* in the "real" world, using the development of skills and supports as its primary types of interventions [20, 35]. Without a process committed to supporting chosen roles and settings, functioning may be improved, but the individual's vision of a meaningful life may still not be achieved. Rehabilitation, therefore, works with social relationships, work, leisure, family life, higher education and other student pursuits, using interventions that focus on increasing competencies or skills and providing environmental supports, rather than focusing on symptoms and pathology. For example, the most internationally studied successful intervention within psychiatric rehabilitation is that of supported employment (SE) [37, 38] which focuses on helping people to get work in the competitive marketplace and then supports them while they acquire the skills to be successful in the job. SE does not deny that symptoms and pathology exist, nor the importance of intervening to reduce these (it includes integrated clinical practice in its fidelity scales), however it itself focuses on changing the environment (getting a job) and then improving skills while receiving intensive support.

16.5 Basic Recovery Values That Guide PCPR

PCPR is a *recovery facilitating* process rather than simply a method of organizing staff service delivery. As such, the underlying values that drive a recovery promoting service are integrated into the process of PCPR. While there are many values cited as important to recovery, at least four are universally recognized as critical: *person orientation, person involvement, self-determination and hope* [34]. These four values together reflect the "person centered" aspect of 'person centered' psychiatric rehabilitation.

Person Orientation—Accounts written by individuals with serious psychiatric disabilities, describe both how appreciative people are when providers express interest in their strengths and talents and how damaging it is when providers reduce individuals to the list of symptoms they have, or the label they carry. Microaggressions based on stereotypic views affect mental health [39]. PCPR expresses the importance of the value of "person orientation" or seeing the person holistically, in that it focuses its assessments of physical, emotional and intellectual functioning and support on both strengths and deficits. Individuals go through a process of identifying their own vision of a recovered life with a specific role that they hope to achieve within it. Their interests shape their perspective on what role they prefer (e.g. part time worker, college student, tenant, mother with children) and that role determines which skills and supports are evaluated.

Person Involvement—The fundamental basis for psychiatric rehabilitation interventions is a commitment to an equal partnership between the provider and the individual receiving services. Recent studies emphasize the importance of partnership in modern clinical services, even in risk management (e.g. [40, 41]). In recovery-oriented services, people with psychiatric disabilities are partners in the delivery of interventions that promote their recovery. They bring their expertise about their own recovery process to the table, while providers bring expertise about interventions. In PCPR, providers use the expertise of the people being served to decide which components of the PCPR process to deliver, to decide on goals and types of interventions used. The entire process is based on the perspective of the person with the disability, with provider skills such as reflective or active listening, forming the core provider competency needed to create equal footing in the partnership. Providers function as coaches and teachers in PCPR rather than as the experts whose role is to solve problems. As such they teach, coach, and consult to the person with the psychiatric disability about what s/he needs to know to be able to choose, get and keep the valued role s/he wants to achieve.

Choice or Self Determination—Self-determination and self-choice is the cornerstone of the process designed to promote an individual's journey to achieving their own vision of a meaningful life. The opportunity to choose one's long term goals, the methods to be used to get to those goals and the individuals or providers who will assist in the process, are all components of a service acknowledging this value. PCPR helps individuals determine where and in what role they want to live, learn, work or socialize. Beginning rehabilitation with this process helps to establish the individual'*s hopes* for a future, rather than beginning with an assessment of strengths and deficits and then determining a goal that "fits". When individuals being served do not have much experience making important choices in their lives, PCPR helps to arrange opportunities for people to experience different options and then helps them to clarify what they learned was important in these options, rather than taking over and making the choice for the person. In mental health services, SDM as a specific process or incorporated into decision-making processes have shown a positive impact on the individual's capability to reflect on old habits in more constructive ways as well as to improve psychosocial functioning [42]. Promoting self-determination and choice does not mean that practitioners have no right to share their opinions and thoughts in the PCPR process [43]. As Anthony [44] points out, while there are times when an individual may have difficulty being the 'captain of his ship', the onus is on the PCPR practitioner to explain why the person *cannot* make their own choice in the moment, rather than operating on the *assumption* that the person cannot do so. The issue of providing choice is important as a value and as a question of empowering individuals to regain control over their lives, their rights and citizenship in society [11, 45].

Hope—Hope is the basis for a willingness to change. Having someone believe in a person, even when s/he does not believe in him or herself, has been identified by individuals as the critical ingredient in their recovery [46]. While research has consistently shown that professionals do no better than random chance in predicting success [20], some staff believe that the people they serve are “too sick” to recover and that the data on recovery surely refers to types of clients other than the ones they serve. For example, many mental health professionals believe that work is too stressful despite abundant evidence to the contrary (e.g., [47]). Unfortunately, these providers contribute to the fear of going to work by focusing on deficits and chronicity, and using professional coercion [48], which can demoralize and distress even the most resilient person [49]. PCPR increases hope by first focusing on the roles that reflect the person’s aspirations. This insistence on a process that helps individuals consider options and choose a role and setting they prefer, communicates to the person that their dreams are valid and that the process of PCPR involves helping them to figure out what skills and resources they have or don’t have in relation to achieving their goal [11, 35]. Some individuals of course, have lost their hope in the years spent struggling with their illnesses, the accompanying poverty, loss of relationships and opportunities. PCPR acknowledges these negative realities and uses a systematic approach to help the person understand where they are currently in relation to considering their future.

16.6 The Process: Values Plus Techniques

PCPR as a process attempts to help people determine the living, education, work and social roles they want to reach over the subsequent 6–24 months. Roles chosen within a period of 2 years are likely to be concrete enough to motivate the person, (as compared to long term goals which are closer to a vision than a goal) and far enough away that the person has the opportunity to improve to achieve them. For example, a goal might be “I intend to live in an apartment with a roommate, in the Falmouth district of the city by July of 2017”. Some people are not prepared to even consider setting a goal. Techniques of assessing and developing readiness for rehabilitation [50, 51] are designed to identify factors that provide obstacles considering change, with techniques designed to inspire that hope. Some of these factors include a lack of satisfaction or success in the person’s current situation (greater dissatisfaction leading to greater willingness to consider a new situation); a perception by the individual that change may be possible, bring positive results and is manageable for the person to do; a level of awareness about options and an awareness of personal values and interests. For those who *are* prepared to set a goal, providers facilitate the individual’s self determination by helping the person to develop the ability to select a role and setting, which they wish to reach or improve on. Such activities are then followed by engaging the person in a systematic method of problem solving [52].

After setting a “role goal”, provider assistance is focused on helping people to identify what they need and what they know how to do well (skills) and what they have or need to have (support or support resources), in order to achieve these goals. The relationship in which this occurs emphasizes an equal partnership, a holistic perspective and hopefulness. For example, the person in the previous goal example might have the intellectual skill of “Organizing my belongings” (a skill important when living with a roommate in a small apartment) but not have the emotional skill of “Resolving conflicts” (a skill equally important to living with a roommate). Functional assessment, or the evaluation of physical, emotional and intellectual skill strengths and deficits are only done in relation to the demands of the preferred role, rather than being a generic checklist of skills that anyone might need to do anything (e.g. budgeting, transportation, grooming)—but that might not be helpful to the specific goal. For example, if the goal is to “live in an apartment in Borne, with a roommate until July 20---”, the roommate might not care about the person’s grooming. Budgeting might only be important to the extent to which the person can pay rent—budgeting for other items may make no difference. In this way, assessments are kept specific to the goal that has been selected by the person and are tailored to be manageable for the precise demands of a specific environment. Therefore, people are helped to develop those unique skills and/or supports intended to help them to become successful and satisfied in the specific roles they have selected. Individuals are thus either taught to perform skills they don’t have, or supported in overcoming obstacles to using the skills they have, but don’t perform sufficiently well to be successful and satisfied in the selected role. Support needs are met by either linking people to resources they might not have or helping to modify existing resources so that they can provide more support. PCPR includes both techniques to help the person make changes in their environment *and* techniques that help to modify the environment around the person (e.g. facilitating changes in laws, attitudes to people with psychiatric disabilities, that create barriers to the person’s achievement of their chosen valued role). In simpler terms, the PCPR rehabilitation process helps people determine their own goals and then obtain the skills and environmental support necessary to achieve them.

PCPR, as described here, has been studied in empirical studies conducted in the United States [53, 54] and in studies conducted in European countries [55–57]. More recent studies have also confirmed the efficacy of this approach. For example, a 2 year follow up study conducted in Sweden followed a group of 71 clients across a county in Sweden where they were receiving psychiatric rehabilitation services. Of these 71 clients, 49 were still being followed at the end of 2 years. Results indicated that 65% of the clients reported that they had mainly or almost completely achieved their self-formulated rehabilitation goals at the 2-year follow-up. There were significant differences with regard to health, empowerment, quality of life and psychosocial functioning for those who reported that they had mainly/completely had achieved their self-formulated rehabilitation goals compared to those who reported that they only had to a small extent or not at all reached their goals [58].

From the perspective of the person for whom the service is intended, PCPR helps people choose their goals, obtain and/or maintain them, depending on their needs and willingness [35]. This client view of the process has been called “Choose-Get-Keep”. A qualitative study [59] conducted on the experience of the person being served in the 2 year follow up study focused on a sub set of 10 participants who had been in services continuously for 24 months and were over 18 years of age. Participants responded to open ended questions and were encouraged to describe their experiences in their own words. The analysis of the clients' experiences resulted in three categories: increased self-understanding, getting new perspectives, and being in a trusting relationship, which can be seen as important part of a sense of being connected to oneself and others. The participants' experiences of being respected as equal individuals and the importance of getting the necessary resources and insights to be able to make decisions and set goals according to individual preferences was a strong theme throughout the interviews. The approach is described by the interviewees as engaging the person by regularly giving them the opportunity to get their perspective reflected and to be able to participate in decision making regarding their own rehabilitation.

Person centered psychiatric rehabilitation is an approach to helping an individuals with serious psychiatric disabilities, among other issues, to choose, get and keep their preferred role in society. Using a wide variety of tools and possible perspectives and strategies to increase activity and participation or disability and handicap, it contributes to the person's recovery journey, helping the individual move towards a unique vision of a meaningful life.

16.7 Neurorehabilitation: Applied Neuroplasticity and Resilience in Practice

Like psychiatric rehabilitation, neurorehabilitation has become a well-accepted tool in the array of interventions important to the successful treatment of neurological disorders, especially in their chronic stage. Enormous strides have been made in increasing the range and efficacy of disease-modifying drugs available for the treatment many neurological disorders e.g. stroke, multiple sclerosis (MS), brain tumours, movement disorders, traumatic brain injury (TBI) etc. in early and remitting stages.

Patient engagement is a vital aspect of neurological management, in which individuals are fully involved and are encouraged to strive and put effort into meeting treatment goals. In this approach, healthcare providers become motivators and patients need less intervention and consume fewer resources. Numerous interventions that promote neurorehabilitation are available, though evidence to support their use is limited by a lack of data from large randomised controlled trials. Combining interventions that promote neurorehabilitation with newer, more effective treatments creates a promising potential to substantially improve the outlook for most patients with chronic neurological disorders.

When initiating a neurorehabilitation programme, it is important to appreciate the value of maintaining resilience and neuroplasticity in patients and to understand the approaches that can encourage these factors and promote neurorehabilitation Resilience includes components such as nutrition, self-belief and physical activity which provide a stronger response to the disease and improved responses to treatment. Neuroplasticity is the capacity of the brain to establish new neuronal networks after lesion damage has occurred and distant brain regions assume control of lost functions.

Medications have limited capacity to ameliorate all the existing disabilities that neurological patients may have, particularly those with progressive diseases. The potential of physical and cognitive therapies, and the benefits that neurorehabilitation can provide for the patient, especially when combined with pharmacological therapy is critical to success. We want to consider here the mechanism of action of neurorehabilitation and interventions that can promote it, in particular with respect to resilience and neuroplasticity [60].

16.7.1 Resilience in Neurological Disorders

Resilience, in the neurological context is related to psychological adaptation, social connection, life meaning, planning and physical wellness. The concept of resilience comprises physical, mental and emotional components including good nutrition, rest and self-belief (see Fig. 16.1).

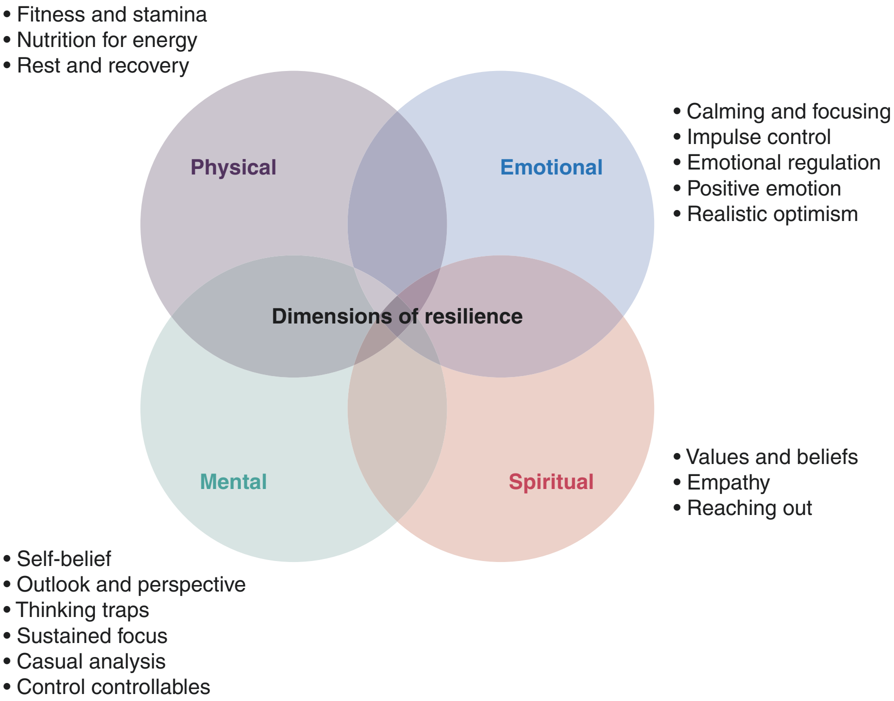


Fig. 16.1 Dimensions of resilience in response to disease and treatment

Without such activity and participation, there is insufficient neuronal stimulation, diminishing or eliminating the prospect of recovery. Patients must be encouraged to develop resilience in order to maximises of their lost physical abilities.

16.7.2 The Importance of Neuroplasticity

Neuroplasticity is another important concept in the treatment of neurological conditions. It is defined as the physical ability of the nervous system to adapt to changes. Not all of the changes in brain activity are adaptive, and thus behaviourally beneficial. Neuroplasticity can also be maladaptive and contribute to or sustain disability [61]. Furthermore, it is not known whether neuroplasticity is diminished with progressive disease.

At the behavioural level, neuroplasticity can be induced using novel motor and cognitive strategies, which counter problems of despair and resignation common to many neurological patients. At cortical sites remote from the lesion, reorganisation of neurons may effectively bypass the damage, suggesting high levels of neuroplasticity in animal brains.

Further work on human brains using fMRI has shown that simple functions such as moving a hand, involve more areas of the brain and more energy usage in non-disabled patients with a chronic neurological condition (e.g. MS) than in normal control individuals [62–64]. In some conditions, such as stroke, there is restoration towards the original physiological network over time and different and more complex patterns of network connections are established [65, 66]. Studies have also shown that, following an initial increase in brain functional connectivity, it then declines over the following 2 years, resulting in a decreased ability to compensate for neuronal damage, which may lead to disability progression.

These studies collectively provide evidence of functional changes at brain sites remote from the injury or lesion and stress the importance of treatments aimed at maintaining neuroplasticity and brain reserve to inhibit or prevent irreversible disability progression. To harness neuroplasticity to achieve neurorehabilitation, we need interventions that combine a strong scientific and biological rationale with monitoring of clinically meaningful functional and structural changes in the brain. As with psychiatric rehabilitation, a multidisciplinary team that centres on the patient and their caregiver is required. This team should involve a neurologist trained in rehabilitation medicine, and multiple other therapists including speech therapists, psychologists, nurses, orthopaedic technicians, physiotherapists, ergo-therapists, occupational therapists, and social service representatives (see Fig. 16.2). This coordinated multidisciplinary team enables all aspects of the disease, including problems with mobility, gait, bladder/bowel disturbances, fatigue and depression to be effectively treated.

All should interact and work to create an integrated clinical care pathway. This should include patient-defined needs and goals, and therapists' assessment of problems (mobility, self-care ADL, communication, daily occupations and social interactions). Setting of common goals should be performed at an interdisciplinary level and should be clear, specific, meaningful, realistic and measurable (e.g. "In seven days you will be able to climb stairs or dress yourself"). Assessment of goal achievements should be regular and goals adapted if necessary. Although limited, available evidence suggested that inpatient or outpatient rehabilitation programmes may improve disability, bladder dysfunction, and participation in neurological patients, and the effects may last up to 12 months. Providing intensive individual attention to all neurological patients is a challenge since access to treatments and services is highly variable and often limited by the availability of healthcare resources.

Neurorehabilitation takes many forms depending on the various physical or mental manifestations of the disease in each patient and the problems they encounter. Some of these symptoms can be addressed using an increased range of effective drug therapies. Other symptoms, however, require treatments that harness the

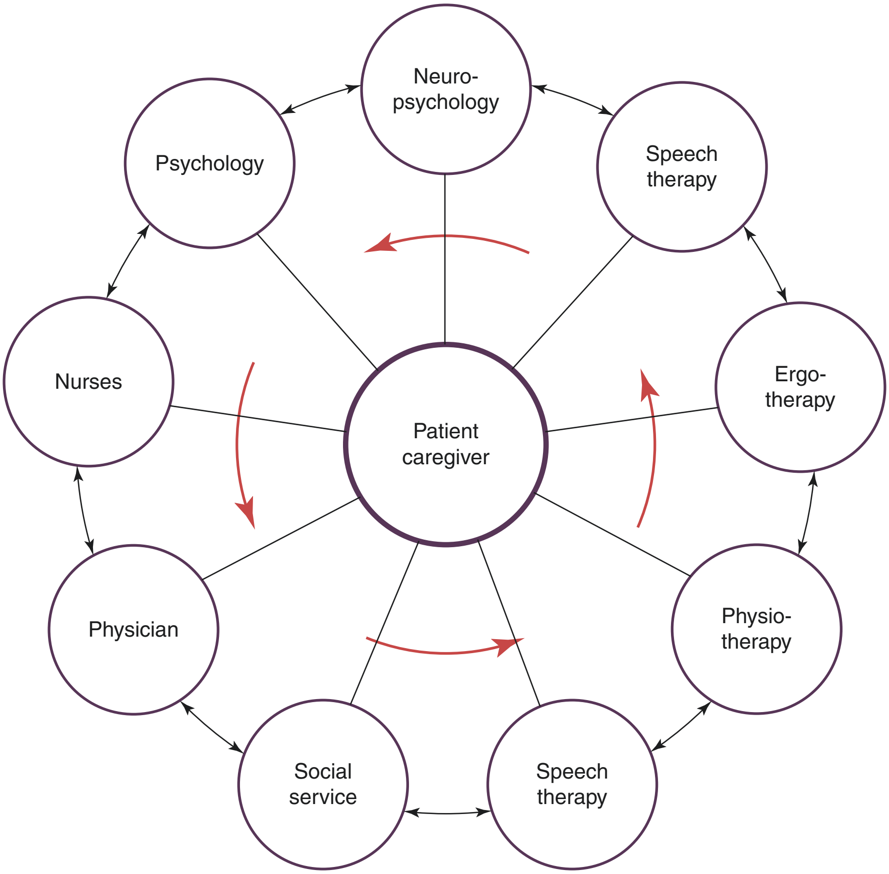


Fig. 16.2 Coordinated interaction of specialists in neurorehabilitation around/for patient & caregiver

neuroplasticity of the CNS, i.e. its innate ability to adapt to change. These include physical therapy such as exercise programs and gait training whereas others require cognitive or psychiatric therapy. Numerous studies have demonstrated the considerable value of such interventions and these are especially effective when used in conjunction with pharmacological treatments. It is essential that standardised measures and endpoints for determining neurorehabilitation interventions are agreed in order to properly assess their value in different neurological patient populations around the world.

There are now strong grounds for optimism in the management of neurological disorders. Increased use of newer medications coupled with defined programmes of education/training and goal setting are likely to substantially improve the prognosis in many patients, particularly during the early disease stages of their diseases. These interventions collectively promote neuroplasticity and neurorehabilitation and have the potential to halt further neurodegeneration. As a result, patients diagnosed with a neurological disorder today can expect substantially more active lives, generally better outcomes than previously, and possibly some recovery of lost function.

16.8 Conclusions and Practical Issues on Implementation of Person Centered Care

There are many barriers to full access to these PC rehabilitation services, such as limited workforce with the skills to deliver this kind of rehabilitation as well as general funding limitations for intensive, long term services. One major barrier appears to be provider perceptions that recovery is not possible and a lack of training in the skills required to deliver the type of interventions described in this chapter. For example, two recent studies found that negative beliefs about the employability of people with serious mental illnesses constituted a significant barrier to their employment [67] and affected the implementation of evidence - based employment practices [68]. Training has been cited as an important element in overcoming the lack of PCC in services. Providers trained in the concept of recovery were less likely to stigmatize or hold “non person oriented” beliefs about the people they were serving [69] while those trained in strengths based interventions were more likely to be willing to support people in positive goal oriented risk taking at 6 month follow up [70].

While these barriers do exist, recent international developments in medicine support person centered psychiatric rehabilitation and neurorehabilitation in its quest for the promotion of functioning and quality of life. Institutions exist to provide such training, such as the Center for Psychiatric Rehabilitation, with the advent of online and blended learning programs making such training more accessible. There is recognition that broad based similarity exists between psychiatric rehabilitation and neurorehabilitation which helps to support the growth of both. Both fields require multidisciplinary teams to deliver a holistic approach based on person engagement and full partnership. Both fields focus on helping to rebuild or strengthen functional capacity in critical areas of a person's life, rather than focus primarily on "curing" the disorder. Both fields understand that helping individuals set personally meaningful goals, harnessing or activating the person's resilience through structured interventions to help them achieve those goals, motivates people to achieve far more than they might have done. This motivation infuses the process both for providers and service recipients and their families with hope, a powerful "drug" in its own right and the importance of recovery for individuals with long term conditions, such a mental illnesses or neurological disorders.

Acknowledgements and Disclosures Authors do not report conflicts of interest.

References

1. Atenelov L, Stiens SA, Young MA. History of physical medicine and rehabilitation and its ethical dimensions. AMA J Ethics. 2015;17(6):568–74. https://doi.org/10.1001/journalofethics.2015.17.6.mhst1-1506.
2. WHO. Rehabilitation. World Health Organization; 2019. https://www.who.int/news-room/fact-sheets/detail/rehabilitation.
3. Stuckl G, Ewert T, Cieza A. Value and application of the ICF in rehabilitation medicine. Disabil Rehabil. 2002;24(17):932–8. https://doi.org/10.1080/09638280210148594.
4. Christodoulou GN, et al. Promoting healthy lives and well-being for all: the contribution of the International College of Person-Centered Medicine (ICPCM). Psychiatriki. 2018;29(1):52–7.
5. Mezzich JE. The Geneva conferences and the emergence of the International Network of Person-centered Medicine. J Eval Clin Pract. 2011;17:333–6.
6. National Quality Forum. Priority setting for healthcare performance: addressing performance measure gaps person-centered care and outcomes. 2014. https://www.qualityforum.org/Publications/2014/08/Priority_Setting_for_Healthcare_Performance_Measurement__Addressing_Performance_Measure_Gaps_in_Person-Centered_Care_and_Outcomes.aspx. Accessed 19 Apr 2020.
7. Hunt M, Ells C. A patient-centered care ethics analysis model for rehabilitation. Am J Phys Med Rehabil. 2013;92(9):818–27. https://doi.org/10.1097/PHM.0b013e318292309b.
8. Hamovitch EK, Choy-Brown M, Stanhope V. Person-centered care and the therapeutic alliance. Community Ment Health J. 2018;54(7):951–8. https://doi.org/10.1007/s10597-018-0295-z.
9. Fulford D, Meyer-Kalos PS, Mueser KT. Focusing on recovery goals improves motivation in first-episode psychosis. Soc Psychiatry Psychiatr Epidemiol. 2020;55(12):1629–37.
10. Voogdt-Pruis H, et al. Improvement of shared decision making in integrated stroke care: a before and after evaluation using a questionnaire survey. BMC Health Serv Res. 2019;19(1):1–15. https://doi.org/10.1186/s12913-019-4761-2.
11. Farkas M, Anthony WA. Psychiatric rehabilitation interventions: a review. Int Rev Psychiatry. 2010;22(2):114–29.
12. Rose A, Rosewilliam S, Soundy A. Shared decision making within goal setting in rehabilitation settings: a systematic review. Patient Educ Couns. 2017;100(1):65–75. https://doi.org/10.1016/j.pec.2016.07.030.
13. FDA and HHS. Guidance for Industry Use in Medical Product Development to Support Labeling Claims Guidance for Industry'. Clin/Med Fed Regist. 2009:1–39.
14. Greenhalgh J, et al. How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? A real synthesis. J Patient Rep Outcomes. 2018;2:42. https://doi.org/10.1186/s41687-018-0061-6.

15. Jesus T, et al. Scoping review of the person-centered literature in adult physical rehabilitation. Disabil Rehabil. 2019;43(11):1626–36. https://doi.org/10.1080/09638288.2019.1668483.
16. Balcazar FE, et al. Participatory action research and people with disabilities: principles and challenges. Can J Rehabil. 1998;12:105–11.
17. Frank L, et al. Conceptual and practical foundations of patient engagement in research at the patient-centered outcomes research institute. Qual Life Res. 2015;24(5):1033–41. https://doi.org/10.1007/s11136-014-0893-3.
18. Neumann V, et al. Interdisciplinary team working in physical and rehabilitation medicine. J Rehabil Med. 2010;42(1):4–8. https://doi.org/10.2340/16501977-0483.
19. Ujeyl M, Rössler W. Psychosocial rehabilitation. Chapter 14. In: Ryznar E, Pederson AB, Reinecke MA, Csernansk JG, editors. Landmark papers in psychiatry; 2020. p. 229–42.
20. Anthony WA, et al. Psychiatric rehabilitation. 2nd ed. Boston: Boston University, Center for Psychiatric Rehabilitation; 2002.
21. Farkas MD, Anthony WA. Psychiatric rehabilitation programs: putting theory into practice. Baltimore, MD: Johns Hopkins University Press; 1989.
22. Farkas M. Identifying psychiatric rehabilitation interventions: an evidence and values based practice (commentary). World Psychiatry. 2006;5(3):6–7.
23. Rossler W. Psychiatric rehabilitation today: an overview. World Psychiatry. 2006;5(3):151–7.
24. Farkas M. Introduction to psychiatric/psychosocial rehabilitation (PSR): history and foundations. Curr Psychiatry Rev. 2013;9(3):177–87.
25. Schinnar AP, et al. An empirical literature review of definitions of severe and persistent mental illness. Am J Psychiatry. 1990;147(12):1602–8. https://doi.org/10.1176/ajp.147.12.1602.
26. Karpetis G. How experienced social workers apply recovery-oriented mental health policies in everyday practice. Eur J Soc Work. 2020;23(1):106–17. https://doi.org/10.1080/13691457.2018.1474855.
27. Van Eck RM, et al. The relationship between clinical and personal recovery in patients with schizophrenia spectrum disorders: a systematic review and meta-analysis. Schizophr Bull. 2018;44(3):631–42. https://doi.org/10.1093/schbul/sbx088.
28. Morgan S, Rees S. An evaluation of recovery in a forensic mental health service. Ment Health Pract. 2018; https://doi.org/10.7748/mhp.2018.e1316.
29. Harding CM. An examination of the complexities in the measurement of recovery in severe psychiatric disorders. In: Schizophrenia: exploring the spectrum of psychosis; 1994. p. 153–69.
30. Harding CM, Zhaniser JH. Empirical correction of seven myths about schizophrenia with implications for treatment. Acta Psychiatr Scand. 1994;90:140–6.
31. Harrison G, et al. Recovery from psychotic illness: a 15-and 25-year international follow-up study. Br J Psychiatry. 2001;178:506–17.
32. Farkas M, et al. Implementing recovery oriented evidence based programs: identifying the critical dimensions. Community Ment Health J. 2005;41(2):141–58.
33. Anthony WA. Recovery from mental illness: the guiding vision of the mental health service system in the 1990s. Psychosoc Rehabil J. 1993;16(4):11–23.
34. Farkas M. The vision of recovery today: what it is and what it means for services. World Psychiatry. 2007;6(2):1–7.
35. Anthony WAA, Farkas M. The essential guide to psychiatric rehabilitation. Boston: Center for Psychiatric Rehabilitation; 2011.
36. Barbato A. Psychosocial rehabilitation and severe mental disorders: a public health approach. World Psychiatry. 2006;5:162–3.
37. Bond G, Drake R. Making the case for IPS supported employment. Adm Policy Ment Health Ment Health Serv Res. 2014;41(1):69–73. https://doi.org/10.1007/s10488-012-0444-6.
38. Reme SE, et al. A randomized controlled multicenter trial of individual placement and support for patients with moderate-to-severe mental illness. Scand J Work Environ Health. 2019;45(1):33–41. https://doi.org/10.5271/sjweh.3753.
39. Barber S, et al. Microaggressions towards people affected by mental health problems: a scoping review. Epidemiol Psychiatr Serv. 2020;29:e82. https://doi.org/10.1017/S2045796019000763.

40. Jorgensen K, Rendtorff J. Patient particiaption in mental health care-perspectives of health care professionals: an integrative view. Scand J Caring Sci. 2018;32:490–501. https://doi.org/10.1111/scs.12531.
41. Rimondini M, et al. Patient empowerment in risk management: a mixed-method study to explore mental health professionals' perspective. BMC Health Serv Res. 2019;19(1):382. https://doi.org/10.1186/s12913-019-4215-x.
42. McCann TV, Clark E. Advancing self-determination with young adults who have schizophrenia. J Psychiatr Ment Health Nurs. 2004;11:12–20.
43. Beyene LS, et al. Being in a space of sharing decision-making for dignified mental care. J Psychiatr Ment Health Nurs. 2019;26(9–10):368–76. https://doi.org/10.1111/jpm.12548.
44. Anthony WAA. Shared decision making, self-determination and psychiatric rehabilitation. Psychiatr Rehabil J. 2010;34(2):87–8.
45. National Council on Disability. From privileges to rights: people labeled with psychiatric disabilities speak for themselves. National Council on Disability; 2000. https://www.ncd.gov/publications/2000/. Accessed 20 June 2020.
46. Deegan P. When the helping professions hurt. Humanist Psychol. 1990;18:301–13.
47. Kukla M, Bond GR, Xie H. A prospective investigation of work and nonvocational outcomes in adults with severe mental illness. J Nerv Ment Dis. 2012;200:214–22.
48. Rapp CA, Goscha RJ. The strengths model: case management with people with psychiatric disabilities. 2nd ed. New York: Oxford University Press; 2006.
49. Drake RE, Bond GR. The future of supported employment for people with severe mental illness. Psychiatr Rehabil J. 2008;31(4):367–76.
50. Cohen MR, Forbess R, Farkas M. Developing readiness for rehabilitation: psychiatric rehabilitation trainer series. Boston, MA: Center for Psychiatric Rehabilitation at Boston University; 2000.
51. Farkas M, et al. Assessing readiness for rehabilitation: psychiatric rehabilitation trainer series. Boston, MA: Center for Psychiatric Rehabilitation at Boston University; 2000.
52. Cohen MR, et al. Establishing an overall rehabilitation goal: psychiatric rehabilitation trainer technology. Boston, MA: Center for Psychiatric Rehabilitation at Boston University; 1992.
53. Rogers E, et al. A randomized clinical trial of vocational rehabilitation for people with psychiatric disabilities. Rehabil Couns Bull. 2006;49(3):143–56.
54. Shern DL, et al. Serving street-dwelling individuals with psychiatric disabilities: outcomes of a psychiatric rehabilitation clinical trial. Am J Public Health. 2000;90:1873–8.
55. Van Busschbach J, Wiersma D. Does rehabilitation meet the needs of care and improve the quality of life of patients with schizophrenia or other chronic mental disorders? Community Ment Health J. 2002;38(1):61–70.
56. Gigantesco A, et al. The VADO approach in psychiatric rehabilitation: a randomized controlled trial. Psychiatr Serv. 2006;57:1778–83.
57. Swildens W, et al. Effectively working on rehabilitation goals: 24-month outcome of a randomized controlled trial of the Boston Psychiatric Rehabilitation Approach. Can J Psychiatry. 2011;56(12):751–60.
58. Svedburg P, et al. A 2-year follow-up study of people with severe mental illness involved in psychosocial rehabilitation. Nord Psychiatry. 2014;68(6):401–8.
59. Jormfeldt H, et al. Client's experiences of the Boston Psychiatric Rehabilitation Approach: a qualitative study. Int J Stud Health Well Being. 2014;9(1):22916. https://doi.org/10.3402/qhw.v9.22916.
60. Kesselring J. Neurorehabilitation in multiple sclerosis—resilience in practice. Eur Neurol Rev. 2017;12(31):1–7.
61. Tomassini V, Matthews PM, Thompson AJ, Fuglø D, Geurts JJ, Johansen-Berg H, Jones DK, Rocca MA, Wise RG, Barkhof F, Palace J. Neuroplasticity and functional recovery in multiple sclerosis. Nat Rev Neurol. 2012;8(11):635–46.
62. Filippi M, Rocca M. Cortical reorganisation in patients with MS. J Neurol Neurosurg Psychiatry. 2004;75(8):1087–9.

63. Kerschensteiner M, et al. Remodeling of axonal connections contributes to recovery in an animal model of multiple sclerosis. J Exp Med. 2004;200(8):1027–38.
64. Reddy H, et al. Functional brain reorganization for hand movement in patients with multiple sclerosis: defining distinct effects of injury and disability. Brain. 2002;125:2646–57.
65. Calautti C, Baron J. Functional neuroimaging studies of motor recovery after stroke in adults: a review. Stroke. 2003;34:1553–6.
66. Dobryakova E, et al. Abnormalities of the executive control network in multiple sclerosis phenotypes: an fMRI effective connectivity study. Hum Brain Mapp. 2016;37:2293–304.
67. Hampson ME, Hicks RE, Watt BD. Beliefs about employment of people living with psychosis. Aust J Psychol. 2018;70(2):103–12. https://doi.org/10.1111/ajpy.12172.
68. Fleming C, et al. Perceptions and practices of mental health professionals regarding the employment of people with serious mental illness. J Vocat Rehabil. 2019;50(1):39–48. https://doi.org/10.3233/JVR-180986.
69. Mötteli S, et al. More optimistic recovery attitudes are associated with less stigmatization of people with mental illness among healthcare professionals working on acute and semi-acute psychiatric wards. Psychiatr Q. 2019;90(3):481–9. https://doi.org/10.1007/s11126-019-09642-3.
70. Deane FP, et al. Changes in mental health providers' recovery attitudes and strengths model implementation following training and supervision. Int J Ment Health Addict. 2019;17(6):1417–31. https://doi.org/10.1007/s11469-018-9885-9.

Chapter 17
Person-Centered Prevention

Salman Rawaf, Celine Tabche, George N. Christodoulou, David Rawaf, and Harumi Quezada-Yamamoto

17.1 Introduction

Identifying novel and more effective intervention strategies in health and healthcare are needed because disability has become an increasing component of disease burden, significant research, development investment, and health expenditure in recent years [1]. With population growth and the rapidly ageing global population, the demands on health services to deal with disabling outcomes will require policymakers to anticipate the magnitude of these changes. Furthermore, the Coronavirus SARS-Cov-2, the causative agent of COVID-19, has changed most if not all of our public health approaches to prevention. During this pandemic, public health developments, including precision public health, were another milestone in this speciality's history [2].

Benefiting the most significant number of people through preventing disease, prolonging life, and promoting health should be the mission of all healthcare workers. This strategy requires collaboration between health leaders involved in education, politics, businesses, and charities. The Robert Wood Johnson Foundation in

---

S. Rawaf (✉) · C. Tabche · D. Rawaf · H. Quezada-Yamamoto
WHO Collaborating Centre, Department of Primary Care and Public Health,
Imperial College London, London, UK
e-mail: s.rawaf@imperial.ac.uk; c.tabche20@imperial.ac.uk; d.rawaf@imperial.ac.uk;
hq4717@imperial.ac.uk

G. N. Christodoulou
Department of Psychiatry, Society of Preventive Psychiatry, Athens University,
Athens, Greece

World Psychiatric Association, Geneva, Switzerland

World Federation for Mental Health, Occoquan, VA, USA

Hellenic Psychiatric Association, Athens, Greece

International College of Psychosomatic Medicine, Florence, Italy

International College of Person Centered Medicine, New York, NY, USA

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_17

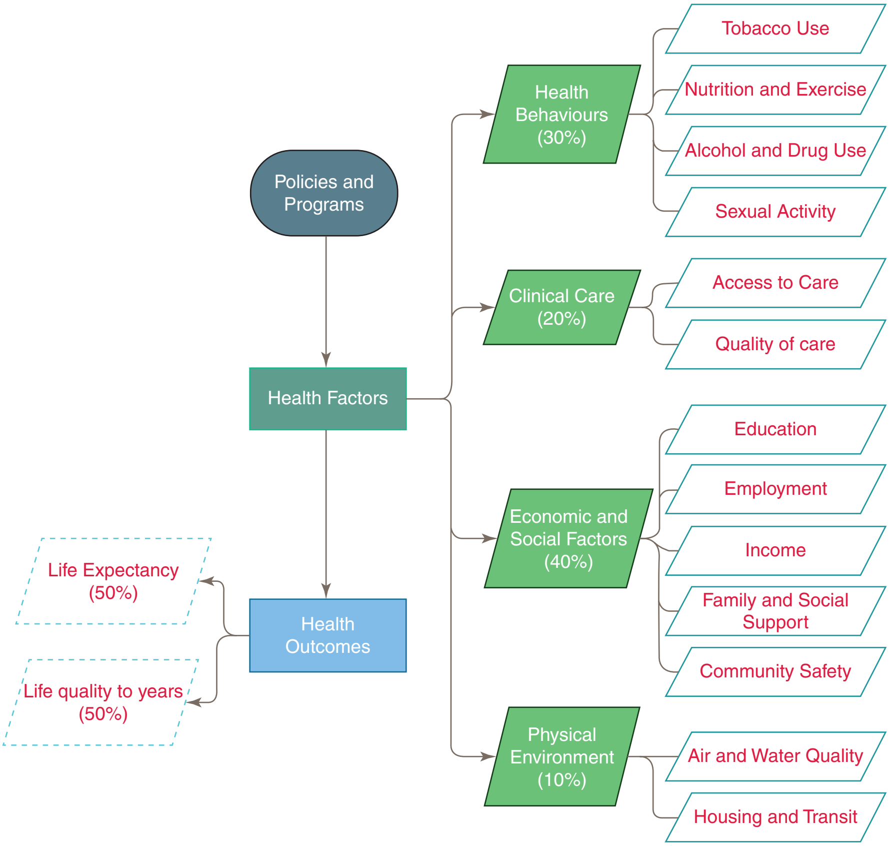


Fig. 17.1 True population health management

2014 described the management of proper population health through a diagram which was slightly edited for this chapter to fit current trends (See Fig. 17.1) [3].

Figure 17.1 clearly illustrates how the health factors are divided and what health systems need to achieve the ultimate goals of adding years to life and improving quality of life by adding life to years. The concept of prevention can be understood more clearly when explained by the fact that the fate of population health management falls on the changes in policies and programs. Prevention covers two core levels: community and person. Community prevention addresses social, economic, and physical environmental factors, while person-centred prevention focuses on individual health, behaviours, and clinical care. While these factors may flow and overlap between the two main levels, community, and person-centred prevention, they represent the general understanding of health systems and how to move forward with any prevention policy.

The outstanding results of small advances in prevention can be seen through history. Dating back to the fifth century BC, the Greek father of medicine, Hippocrates, has an aphorism attributed to him, “*It is more important to know what sort of person has a disease than to know what sort of disease a person has*”. He distinguished personal characteristics and lifestyle patterns from disease symptoms experienced by the individual. Hippocratic therapies mainly focused on changes in exercise, food, and lifestyle patterns that include sleep, baths, sexual practice, and other habits [4].

The nineteenth century presented one of the most symbolic examples of prevention during the cholera epidemics in London. Around 50,000 deaths were reported per season, which is approximately 20 per 1000 individuals in the population at the time [5]. Doctor John Snow had kept records of patients with the disease, trying to figure out the common factor between them. As a result, he realised that all cases had direct contact with water or food contaminated with water from the Broad Street Pump in Soho. It was unnecessary to know all the facts about cholera before taking preventative public health action that targeted individual homes and routines. The pathogen vibrio cholera was not discovered for another 30 years.

Another example is that of James Lind who used lime juice to prevent scurvy when ascorbic acid's chemical pathway had not yet been discovered. Typhoid and paratyphoid provide another successful story of prevention. The provision of safe water supply, sanitation, and further measures to ensure food safety (dairy, fish, etc.) by the end of the nineteenth century, led to enteric fever being rare in England and Wales nowadays [6]. More recently, vaccines have played a significant role in prevention and particularly during the twentieth century. Diseases such as polio, tetanus, rubella, measles, whooping cough, and diphtheria are rarely seen by doctors today while smallpox has been eradicated [7]. The reduction of maternal mortality can also be attributed to prevention [8].

From the use of gloves and other public health techniques to higher professional standards among doctors and other health professionals, legislative and administrative mechanisms, prevention has been the main reason some diseases have been avoided or eradicated. Prevention requires a nationally led drive that makes people the priority instead of the system; this can help reduce lifestyle causes of poor health and target those with the highest risks of ill health. The users', carers', and families' priorities should be critical points to organise health services. Carer, voluntary, and community sectors contribute massively to help individuals and support prevention services. Therefore, their input is vital to design and provide person-centred care. Equally as important is the government's ability to secure the funding for this activity and increase public financing because, without this source, any policy's goals will be unachievable [9]. This central notion leads to the role of public health as described by the Centers for Disease Control and Prevention (CDC). There are ten essential services provided through the role of public health that link all healthcare processes and allow policy development to improve the community's health (See Fig. 17.2) [10].

It is important to note that research is a critical element of assessment, policy development, and assurance, which has not been highlighted in the figure produced by the CDC in 2020. Research is the only route that brings beneficial real-world evidence to the legislative process, allowing policy change and development. The main goal for the CDC in Fig. 17.2 was to achieve optimal

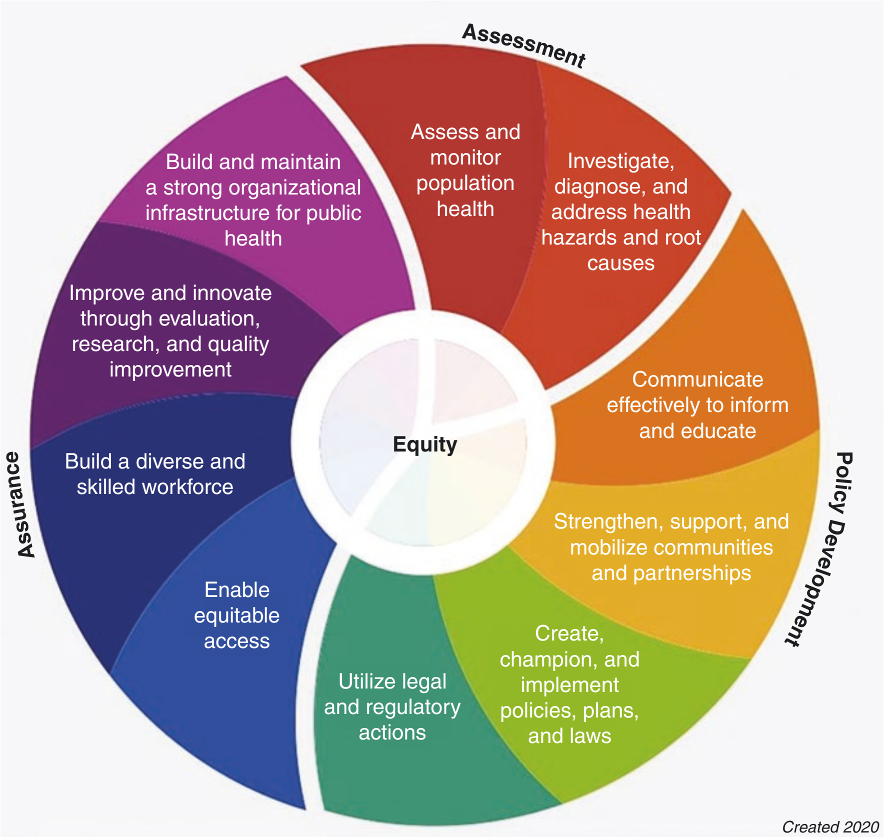


Fig. 17.2 Ten essential public health services. (Source: CDC—10 Essential Public Health Services—CSTLTS [10])

equity while removing obstacles that might result in health prejudice. Moreover, these public health services will help draw out proper disease prevention strategies and be key pillars for health systems and policymakers in individual and population health improvements.

Every year, it is more evident that we need to shift away from the traditional models of care to a tactic focused on self-care, empowerment, and prevention on the grounds of efficiency. Community-based services, for example, can deliver preventive support for people with chronic conditions. Patient empowerment is achieved through self-care with action plans, support, and follow-up in primary care rather than secondary care [11]. Patient involvement in prevention has become a priority in the policy agenda and is connected with the system's transformation. Now that the basic understanding of the person-centred prevention approach has been discussed, prevention recommendations will be tackled along with their unique characteristics and challenges.

17.2 The Knowledge Base of Person-Centred Prevention

17.2.1 Prevention Vs Curative Approach

The emphasis on prevention starts simultaneously at every level of care: primary, secondary, and tertiary. The target can be as big as the whole population, a specific group in the population, and can also be delivered to one person on a one-to-one basis. It is important to note that the disease model typically focuses on the individual instead of targeting the larger group. Also, it tends to jump in with a cure after the problem has struck the individual and affected them physically, mentally, and financially. This model can be reformed through primary care, hospitals, state's decisions, and international organisations [12]. At the population level, measures were taken previously similar to the water fluoridation decision, where 1 mg of fluoride was added per litre of water. Fluoridation was introduced to the USA and UK in the early twentieth century to reduce tooth decay by 1970; fluoride was also added to toothpaste [13]. Another measure taken due to the iodine deficiency was salt iodisation [14].

For a specific group in a population, like the elderly or children, measures can be taken similar to those taken during the COVID-19 lockdown. The Royal Society for the Prevention of Accidents (RoSPA) aimed to reduce the pressure on the health service because almost 17,000 unintentional injury hospital admissions happen per year in Northern Ireland. They started encouraging and campaigning for an accident-free home by changing the house's design and removing objects from the child's reach [15]. In the elderly population, preventive measures can avert falls, accidents, and related injuries, reducing the burden on healthcare systems [16].

At the level of person-centred prevention, it starts with the person and their capabilities which includes their medical condition, physiology, and carer focus. Person-centred prevention should encompass some main principles like understanding the patients' goals with respect and maintaining confidentiality. Empowering the patient through communication, participation, and education is another main principle that supports this approach while always creating accessible resources. For example, the CDC has placed new goals for early detection of dementia by 2023; local public health agencies will prepare all communities by changing the environment, systems, and policies. One of the developed actions, E-1, talks about educating the families and public about all cognitive and brain health age-related issues and the benefits of early detection and diagnosis [17]. Person-centred prevention can be incorporated into primary, secondary, and tertiary care through the practitioners, community, state, and international organisations contribution.

17.2.1.1 Primary Prevention

The WHO and UNICEF have defined primary health care as "*a whole-of-society approach to health that aims at ensuring the highest possible level of health and well-being and their equitable distribution by focusing on people's needs and as* *early as possible along the continuum from health promotion and disease prevention to treatment, rehabilitation, and palliative care, and as close as feasible to people's everyday environment*" [18].

These organisations have identified what modification is needed for the health systems to truly hold the universal health coverage (UHC) principles. This shift highlights the importance of a government's support beyond the health sector on all levels. The health systems switch from being designed around the organisations and disease and start working towards being developed with the people for the people. It provides quality, inclusive care throughout one's lifespan instead of being just for specific diseases. This care ranges from promotion and prevention to treatment, rehabilitation, and palliative care. The leading role of doctors is to prevent disease as part of their Good Medical Practice [19]. They should always put patient care as their first concern. They have significant opportunities to educate the general public about preventable diseases and avoidable deaths, such as type 2 diabetes, heart disease, and some types of cancer. This teaching process is a form of patient empowerment that can lead to great results in prevention.

Community's role in primary care prevention: These community-based programs in primary care settings are created and tailored to receive optimal outcomes in the area. For example, a nutrition program delivered on services for pregnant and lactating women similar to the one done in India called Tamil Nadu Integrated Nutrition Program [20]. This program was done to educate and empower local women on resources to prevent malnutrition and improve maternal and child health. The integration of community care into primary care prevention is essential for effectiveness, sustainability, and longevity of health systems.

The state's role in legislation and enforcement has a massive influence on prevention, such as the seat belt, mobile phones in cars, road taxation for maintenance, and the crash barrier laws which has also been cost-effective to any state which has enforced these rules [21]. During the COVID-19 pandemic, governmental surveillance, monitoring, and prevention measures have proven to be essential for all health systems worldwide; practitioners in primary care could not have done it on their own [22]. The state should be approached by public health organisations and professionals in primary care with economic and political evidence on how policy changes can benefit the individual and the nation. This step requires research and data collection to draw out evidence-based conclusions and policies on a solid foundation in primary care.

International institutions' role in prevention, such as the International Health Regulations, protects against disease at a personal and community level. Their COVID-19 position was evident by declaring a global pandemic and supporting countries worldwide with policies and guidelines to keep the population safe, even though one could argue that the decisions on the vaccination process have not been the best globally [23]. However, enforcing lockdown, social distancing, and travel restrictions were public health measures dependent on individuals. These measures have helped everyone in the healthcare system by reducing the pressure on primary care and the wider public health workforce [24].

17.2.1.2 Secondary and Tertiary Prevention

Secondary prevention highlights early disease detection where healthy-looking individuals are the main target with underlying forms of the disease; hence, no overt symptoms are present, which is also known as asymptomatic individuals. Therefore, screening is the focus of secondary prevention, as seen in some cases during the COVID-19 pandemic. Both the medical and outcome stages of a disease are focused on tertiary care prevention. It aims to lessen the severity of the disease in symptomatic patients. While secondary prevention seeks to detect a disease early and prevent deterioration, tertiary prevention seeks to reduce the effects of established disease in an individual, improve quality of life, and reduce symptoms. Ordinarily, rehabilitation work is also a form of tertiary prevention for patients.

Hospital's role in prevention can be done during consultations to identify the risk in the patient and link them to the corresponding clinic that can deal with the patient's situation to avoid any future complications. For example, someone admitted with heart problems who might have inadequate knowledge about nutrition, alcohol consumption, or smoking should be referred to a clinic that educates them on these topics to try and avoid any future predictable complications.

The specialist's role is to make sure diseases do not progress to damage or cause long-term disabilities to patients. This control can be presented in diabetes and corresponding complications resulting from high cholesterol, high blood pressure, neuropathy, etc. The patients admitted into hospitals are given a care plan to prevent further obstacles in that particular disease and a rehabilitation plan to maintain their current normal state with disabilities.

The examples mentioned above show how prevention can be person-centred instead of prioritising the system and the disease. Policies need to be changed to empower the patient and the public to make sure more diseases can be avoided. Hence, the interacting themes (See Fig. 17.3) in person-centred care and prevention are health, education, legislation, and sustainability to reach a better future for all.

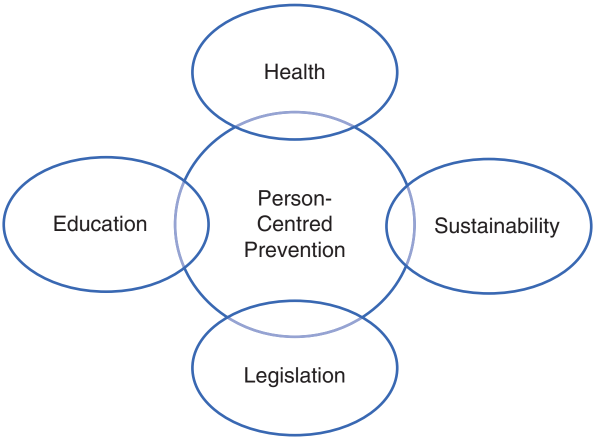


Fig. 17.3 Interacting themes

17.2.1.3 Person-Centred Prevention in Psychiatry

The application of the principles and methods of Prevention in Psychiatry is crucial not only because of the ancient and wise dictum "prevention is better than treatment" (as exemplified in the Hippocratic Oath where Hygeia, the Goddess of Preventive Medicine, is mentioned before Panacea, the Goddess of Therapeutic Medicine) but also because of evidence derived from the WHO indicating that in many countries "as much as one third to one-half of all mental and neurological disorders could be averted by primary prevention methods" [25].

The person-centred perspective is, of course, more relevant when applied in clinical practice and preventive lifestyle practices. However, person-centred psychiatry recognises the person in the singular and in the plural (i.e., as people in society) [26]; therefore, public health preventive practices also, are within the context of person-centred prevention.

Regarding clinical practice and, more specifically, diagnosis, the inclusion of a personalised (or idiographic) formulation and the standardized diagnosis is characteristic of the emerging person-centred trend [27]. Primary Psychiatric Prevention is, of course, prevention "par excellence" and involves the person even before its birth (as is the case with genetic psychiatric counselling). Secondary prevention involves screening for emerging psychopathological symptoms such as precursors of schizophrenic symptoms in adolescence or symptoms and signs indicative of increased suicidal risk. Tertiary prevention has been the focus of attention in the last years. Following the introduction of effective medication, it has been possible to de-institutionalise persons with severe psychopathology and thus avoid the long-term effects of the illnesses themselves and the deleterious effects of how the patients were kept and treated (institutionalisation).

For further reference, please find the two chapters that discuss Person-centred Prevention in Psychiatry and Person-centred Mental Health Promotion and Public Health Perspectives in the Person-centred Psychiatry book published in 2016 [28, 29].

17.2.2 The Added Value

It should suffice to say that prevention will decrease the number of new patients and reduce the cases of people who are already suffering, translating into a reduced workload for the practitioners and the whole health system. Furthermore, health services are costly to the state and individuals, and their effectiveness must be justified and guaranteed. In some instances, prevention has been proven to be cost-saving and cost-effective in the long run [30]. Cost reduction due to prevention encompasses fewer admissions, fewer referrals, and in consequence, decreased curative treatments and long-term care needed for patients.

In 2010, a report titled "Assessing Cost-Effectiveness in Prevention" gathered existing evidence to ensure that the present scarce resources are directed as meticulously as possible to the services provided [31]. This work evaluated 150 preventive health interventions covering mental health, diabetes, tobacco use, alcohol use, nutrition, body weight, physical activity, blood pressure, blood cholesterol, bone mineral density, and many more. The authors concluded that the impact of investing in prevention relies not only on achieving efficient health systems but also on fairer systems, as mentioned previously in Fig. 17.2. The most cost-effective interventions with the most significant population health impact were those that included alcohol, tobacco, unhealthy foods taxation, mandatory salt limits on processed food, and laparoscopic gastric banding as a preventive treatment for individuals with BMI >35 [31].

17.2.3 The Challenges to Person-Centred Prevention

In a perfect world, doctors would not be needed for treating preventable diseases. However, most budgets are allocated towards curing rather than prevention; therefore, most medical specialities praise and adhere to curing roles for prestigious purposes. From the operational perspective, prevention can be task-focused by creating checklists due to current pressures such as low budget, understaffing, and disintegrated services. Nevertheless, public health preventive interventions should not neglect the person since health behaviour and clinical care are person-focused, which make up 50% of the health factors, according to the diagram mentioned previously in Fig. 17.1.

17.2.4 An Environment Conducive to Person-Centred Prevention

17.2.4.1 Inform and Educate About Healthy Choices

One-to-one patient education for prevention should focus on the individual's concerns and the support they may need to keep healthy. It should involve sharing information, identifying medical and non-medical support needs, discussing options, contingency planning, setting goals, documenting the discussion (care plan), and monitoring progress through regular reviews, which the English NHS has set as a priority in 2017 [32]. Another vital part is the patient's mental health, where the services provided can be tailored to one's personal life goals and barriers. The health care provider's role as a face-to-face educator should guide the patient to improve their health literacy while being responsive to the individual patient's needs. Some consider health literacy the primary responsibility of all physicians. Moreover, other health professionals such as nurses, have shown to be very effective in delivering information by avoiding medical jargon, engaging in patient questions, explaining unfamiliar forms, and using "teach-back" as a method to ensure understanding [33]. Teach-back is a technique used by practitioners to ensure that the patient has understood what care plan they need to abide by, which in turn confirms that everything has been thoroughly and clearly explained.

Mass education for healthy choices must follow marketing principles to make it more attractive. The health sector is competing with the appeal of commercial advertisements for unhealthy products aimed at our population, who have to decide on the best choices for their well-being. Social media marketing adopts retail marketing tools and techniques, such as audience mapping, insight generation, and customer relationship management. It uses them to create marketing and communication campaigns that address critical public health challenges [34]. After understanding the individual's journey, behaviour changing programmes and focused campaigns can be created to inform the public and offer tools to withstand a behavioural change. This transformation can be achieved by supporting an environment encouraged to change, help drive cultural acceptance of healthy behaviours, and in the end, influence policy changes. Making sure to identify the people that are willing to learn, give them a chance, and praise them for their enthusiasm invites more individuals to join and learn more. Health education has the task of modifying individual behaviour and social norms that make healthy choices difficult. Different behaviour change models are used for designing these types of interventions in the context of a policy market. Still, the Capability, Opportunity, Motivation, Behaviour (COM-B) model is probably one of the most popular and widely accepted. Developed by Professor Susan Michie and her colleagues at University College London, the model looks at the interplay between context, policy, and behaviours to help define behavioural change strategies [34]. The model suggests that the interaction between capability, opportunity, and motivation influences behaviour. Capability refers to the individual's psychological and physical capacity, opportunity signifies factors outside the individual such as societal and environmental influences, and motivation shows unconscious processes like emotional responding and analytical decision-making; these three components influence behaviour. This model can be used to understand how to target behavioural change through healthcare education.

17.3 Opportunistic and Systematic Screening

As mentioned above, primary prevention embraces activities to reduce the incidence of a disease, while secondary prevention aims to detect and treat presymptomatic disease. On the other hand, tertiary prevention includes activities such as rehabilitation that reduce chronic incapacity, recurrences of an illness, or deterioration and are designed to help the patient return to educational, family, professional, social, and cultural life [35].

Opportunistic screening is a modality of secondary prevention that occurs when a test is offered by a health professional or requested by a patient outside an organised programme. Pharmacists, walk-in centres with nurses, and General Practitioners (GPs) are frequent points of contact. For example, the Royal College of General Practitioners and The Royal College of Australian GPs agree that family physicians and primary care doctors have a crucial role in active prevention, including opportunistic screening by targeting high-risk patients or groups [35]. Nevertheless, staff in hospitals (secondary care) are equally relevant to this purpose. Although specialist care is predominantly delivered within a reactive model of care, which contradicts the concept of prevention, secondary care doctors should receive appropriate training to perform opportunistic screening, regardless of their speciality. This screening training will be on smoking, obesity, hypertension, high cholesterol level, bone density etc., to enhance prevention measures [36].

Systematic (organised) screening is another form of secondary prevention conceived to detect disease before symptoms develop. These pre-established national programmes are regularly accompanied by law or policy that supports them. The process is similar to sifting people through a sieve with a few picked up in the mesh and is potentially cost saving [37]. Screening tests vary throughout an individual's lifetime, from pregnancy and birth to adult heart diseases and cancers.

An example of systematic screening made person-centred is the NHS Health Check programme, introduced in England in 2009. The programme invites individuals aged 40–74 years without pre-existing cardiovascular disease (CVD), kidney disease, type 2 diabetes, or dementia to perform a health check [38]. A risk assessment including questions about alcohol use, physical activity, smoking status, weight, height, blood pressure, and blood tests for cholesterol and diabetes is performed, and they are given access to lifestyle and health advice tailored to the patients' needs [39].

17.4 Preventable Risk Factors

Risk factors have their causes, sometimes in a complex chain of events (with many entry points for intervention), covering socioeconomic factors, environmental and community conditions, and individual behaviour; however, many are avoidable. Some elements are interconnected; for example, in ischaemic heart disease, cholesterol or high blood pressure act as a relatively direct cause of the disease. Whereas physical inactivity, alcohol, smoking, or fat intake contribute to their development. Hence, these have amenable risk factors, such as education, social status, and income. It has been understood that modifying these background causes is more liable to amplifying effects by influencing multiple proximal causes [35]. Therefore, these preventable risk factors can establish sustained improvements to health if addressed early on.

17.5 Stakeholder Engagement

Stakeholder engagement is an irreplaceable element that creates the canvas to make all of the above possible. At the same time, trust and credibility are required to achieve this. Trust can be gained through good communication or a solid doctor-patient relationship by listening and being open-minded. Credibility is gained through good research and using evidence-based proposals. There are two types of motivators for engagement that can play on the psychological aspect of reward and

Intrinsic Motivators	Extrinisic Motivators
• Autonomy • Belonging • Curiosity • Learning	• Badges/ Gold stars • Competition • Fear of failure or punishment • Money/ Rewards

Fig. 17.4 Intrinsic and extrinsic motivators

punishment: intrinsic (part of the stakeholder's constitution), extrinsic (representing a benefit or a menace for the stakeholder), which are illustrated in Fig. 17.4 [40].

17.6 The Public Health Laws

Nothing can be regulated without some laws that are intended as health interventions in what is called Public Health Laws. They define health agencies' powers, duties, boundaries, systems, and regulations impacting health [41]. Nowadays, public health professionals, legal and scientific expertise are more frequently brought together to develop, enforce, and evaluate health-related laws. Public Health Laws are responsible for protecting people from harmful exposures such as smoking, unhealthy food, antibiotics, alcohol, drugs, and even children abuse. These laws can also regulate the influential people known to be the stakeholders in the health system, such as practitioners, registration staff for birth and death, reporters of infectious diseases and many more. These laws should be approached to appeal to the stakeholder's interest and plans to motivate them to start benefiting the whole population. Learning how to negotiate with each entity using the tools listed in the section above and the evidence needed to support each conversation will help reach the desired goal and laws for person-centred prevention in the health systems around the world faster and with all sides on board [42]. This tactic can protect people against biological, chemical, and radiological risks, preventing injuries and diseases.

17.7 Practical Implications

17.7.1 A Model for Person-Centred Prevention

A new preventive person-centred model in primary care is needed to achieve better health outcomes, experiences, costs, and higher staff satisfaction. This model is possible only when the broader determinants of health are addressed alongside what the system currently provides [43]. The paradigm shift from curative to preventive is a challenge in the current context of pressures on the health care systems. Under this rationale, a primary care-based model focused on self-care, with minimal additional

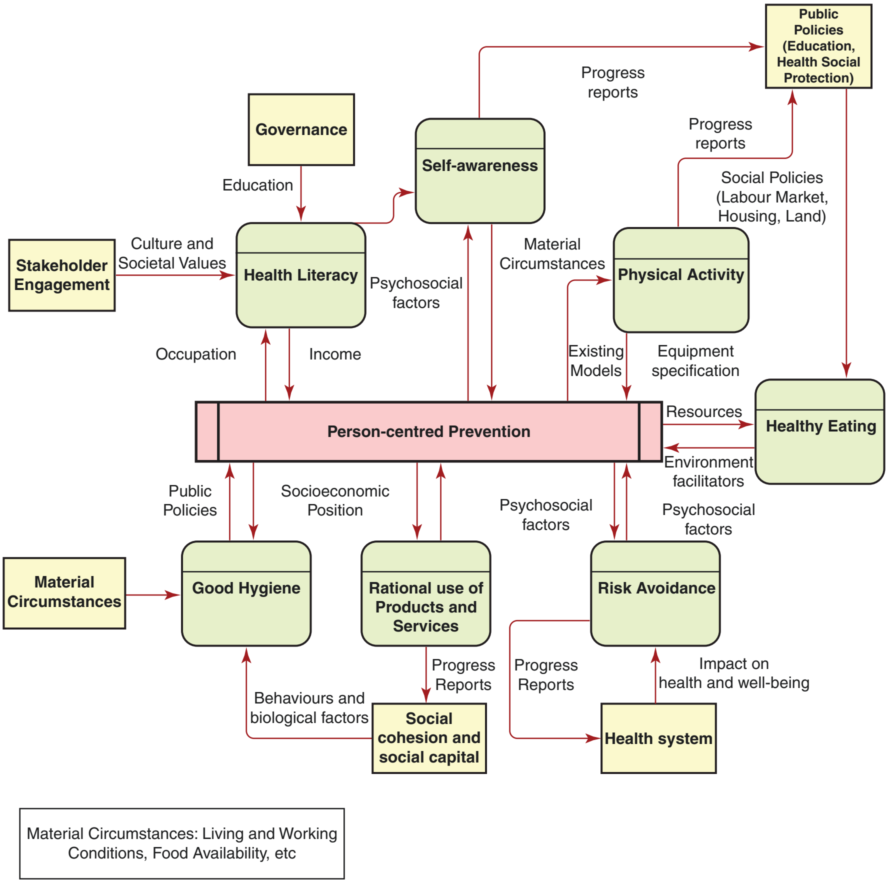


Fig. 17.5 Model for person-centred prevention

resources to an efficient resource redistribution tailored to the individual's needs, will be proposed.

The model combines the patients' perspective, the psychosocial context, and shared decision-making between patients and health professionals based on the Seven Pillars of Self Care [44], the WHO Commission on Social Determinants of Health Conceptual Framework [45] and the comments of Roy et al. in 2014 (See Fig. 17.5) [46]. The model highlights the importance of the person as an active participant in health fulfilment.

17.7.2 *Assessing the Implementation of Person-Centred Prevention*

The necessary steps for being able to evaluate a person-centred prevention intervention are presented in Fig. 17.6.

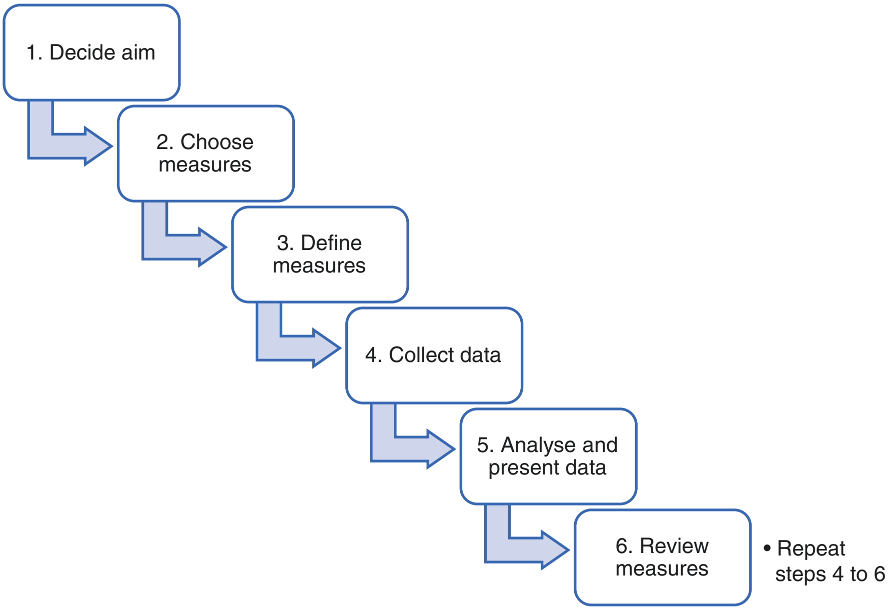
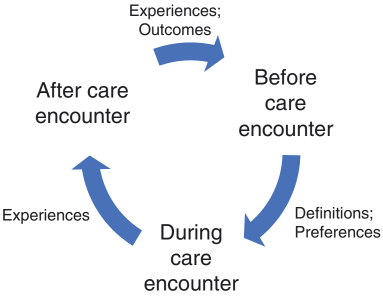


Fig. 17.6 Steps to evaluate person-centered prevention

Fig. 17.7 Measuring different aspects of person-centred care. (Source: de Silva [47])



Source: (Silva, 2014)

Most published research about measuring person-centred care has taken place in a hospital context with a rising primary and community care trend [47]. The main features measured are preferences, experiences such as empathy, communication, self-management, and shared decision-making. Other featured measured outcomes are through patient experience and empowerment, which can be done through surveys or consultations. These can be measured before, during, or after the contact with any preventive services, as seen in Fig. 17.7.

17.8 Discussion

Prevention in public health is proven to be the best measure to prolong life and improve the quality of the individual's and the community's health even though it may take some investments and longer time to implement [48]. The COVID-19 pandemic demonstrated how valuable public health measures are in stopping the transmission, saving lives, and protecting the health service. Social cohesion plays a vital role in patient-centred prevention, expanding its aim to be seen as a means for ensuring the protection of adverse events and the broader concept. In its constitution in 1946, the WHO embraced that concept by defining health not solely as the absence of disease but also a state of complete physical, mental, and social well-being [49].

From this perspective, integrating the predominant biomedical-technological approach that emphasises the biological aspects of both diseases and curative strategies with the social context and developing the concept of social determinants of health is needed. In Alma-Ata year 1978, WHO embraced the goal of "Health for All in the year 2000" with primary health care as a vehicle to achieve this vision of health [50]. These were reiterated in the new Declaration on Primary Care in Astana in 2018 [51] including the call for more integration of public health into primary care. In 2005, WHO created the Commission on Social Determinants of Health, which adopted a conceptual framework based on the Diderichsen model [52], identifying structural and intermediate determinants. The first is the primary producer mechanisms of stratification and social divisions, such as macroeconomic policies, public policies (education, health), social policies, resulting in income differentiation, ethnicity, social class, and schooling. The latter contributes to generating more inequality as modulators than primary causes [45]. Following this, Marmot collected evidence of efficacy in counteracting health inequities and published it in Fair Society Healthy Lives the Marmot Review [53]. In this review, the existence of a social health gradient (the lower the social class, the worse their health) and the need to act on the social determinants of health was highlighted with a strengthened role of prevention and to allow people control over their lives (empowerment) as key components. To enable primary care to deliver effective preventive measures, both at the individual and the community level, Rawaf has proposed various models to integrate public health into primary care in a WHO document. These models were suggested to reach preventive care and start taking a broader perspective. Therefore, individual care can be outlined in population outcomes like equity and social cohesion and easily applied to hospital care. Some of the leading models proposed were "public health services and primary care providers work together" and "multidisciplinary training of primary care staff in public health" [54].

Given the above, we feel that change from voluntary to compulsory vaccination should be considered to protect the population in a situation that mirrors the pandemic that has hit the world in 2020. The measles re-emergence due to anti-vaccination parents may eventually force the governments to proceed with compulsory vaccination if prevention is our primary goal. The return of eradicated diseases mentioned in the introduction, like the horrors of polio with the consequent disabling of populations, will be near. When the health system moves towards a more person-centred approach to any health risk, that is when one can see a difference in health status across the world.

17.9 Conclusions

After this discussion on how person-centred prevention can help with the current health sector crisis, it was made clear that a shift in investment from the curative biomedical approach to a preventive approach to care is needed. History has shown that preventive methods can be significant changers to population health outcomes. Many of the current pathologies burdening our health systems now have their origins in our lifestyle, behaviour, and environment.

Smoking, alcohol consumption, and obesity have preventive measures which rely on public policy and rely heavily on self-empowerment and self-care while being highly cost-effective on the whole system. Other factors that require consideration are genetics, climate, occupation, the general environment, access to quality health services, education, and economics. Therefore, screening and testing in high-risk and vulnerable groups are encouraged. Why are physicians and other health professionals not practising prevention at all levels during their daily encounters with patients [55]? Is it because of the lack of training (not part of their training programmes), absence of policy, systems' resistance to change, or lack of incentive?

This chapter has identified elements for a model to person-centred prevention and showed the steps towards assessing the corresponding interventions. Nevertheless, it is important to remember, without stakeholder engagement as a solid foundation, implementation is not feasible. Part of the stakeholder engagement requires public health laws to support person-centred intervention, which requires the training of the health professionals accordingly [42]. We need to legislate, educate, and inoculate!

We hope that this chapter will contribute to greater attention to person-centred illness prevention and health promotion.

Acknowledgements and Disclosures The authors report no conflicts of interest in the preparation of this manuscript.

References

1. Institute of Medicine (US) Committee on Assuring the Health of the Public in the 21st Century. The future of the public's health in the 21st century. The health care delivery system. Washington, DC: National Academies Press (US); 2002.
2. Rasmussen S, Khoury M, del Rio C. Precision public health as a key tool in the COVID-19 response. JAMA. 2020;324(10):933–4. https://doi.org/10.1001/jama.2020.14992.
3. Stoto M. Population health measurement: applying performance measurement concepts in population health settings. EGEMS. 2014;2(4):6. https://doi.org/10.13063/2327-9214.1132.
4. Tsiompanou E, Marketos SG. Hippocrates: timeless still. J R Soc Med. 2013;106(7):288–92.
5. The National Archives, UK. Coping with Cholera—The National Archives. 2021. https://www.nationalarchives.gov.uk/education/resources/coping-with-cholera/.
6. Prince AW. Prevention and health—everybody's business. J R Coll Gen Pract. 1976;26(167):460.
7. Historyofvaccines.org. Disease eradication | History of vaccines. 2021. https://www.historyofvaccines.org/content/articles/disease-eradication.
8. Gülmezoglu AM, Lawrie TA, Hezelgrave N, Oladapo OT, Souza JP, Gielen M, et al. Interventions to reduce maternal and newborn morbidity and mortality. In R. E. Black (Eds.) et. al., Reproductive, maternal, newborn, and child health: disease control priorities, Third Edition (Volume 2). The International Bank for Reconstruction and Development / The World Bank. 2016.
9. National Voices. Person centred care 2020: calls and contributions from health and social care charities. 2014.
10. Cdc.gov. CDC—10 essential public health services—CSTLTS. 2021. https://www.cdc.gov/publichealthgateway/publichealthservices/essentialhealthservices.html.
11. Ahmad N, Ellins J, Krelle H, Lawrie M. Person-centred care: from ideas to action. London: The Health Foundation; 2014.
12. Who.int. Primary health care. 2021. https://www.who.int/news-room/fact-sheets/detail/primary-health-care#:~:text=PHC%20addresses%20the%20broader%20determinants,a%20set%20of%20specific%20diseases.
13. White S. Water fluoridation—what it is and how it helps dental health—Public health matters. 2021. Publichealthmatters.blog.gov.uk. https://publichealthmatters.blog.gov.uk/2016/04/13/water-fluoridation-what-it-is-and-how-it-helps-dental-health/.
14. Leung AM, Braverman LE, Pearce EN. History of U.S. iodine fortification and supplementation. Nutrients. 2012;4(11):1740–6. https://doi.org/10.3390/nu4111740.
15. Publichealth.hscni.net. Preventing accidents at home. HSC Public Health Agency; 2021. https://www.publichealth.hscni.net/node/5206.
16. McClure RJ, Turner C, Peel N, Spinks A, Eakin E, Hughes K. Population-based interventions for the prevention of fall-related injuries in older people. Cochrane Library; 2005.
17. Cdc.gov. Advancing early detection. 2021. https://www.cdc.gov/aging/healthybrain/issue-maps/early-detection.html.
18. Who.int. WHO | Track 3: Strengthening health systems. 2021. https://www.who.int/healthpromotion/conferences/7gchp/track3/en/.
19. Gmc-uk.org. Good medical practice. 2021. https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/good-medical-practice.
20. Lassi ZS, Kumar R, Bhutta ZA. Community-based care to improve maternal, newborn, and child health. In R. E. Black (Eds.) et al. Reproductive, maternal, newborn, and child health: disease control priorities, Third Edition (Volume 2). The International Bank for Reconstruction and Development / The World Bank. 2016.

21. García-Altés A, Suelves JM, Barbería E. Cost savings associated with 10 years of road safety policies in Catalonia, Spain. (WHO | Who.int.). 2021. https://www.who.int/bulletin/volumes/91/1/12-110072/en/.
22. OECD. The territorial impact of COVID-19: managing the crisis across levels of government. 2021. https://www.oecd.org/coronavirus/policy-responses/the-territorial-impact-of-covid-19-managing-the-crisis-across-levels-of-government-d3e314e1/.
23. Un.org. Unequal vaccine distribution self-defeating, World Health Organization Chief Tells Economic and Social Council's Special Ministerial Meeting | Meetings Coverage and Press Releases. 2021. https://www.un.org/press/en/2021/ecosoc7039.doc.htm.
24. Rawaf S, Quezada Yamamoto H, Rawaf D. Unlocking towns and cities: COVID-19 exit strategy. East Mediterr Health J. 2020;26(5):499–502. https://doi.org/10.26719/emhj.20.028. PMID: 32538441.
25. Sartorius N. Preface. In: Christodoulou GN, Lecic-Tosevski D, Kontaxakis VP, editors. Issues in preventive psychiatry, vol. VII. Basel: Karger; 1999.
26. Christodoulou G, Van Staden C, Jousset D, Schwartz M, Mishara A. Ethics in person-centered psychiatry. In: Mezzich JE, Botbol M, Christodoulou GN, Cloninger CR, Salloum IM, editors. Person-centred psychiatry. Cham: Springer; 2016.
27. Mezzich J, Schmolke M. The relevance of comprehensive clinical diagnosis to prevention and health promotion. In: Christodoulou GN, Lecic-Tosevski D, Kontaxakis VP, editors. Issues in preventive psychiatry. Basel: Karger; 1999.
28. Christodoulou N, Lecic-Tosevski D, Kallivayalil R. Person-centered prevention in psychiatry. In: Mezzich JE, Botbol M, Christodoulou GN, Cloninger RC, editors. Salloum IM person-centered psychiatry. Cham: Springer; 2016.
29. Christodoulou G, Rutz W, Herrmann H, Christodoulou N, Schmolke M. Person-ce ntered mental health promotion and public health perspectives. In: Mezzich JE, Botbol M, Christodoulou GN, Cloninger RC, Salloum IM, editors. Person-centered psychiatry. Cham: Springer; 2016.
30. Ferguson B. "Investing in prevention: the need to make the case now," UK Health Security Agency. Gov.uk, 22 February. 2016. Available at: https://ukhsa.blog.gov.uk/2016/02/22/investing-in-prevention-the-need-tomake-the-case-now/.
31. Vos T, Carter R, Barendregt J, Mihalopoulos C, Veerman L, Magnus A, et al. Assessing cost-effectiveness in prevention. 2010.
32. NHS England. Involving people in their own health and care: statutory guidance for clinical commissioning groups and NHS England. NHS England; n.d.
33. Paterick T, Patel N, Tajik AJ, Chandrasekaran K. Improving health outcomes through patient education and partnerships with patients. Proc (Bayl Univ Med Cent). 2017;30(1):112–3.
34. Public Health England. Social marketing strategy 2017 to 2020. Public Health England; 2020.
35. Boyce T, Peckham S, Hann A, Trenholm S. A pro-active approach. Health promotion and ill-health prevention. London: The King's Fund; 2010.
36. Bauer U, et al. Prevention of chronic disease in the 21st century: elimination of the leading preventable causes of premature death and disability in the USA. Lancet. 2014;384(9937):45–52.
37. Labeit A, Peinemann F, Baker R. Utilisation of preventative health check-ups in the UK: findings from individual-level repeated cross-sectional data from 1992 to 2008. BMJ Open. 2013;3(12):e003387. https://doi.org/10.1136/bmjopen-2013-003387.
38. Harte E, MacLure C, Martin A, Saunders CL, Meads C, Walter FM, et al. Reasons why people do not attend NHS Health Checks: a systematic review and qualitative synthesis. Br J Gen Pract. 2018;68(666):e28–35. https://doi.org/10.3399/bjgp17X693929.
39. Woringer M, Cecil E, Watt H, Chang K, Hamid F, Khunti K, et al. Evaluation of community provision of a preventive cardiovascular programme—the National Health Service Health Check in reaching the under-served groups by primary care in England: cross sectional observational study. BMC Health Serv Res. 2017;17
40. Makki A, Abid M. Influence of intrinsic and extrinsic motivation on employee's task performance. Stud Asian Soc Sci. 2017;4(1):38–43.

41. Géraldine M-S, Feng-jen T, Anderson E, Kastler F, Sprumont D, Burris S. National public health law: a role for WHO in capacity-building and promoting transparency. World Health Organization; 2016. https://www.who.int/bulletin/volumes/94/7/15-164749/en/.
42. Toebes B, Ferguson R, Markovic MM, Nnamuchi O. The right to health: a multi-country study of law, policy and practice. The Hague: T.M.C. Asser Press; 2014.
43. Santana MJ, Manalili K, Jolley RJ, Zelinsky S, Quan H, Lu M. How to practice person-centred care: a conceptual framework. Health Expect. 2018;21(2):429–40.
44. International Self-care Foundation. The seven pillars of self-care framework. 2011. https://isfglobal.org/seven-pillars-self-care-framework/.
45. Solar O, Irwin A. A conceptual framework for action on the social determinants of health. Geneva: World Health Organization; 2010.
46. Mathieu R, Levasseur M, Couturier Y, Lindström B, Généreux M. The relevance of positive approaches to health for patient-centered care medicine. Elsevier; 2014.
47. de Silva D. Helping measure person-centred care. London: The Health Foundation; 2014.
48. Marks L, Hunter DJ, Alderslade R. Strengthening public health capacity and services in Europe. [ebook]. WHO Regional Office for Europe; 2011. https://www.euro.who.int/__data/assets/pdf_file/0007/152683/e95877.pdf.
49. World Health Organization. Official records of the World Health Organization. New York: International Health Conference; 1946.
50. WHO. Declaration of Alma-Ata International Conference on Primary Health Care. Geneva: Alma-Ata, USSR; 1978. http://www.who.int/publications/almaata_declaration_en.pdf.
51. WHO, UNICEF. Declaration of Astana. Geneva: WHO; 2018.
52. Diderichsen F, Evans T, Whitehead M. The social basis of disparities in health. In: Evans T, et al., editors. Challenging inequities in health: from ethics to action. New York: Oxford UP; 2001.
53. Marmot M, Allen J. Social determinants of health equity. Fair society healthy lives: The Marmot review. AJPH. 2014;104(4):S517–9.
54. Rawaf S, et al. Primary health care: closing the gap between public health and primary care through integration. Geneva: World Health Organization; 2018.
55. Levine S, Malone E, Lekiachvili A, Briss P. Health care industry insights: why the use of preventive services is still low. preventing chronic disease. 2019;16:E30. https://doi.org/10.5888/pcd16.180625.

Chapter 18
Person-Centered Health Promotion

Susan P. Phillips, Margit Schmolke, and Christine C. Leyns

18.1 Placing the Person at the Center of Health Promotion

18.1.1 What Is Health Promotion?

Health promotion is the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy life-styles to well-being [1].

S. P. Phillips (✉)
Department of Family Medicine, Queen's University, Kingston, ON, Canada
e-mail: phillip@queensu.ca

M. Schmolke
Munich Training and Research Institute of the German Academy for Psychoanalysis, Munich, Germany

C. C. Leyns
Department of Public Health and Primary Care, Faculty of Medicine, Ghent University, Ghent, Belgium

Fundación Vida Plena, Sacaba, Cochabamba, Bolivia

Faculty of Social Sciences, Universidad Mayor de San Simon, Cochabamba, Bolivia

Physician and Community Educator, Cochabamba, Bolivia
e-mail: christine.leyns@ugent.be

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_18

18.1.2 Obstacles for Individual Health Promotion at the Primary Care Level

Regardless of, and sometimes despite a patient's reason for wishing to see a physician, current standards and professional expectations for the typical primary care encounter increasingly focus on health promotion [2]. Although evidence of the merit for many of these at individual level, and particularly those involving lifestyle changes is limited, the number of health recommendations has increased to the point where the responsible general practitioner could spend more than 7 h a day addressing these with patients [3]. The ensuing time pressure felt by doctors predisposes to coercion and against person-centered autonomy, discussion, or shared decision-making [2]. It also frustrates patients as the opportunity for them to present their reason for visiting the doctor and to tell their story is hijacked by a physician intent on getting through a health checklist.

What Is All This Health Promotion About? Traditionally, health promotion revolved around lifestyle and healthy behaviors—discussions known to be of limited benefit but also to be neither onerous or time consuming. Increasingly, however, they include a search for risks of disease or risks of markers of disease, with potential and frightening diagnoses like cancer being named and dangled as threats of non-compliance, despite a lack of current illness or suffering. Such risky health promotion is named in the WONCA international dictionary for general/family practice under the term ***quaternary prevention***: 'Action taken to identify patients at risk of overmedicalisation, to protect them from new medical invasion, and to suggest to interventions, which are ethically acceptable [4, 5]'.

At present, guidelines identifying who should be exposed to 'the search', that is, which people to test requires reducing individuals to demographic characteristics such as age, or sex. This further renders the individual invisible as the care provider abandons the social identity of the patient, the ability to explore or understand individual's strengths, suffering or symptoms, or to form a health alliance with the whole person rather than those body parts at theoretical risk of disease. The patient becomes, for example, a 52 year-old male with hypertension and pre-diabetes instead of a man with stories, hopes, and fears.

18.1.2.1 Persons Centered Health Promotion

A more contextualized and dynamic health promotion construct would be oriented to:

(a) The person's identity (person in totality, not just as symptoms or clinical markers)
(b) Conscious and unconscious dynamics and processes

(c) The person as expert about her/his competencies in daily life
(d) Relationships influencing the person and group dynamic processes
(e) Context (acknowledge the person's social context and identities)
(f) Biography (recognize the person's life history, roots, story)
(g) Development of the potentials of a person, noting that crises and illness as well as failure are important developmental and learning experiences
(h) Recovery (hope, healing, individual recovery processes) [6]

The gap between population level health promotion and person-centered approaches is ever widening. We will explore this gap and argue that in fact, a person-centered approach is essential for effective health promotion.

18.1.2.2 People Centered Health Promotion

In health care in general as well as in health promotion it is necessary to look at the whole population as a way to ensure that nobody is left behind. Many people are not able to access health services, and active community oriented strategies are needed to correct this. Person centered care incorporates prevention, health promotion and health education including health system navigation. Health education in its broad sense is known in the literature as 'health literacy' and defined as the personal and relational factors that affect a person's ability to acquire, understand and use information about health and health services [7]. To enhance health literacy in a community, a multilevel intervention is needed that brings attention to the accessibility of health materials and tools, including sectors like education, the communication skills of health professionals, and the institutional characteristics that support the active engagement of patients and communities [8]. Community education is crucial in large parts of Latin America, Asia and Africa where health decisions related to a person are often dominated by the person's family and community. Education limited to the individual patient would be inadequate in this context. Including communities and not only individuals to promote health is paramount since the social determinants of health and their distribution are identified and prioritized in the community and since health is a human right for all, although, for a community, health education is insufficient to empower people to take control over what determines their health. The community needs enabling social, economic and environmental conditions and real power [9]. Furthermore, it is important to reach out to people who either cannot or do not enter the formal health system or those living at the margins of society. Their representation in decision making related to health must be guaranteed [10, 11]. Although direct links between community participation and health outcomes have not been documented in the literature, the importance of obtaining community uptake, ownership, health equity and sustainability have been observed [11–13].

18.2 Evidence-Based Medicine and the Disappearing Person

Those of us who embrace person-centered care often do so because, intuitively, it seems the right thing to do. Patients are people, a statement that would seem self-evident anywhere except in a scholarly medical journal. Individuals should be respected as such, rather than conceptualized as machines with potentially faulty parts to be identified and either fixed or replaced [14]. Evidence-based medicine (EBM) of necessity categorizes patients by lists of physical symptoms and findings, while dismissing, (or in the language of research, controlling for) individual characteristics, circumstances, hopes, or dreams as irrelevant fluff.

Prior to writing this chapter we reviewed the literature on person-centered care and maintenance of health or health promotion. Alas, there isn't much, and most is from decades ago. Perhaps this speaks to the elevation and narrowing of evidence-based medicine from what Sackett originally described (the research, the person, the doctor's experience) to algorithms and checklists devoid of who the patient is [15–17]. I can hear my colleagues now, saying that medical care must rest on research, on the scientific method of asking a question, objectively studying it, analyzing the findings and then replicating the process. This is how evidence is produced and at present, medicine lives and dies by evidence and evidence, alone. Yes, without evidence we have nothing, but without patients' stories, values and our relationships with those patients we have only a single path to follow and it is the same path for everyone. John Ioannidis, a wise and skilled epidemiologist has skewered current research, showing that much of the time published findings are false [18]. In 35% of randomized controlled trials (the pinnacle of robust research methodology) re-analyses of findings lead to changes in conclusions. These are shortcomings of the methodology, itself, that cast some doubt on just how robust all that evidence actually is, and especially when the person Sackett saw as central to EBM is eliminated from view.

EBM has come to focus on the disease, isolated from the person who may have a disease or the practitioner's experience in general and with a specific patient. Trish Greenhalgh [15] has looked at the impact of the missing human on the utility of EBM, identifying six sources of bias arising from that invisibility:

1. limited patient input to research design
2. low status given to experience in the hierarchy of evidence
3. a tendency to conflate patient-centered consulting with use of decision tools
4. insufficient attention to power imbalances that suppress the patient' s voice
5. over-emphasis on the clinical consultation
6. focus on people who seek and obtain care (rather than the hidden denominator of those that do not seek or cannot access care).

18.2.1 When There Are No Individuals, Only Categories

By its very nature, risk factor research must categorize those being studied to compare the outcomes for a particular risk across different groupings. For example, to study the risk of whether early childhood adversity (ACE), about which more will be said later, foreshadows earlier death, one must first categorize all being studied as either exposed (having a higher ACE score) or unexposed (no ACE). The proper methodology dictates that to avoid assuming that the impact of ACE are uniform across the exposed group there should be a sub-classification of participants or subjects by, for example, sex. In fact, when this is done, it seems that the long-term harms of ACE are different for men and women [19], demonstrating the importance of categorizing. However, the need to categorize brings with it an assumption of homogeneity within the category. Are all women really the same and different from all men? And this brings us back to person-centeredness, to knowing more about a person than their ACE score and their sex. The person living in a homeless shelter and the President of the US may both have been exposed to ACE and be male (or female) but beyond that, the social influences on their health and well-being are unlikely to overlap. For research evidence to be applicable to the individual we must know that individual. In other words, science is necessary but insufficient in guiding medical prevention and care. Rather than trapping patients by categorizing them as diseases and risks devoid of human and social traits we must open those categorical boxes and see who is inside.

18.3 Adding Person-Centered Approaches to Medicine

18.3.1 A First Person's Story

"I killed my first moose when I was 11." JG was speaking in Cree and answering the question "tell me about your health." This was 2 weeks before he died at age 78. He had been diagnosed with end stage heart failure and COPD, and transferred from a remote Indigenous community to the small, northern Canadian hospital where I (SPP) worked. He then told me about the signing of the Treaties with the Canadian government 60 years earlier, and a life lived mostly on the land hunting and trapping. In response to my standard medical interrogation about chest pain, cough and whether he became short of breath when he lay down he told me his life story. That was all that mattered. With far greater insight than his young doctor displayed, JG metaphorically explained that after a harsh life, but also one of resilience and strength, he was at ease with dying, saying that there were traditional medicines that might have helped him but that he accepted the White Man's Treaty agreement to provide medical care for him and his people. A lesson in the importance of knowing the person, and one I have thought about many times over the intervening four decades. At a minimum I learned to ask patients about themselves rather than merely about their medical problems, realizing that the two are inextricably linked. I think JG wanted me to understand that context matters; that from adversity he developed strength, and that what he viewed as traditional preventions and cures were not as simple as sipping a tea made from plants. Instead they were an adjunct to an environment and a way of life that disappeared along with a disappearing culture.

18.3.2 Population Level Risks: Environment, Social Connectedness and Epigenetics

My immediate thought was that JG was rewriting history through a fog of nostalgia. Even then I knew there was no miracle, whether in his context or mine, to prevent a heart from failing. I have now had years of medical experience teach me over and over to be cynical about miracles. Many have come and gone, most a miracle of marketing rather than cure. Nevertheless, the prospect of prevention and treatment that builds on context and is not explained simplistically by biochemistry or pathophysiology can be scientifically plausible. We now know, for example, that the outside world and a person's **lived environment** 'flip' the biochemical and epigenetic switches that augment or deplete health. An elegantly designed systematic review of whether, and to what degree, **social relationships** (and consider here not just relationships between family and community but also between physician and patient) alter longevity offers an example [20]. Holt-Lundstad et al. synthesized 148 studies that asked whether loneliness kills. An interesting question and one that, on first glance, lacks the aura of science that medicine embraces. However, recent concepts of epigenetics inject science into the observation that social connectedness can get under the skin to build immunity and prevent the inflammation that precipitates or exacerbates many chronic diseases. The currency of medicine and particularly of prevention is risk reduction and, ultimately, increased life expectancy. Across those 148 studies the impact on longevity of social relationships, defined in a number of ways, exceeded that of preventions including smoking cessation, exercise, reduction of alcohol intake, influenza vaccines, control of hypertension or decreasing air pollution. There was an astonishing 50% increase in survival among those with strong social relationships. Might it be that social engagement or connection is a miracle cure, or more accurately, a prevention, for multiple illnesses and premature mortality? Perhaps this is an area that merits further examination, and one that provides a scientific link between knowing the person, person-centered care, prevention, and health promotion. And maybe somewhere in this sort of research is the science that connects with JG's story.

The same strong relation can be identified between health and the environment or the social determinants of health. The social determinants of health are the conditions in the environments where people are born, live, learn, work, play, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks [21]. In Marmot's review of the social gradient in health—the lower a person's social position, the worse his or her health is, although this is more evident among men than women. In the wealthiest part of London, one ward in Kensington and Chelsea, a man can expect to live to 88 years, while a few kilometers away in Tottenham Green, one of the capital's poorer wards, male life expectancy is 71. Underlying this disparity are avoidable inequalities in society: of income, education, employment and neighbourhood circumstances. Health inequalities result from social inequalities. Action on health inequalities requires action across all social determinants of health. Avoidable health inequalities are unfair and putting them right is a matter of social justice [22]. This same understanding was translated by the United Nations in 2015 into a universal call to action to end poverty, protect the planet, and ensure that by 2030 all people enjoy peace and prosperity.

18.3.3 Individual Risks: Adversity and Resilience

Entwined in looking at how population level prevention translates to individual level well-being are adversity and resilience. Back to adversity in childhood (ACE). Over the past 20 years a series of studies on ACE have demonstrated that early social adversities, whether from disrupted families or exposure to violence, have lifelong impacts on physical and mental health [23]. This is not an effect of poverty; the research included only middle-class Americans, all of whom had private medical insurance. Their economic security and access to medical care did not, however, override the ability of early life circumstances to figuratively get under the skin and harm. However, some individuals, despite having high ACE scores, did not go on to develop illnesses to which they seem socially predisposed. These are the resilient ones—individuals who adapt positively when faced with adversity. Resilience is the process by which one's intrinsic assets and external resources are used to surmount challenges [24, 25]. The ability to 'bounce back' from trauma, deprivation, or violence is dynamic and can be learned and amplified throughout life [25]. Protective characteristics and circumstances that predict resilience include self-efficacy, optimism, empathy, flexibility, sense of purpose, self-control, connectedness, having a supportive family, and living in a cohesive community [26].

Studies on resilience and health sometimes examine stories of those who function well physically and socially despite having symptoms of a physical or mental illness. Such research conveys the message of how to understand life stories, to learn from them and to apply this knowledge to prevention and treatment [27]. The findings suggest that resilience is not an innate personality trait but rather a way of being that can be acquired across the life course, and further, that the interaction of person and environment is central. Of course, resilience is not a cure for the impact of adversity nor does the potential to foster it absolve society from striving to minimized social adversity. Traumatized persons may be suffering and resilient at the same time [28]. German development researchers Grossmann and Grossmann [29] emphasize that traumatic and adverse experiences in life always leave tracks/traces and scars. They question the construct of resilience, hypothesizing that no person bounces back to the original position after adverse or traumatic experiences. Nevertheless, in favourable conditions (e.g. social support, important persons and positive attachment) persons can lead a meaningful and fulfilled life. This hypothesis may well explain the incremental response of poorer health with greater number of ACE, even though the resilience of some will temper that harm. The research of others suggests that resilience can 'neutralize' the impact of adversity on health and turn harm into thriving [24, 30–33]. The extent to which resilience offsets social harms is an evolving area of study.

What Does All This Have to Do With Providing Medical Care? There is evidence that health care practitioners, among others, can ameliorate some of the impacts of ACE by **identifying and fostering the individual strengths** that build resilience [30, 32, 33]. As small and simple as it may seem, being person-centered and asking patients about their past and how it has affected them can augment current and future well-being [34]. As part of the original ACE studies patients at throughout the large Kaiser Permanente healthcare system in the US completed the 10 item ACE scoring questionnaire. In response to any 'yes' answers the physician then asked, "Tell me how that has affected you later in life." An external assessment of the impact of asking this question, of 'opening of the door' found a 35% decrease in primary care visits, an 11% decline in trips to the emergency and a 3% decrease in hospitalizations for the following year. With no further discussion these utilization rates reverted to baseline in the second year, suggesting that opening the door is a beginning but not a stand-alone solution. The remarkable thing is not that early adversity affects health forever more, but rather that something as simple as caregivers asking patients about who they are and what their early life was like, of shifting the lens from patient to person with a story, can move that person's trajectory from dysfunction towards health. The current term for this is trauma informed care, which really distils down to fostering resilience by being sensitive to individual stories, needs, and vulnerabilities, and then, together, **reframing those narratives** [35].

18.4 Person-Centered Health Promotion

As pointed out wisely by Heath [36], *When the prevention of disease begins to assume greater priority than the relief of suffering, something very fundamental begins to go awry.*

Overall, Where Does a Person-Centered Approach Fit into Health Promotion? As explained earlier, the standard of evidence-based preventive care has become a search for risks or even risks of risks, for tests of possible future disease [2, 36]. For example, we now diagnose pre-diabetes, creating the specter of a feared chronic disease among people whose blood sugar is actually normal. Similarly, screening protocols assume that all women over age 50 but under age 74 are at increased risk of breast cancer and should have periodic mammography screening. This despite the reality that because the risk of this cancer increases with increasing age and further, that the evidence in favor of the recommended screening test is contradictory, individualized discussions should replace age-based testing. Recommendations linked to a few demographic indicators preclude the need to know the person, as do standardized approaches to checking blood pressure, cholesterol, blood sugar along with many other such tests.

Usual screening tactics, with their focus on problems and deficits, emphasize what needs repair, creating passivity and a sense of impending disaster that often leads to reliance on prescribed ‘treatments’ for potential but, at present, non-existent disease [37]. Broadening the medical paradigm from a **search for risks and vulnerability** to also identifying and developing individual **strengths and resourcefulness** might have greater impact on patient health than does creating a cohort of the ‘worried well’. Physicians could rethink concepts of health promotion and demonstrate the links between a strengths-based narrative and long-term well-being. Highlighting patient strengths and offering resources to build these and foster resilience could enhance wellness. Working with patients to do this requires the physician to hear each unique story, to know the person who is their patient.

18.4.1 The Doctor-Patient Relationship as Medicine

In keeping with Holt-Lundstad’s findings that social relationships are salutogenic, there is evidence that feeling connected to one’s physician may promote health, in and of itself, and also foster healthy behaviors [38]. This story from my practice (SPP) is illustrative. For most of their 60+ years the Johnsons (name changed) have been defined by medicine and social services as drug abusers. Others had occasionally and unsuccessfully imposed ‘treatments’ upon them using guardianship of their children as blackmail. The pattern of drug dependence continued for them and two of their five now adult children. Medical students working with me read the family’s charts, roll their eyes and sometimes speak of them with distain. Over 30 years as their family doctor I have come to know the Johnsons well—her childhood of sexual abuse, his of poverty, loss and abandonment, their 40-year relationship built on constant communication and respect, their love for their children and steadfast parenting of their grandchildren. About 6 years ago they stopped using drugs. When I asked them why, he said, “Because of you. I swore at you once in the office when I was high and I was mortified and knew I had to stop.” Of course it’s a bit more complicated than that, but only a bit. To me this was a triumph of person-centered care/health promotion rather than of medicine. One of many I have seen.

The impact of the relationship developed and of their understanding that I **respect** them and hold them in high regard somehow got under the Johnsons' skin. Medicine and public health offer many treatments and preventions of high efficacy, that is, of significant theoretical benefit. But effectiveness (impact in a real life situation) is another matter. All interventions ultimately must filter through the individual. So, for example, laudable measures that increase the walkability of a city with the aim of increasing individual physical activity will be undermined by an individual's fear of violence in the environment [39].

To make health promotion and prevention work we must know the person targeted by any program and that person must know that we are doing more than offering them a template for care at a given age.

Two authors of this chapter have engaged in research that examines the link between person-centeredness and health promotion. We have both noted that there seem to be far more young people with anxiety in recent years than two or three decades ago. Are we just seeing the same thing through a different lens or are youth actually struggling more than in the past? And why does it often seem that young people with the most supportive, economically stable families are particularly vulnerable. I (SPP) decided to interview 13–16 year olds and asked them about stresses and their ways of managing them. What unfolded was a most educational and uplifting experience and one of few where the research itself seemed to be of benefit to participants [40]. With the first few interviews I realized that although I had known most of the kids I interviewed all their lives I had never really talked to them directly and alone. I had made assumptions about their lives based on my knowledge of their families' medical and social histories. All those invited to participate showed up, on time, and demonstrated a politeness that prompted the receptionist to say, "Who are these kids? They are wonderful". Remember, they were all teenagers. They talked and talked and would have stayed well beyond the hour set aside for each interview. Most could name their sources of stress—often school and a self-imposed pressure to succeed. But more important was their sense of self-control and of mastery over these stresses. Their responses could have been collated into a guide for youth about managing stress and being resilient. For example, one was writing a book in which she rethought and changed the script of difficult situations, another was a budding artist (and proudly showed me his drawings on his cellphone), many found an outlet in sports, and some diverted their attention away from stresses recognizing that a sort of 'time out' could defuse most situations. Interesting and fruitful research but more important, a lesson for their doctor in the value of knowing the person rather than making assumptions based on medical histories and scripts. A number of the participants came back to discuss medical matters, some of quite a sensitive nature, and it was clear that we had a bond and a connection that arose from that hour of **conversation in which they were people**, not patients, and young adults rather than children being talked about by their parents.

In a study on the quality of life of chronically unwell, schizophrenic patients living outside of mental hospitals in the city of Leipzig, Germany [6, 41], Margit Schmolke found that these persons don't view themselves only as "passive victims" of their illness. They have developed, step by step, an "**expert knowledge**" (e.g., regulation mechanisms in crisis situations) in the course of dealing with illness. Interpersonal networks and social relationships have proved to be stabilizing and health promotive factors. Of particular importance for many of them was the personal experience of being needed by others, by family members, by a partner or friends, and their need to be part of society. One interviewee said that the family and its coherence is most important in her life, "it is like the thread" which was interrupted in phases of her illness. A long marriage, the births of her sons, relationship to her spouse and to the grand-children took a great part of the interview. It is this 'expert knowledge' of the individual and by the individual that will prevent illness, at least as effectively as repeated monitoring of standard medical measures.

18.5 Research Directions

"The pursuit of cure at all costs may restrict the supply of care" [42]. So wrote Archie Cochrane, considered to be the father of evidence based medicine, as he set out to assess the two roles of the British medical system: therapy and "board, lodging and tender, loving, care." What might he think of EBM five decades later? Certainly medicine has accepted the importance of prevention and cure based on research evidence. Perhaps because it is so much more challenging to measure, care has never really been part of the EBM research agenda and seems to have become a nice 'add-on' for when the real work of medicine is done. Although, as stated above, person centered care seems like "the right thing to do" the rigor of medical evidence begs for more than anecdotal 'proof' or modelling of whether caring translates into better health and cure. A study published in 2019 offers a model for how such proof might be gathered using a validated tool for scoring caregiver empathy [43]. The 10 question scale used might be viewed as a proxy measure for person-centered care. Findings showed a trend (but not statistical significance) in the association between perceived **caregiver empathy** and a decrease in likelihood of a subsequent serious cardiovascular event. Not 'proof', perhaps because the sample size was insufficient, but a methodology worth utilizing and a promising outcome.

> "We need to build bridges between clinicians and researchers in the fields of health promotion and resilience in order to integrate medical scholarship about origins and treatments of illnesses with knowledge about **protective and healing factors** tied to a person's **social circumstances, life story**, connections, in other words, to who the patient is. If we are open to understanding the patient's suffering and joys, and if we listen to them carefully, we can learn a lot about that person's competencies, strengths, skills, experiences in navigating away from and dealing with illness and their deep hope of and motivation towards recovery." [6]

18.6 Conclusions

As we know it, health promotion and its tandem concept of prevention represent challenging efforts [2, 36]. With ever lowering thresholds for defining and 'treating' risks comes earlier and more frequent naming of those risks. In general, the incidence of the very diseases that preventive testing aims to stop have not decreased, nor has longevity increased. Instead 'at risk' labeling has created a population of 'worried well', people who fear that their future is one of multiple chronic diseases. In parallel, although not because of the limits to current preventive interventions, existing clinical practice guidelines are blind to the individual, the story, the context, and standards for preventive care are divorced from person-centeredness.

What if the measure of benefit from health promotion were improved function and quality of life at the individual and contextual levels? What if health promotion focused on the strongest and most alterable determinants of health, social circumstances? Caring for and about a patient's life rather than only their risk of disease, is not what doctors traditionally do. Interesting, though, that when older adults are asked whether they are aging successfully and about life satisfaction neither is found to parallel absence of chronic disease [44]. To some extent, these align, instead, with social connectedness [44], including connection with and empathy from one's caregiver [43]. This may mean that as physicians and health professionals, we would be more effective if we got to know and made a real connection with the person whose blood sugar we keep checking, rather than slavishly checking it over and over until we can apply a label of pre-diabetes. Goal oriented care, based on the person's life project and aims can promote much better the health of the person than can a sole focus on health problems [45, 46].

The gulf between population level efficacy and individual level effectiveness in medical care and health promotion is large. In fact, there is stronger evidence for benefit arising from knowing the person who is one's patient than from most standard preventive interventions combined. By fostering a therapeutic relationship of openness, empathy, understanding, trust and individualization of care, the people who are our patients are more likely to flourish and develop truly preventive traits and ways of being healthier, perhaps mediated through resilience. We are grateful for the tools that keep being developed that enable diagnosis and treatment of disease. The necessary but insufficient tools. They are most helpful only when used cautiously and thoughtfully, and shared and integrated with the person, their narrative, their life story.

As stated throughout this chapter, context shapes individual health. We believe it is our duty as health professionals, to look at the global, national and regional inequities that harm individual health and tackle these. By understanding and hearing the people who are our patients and recognizing that they are experts of their life, context and history, health professionals and policy makers can join with those life experts to increase equity and health. This may be the salutogenesis of person-centred care.

Acknowledgements and Disclosures The authors do not report conflicts of interest in the preparation of this manuscript.

References

1. WHO. Ottawa charter for health promotion: an International Conference on Health Promotion, the move towards a new public health 17–21 November. Ottawa, Geneva: World Health Organization; 1986.
2. Getz L, Sigurdsson A, Hetlevik I. Is opportunistic disease prevention in the consultation ethically justifiable? BMJ. 2003;327:498–500.
3. Yarnall KSH, Pollack KI, Östbye T, Krause KM, Michener JL. Primary care: is there enough time for prevention? Am J Pub Health. 2003;2003(93):635–41.
4. Jamoulle M. Quaternary prevention, an answer of family doctors to overmedicalization. Int J Health Policy Manag. 2015;4(2):61.
5. Bentzen N. Wonca International Classification Committee. Wonca international dictionary for general/family practice (Copenhagen); 2003. http://www.ph3c.org/PH3C/docs/27/000092/0000052.pdf. Accessed 6 Jun 2021.
6. Schmolke M. Embedding protective factors and resilience in a dynamic health and treatment concept. Dyn Psychiatry. 2005;38:303–15.
7. Batterham RW, Hawkins M, Collins PA, Buchbinder R, Osborne RH. Health literacy: applying current concepts to improve health services and reduce health inequalities. Public Health. 2016;2016(132):3–12.
8. McCormack L, Thomas V, Lewis MA, Rudd R. Improving low health literacy and patient engagement: a social ecological approach. Patient Educ Couns. 2017;100(1):8–13.
9. De Vos P, Malaise G, De Ceukelaire W, Perez D, Lefèvre P, Van der Stuyft P. Participation and empowerment in primary health care: from Alma Ata to the era of globalization. Soc Med. 2009;4(2):121–7.
10. South J, Connolly AM, Stansfield JA, Johnstone P, Henderson G, Fenton KA. Putting the public (back) into public health: leadership, evidence and action. J Public Health. 2019;41(1):10–7. https://doi.org/10.1093/pubmed/fdy041.
11. Wallerstein N. Empowerment to reduce health disparities. Scand J Public Health. 2002;30:72–7.
12. Harris J, Cook T, Gibbs L, et al. Searching for the impact of participation in health and health research: challenges and methods. Biomed Res Int. 2018;2018:9427452. https://doi.org/10.1155/2018/9427452.
13. Leyns CC, De Maeseneer J, Willems S. Using concept mapping to identify policy options and interventions towards people-centred health care services: a multi stakeholders perspective. Int J Equity Health. 2018;17:177. https://doi.org/10.1186/s12939-018-0895-9.
14. Phillips S. Problem based learning in medicine: new curriculum, old stereotypes. Soc Sci Med. 1997;1997(45):497–9.
15. Greenhalgh T, Snow R, Ryan S, Rees S, Salisbury H. Six biases against patients and carers in evidence-based medicine. BMC Med. 2015;13:200. https://doi.org/10.1186/s12916-015-0437-x.
16. Mykhalovskiy E, Weir L. The problem of evidence-based medicine: directions for social science. Soc Sci Med. 2004;2004(59):1059–69.
17. Sackett DL, Rosenberg WMC, Gray JAM, Haynes RB, Richardson WS. Evidence-based medicine: what it is and what it isn't: it's about integrating individual clinical expertise and the best external evidence. BMJ. 1996;1996(312):71–2.
18. Ioannidis J. Why most published research findings are false. PLoS Med. 2005;2:e124.
19. Phillips S, Auais M, Belanger E, Alvarado B, Zunzunegui MV. Early and current social and economic circumstances and resilience in older adults: findings from the longitudinal International Mobility in Aging Study (IMIAS). SSM Popul Health. 2016;2:708–17. https://doi.org/10.1016/j.ssmph.2016.09.007.
20. Holt-Lundstad J, Smith TB, Bradley Layton J. Social relationships and mortality risk: a meta-analytic review. PLoS Med. 2010;2010(7):e1000316.

21. WHO. Closing the gap in a generation: health equity through action on the social determinants of health—final report of the commission on social determinants of health. Geneva: WHO; 2008. https://www.who.int/publications/i/item/WHO-IER-CSDH-08.1.
22. Marmot M, Allen J, Goldblatt P, Boyce T, McNeish D, Grady M. Fair society, healthy lives. Strategic review of health inequalities in England post-2010. 2011.
23. Felitti VJ, Anda RF, Nordenberg D, et al. Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The Adverse Childhood Experiences (ACE) Study. Am J Prev Med. 1998;14:245–58.
24. Fergus S, Zimmerman MA. Adolescent resilience: a framework for understanding healthy development in the face of risk. Annu Rev Public Health. 2005;2005(26):399–419.
25. Levin B, Ungar M, Schonert-Reichl K. From risk to resilience: final report for the Canadian Council on Learning, Winnipeg, Canada; 2009. http://www.ccl-cca.ca/pdfs/OtherReports/ResilienceReport.pdf.
26. Afifi TO, MacMillan HL. Resilience following child maltreatment: a review of protective factors. Can J Psychiatry. 2011;56:266–72.
27. Coatsworth JD, Duncan L. Fostering resilience. A strengths-based approach to mental health. A CASSP discussion paper. Harrisburg, PA: Pennsylvania CASSP Training and Technical Assistance Institute; 2003.
28. Harvey MR, Tummala-Nara P, editors. Sources and expressions of resiliency in trauma survivors. Ecological theory, multicultural practice. Birmingham: Haworth; 2007.
29. Grossmann KE, Grossmann. “Resilienz”—Skeptische Anmerkungen zu einem Begriff. In: Fooken I, Zinnecker J (Hrsg.). Trauma und Resilienz. Chancen und Risiken lebensgeschichtlicher Bewältigung von belasteten Kindheiten. Juventa, Weinheim; 2007. S. 29–38.
30. Bowes L, Jaffee SR. Biology, genes, and resilience: toward a multidisciplinary approach. Trauma Violence Abuse. 2013;2013(14):195–208.
31. Champagne FA, Curley JP. Epigenetic mechanisms mediating the long-term effects of maternal care on development. Neursci Biobehav Rev. 2009;2009(33):593–600.
32. Chen E, Miller GE. ‘Shift-and-persist’ strategies: why being low in socioeconomic status isn’t always bad for health. Perspect Psychol Sci. 2012;2012(7):135–58.
33. Klika JB, Herrenkohl TI. A review of developmental research on resilience in maltreated children. Trauma Violence Abuse. 2013;2013(14):222–34.
34. Lanius R, Vermetten E. Relationship of adverse childhood experiences to adult medical disease, psychiatric disorders, and sexual behavior: implications for healthcare in the hidden epidemic: the impact of early life trauma on health and disease. Cambridge University Press; 2010.
35. Purkey E, Patel R, Phillips SP. Trauma-informed care: better care for everyone. Can Fam Physician. 2018;2018(64):170–2.
36. Heath I. Person-centered prevention and health promotion. Int J Integr Care. 2010;10 Suppl(Suppl):e032. https://doi.org/10.5334/ijic.502.
37. Hammond W. Final report: mapping a pathway for embedding a strengths-based approach in public health practice. Calgary: Resiliency Initiatives; 2013.
38. DiMatteo MR. Social support and patient adherence to medical treatment: a meta-analysis. Health Psychol. 2004;2004(23):207–18.
39. Baldock KL, Paquet C, Howard NJ, Coffee NT, Taylor AW, Daniel M. Gender-specific associations between perceived and objective neighbourhood crime and metabolic syndrome. PLoS One. 2018;13(7):e0201336. https://doi.org/10.1371/journal.pone.0201336.
40. Phillips SP, Reipas K, Zelek B. Stresses, strengths and resilience in adolescents: a qualitative study. J Prim Prev. 2019;40:631–42.
41. Schmolke M. Gesundheitsförderung und Schizophrenie: Die Bedeutung sozialer Ressourcen für den Patienten. (Engl. abstract: Health promotion and schizophrenia: the importance of social resources for the patient). Dyn Psychiat. 2001;34:206–20.
42. Cochrane AL. Effectiveness and efficiency: random reflections on health services. Nuffield Trust; 1972.

43. Dambha-Miller H, Feldman AL, Kinmonth AL, Griffin SJ. Association between primary care practitioner empathy and risk of cardiovascular events and all-cause mortality among patients with type 2 diabetes: a population-based prospective cohort study. Ann Fam Med. 2019;2019(17):311–8.
44. Stewart JM, Auais M, Bélanger E, Phillips SP. Comparison of self-rated and objective successful ageing in an international cohort. Ageing Soc. 2018;2018:1–18. https://doi.org/10.1017/S0144686X17001489.
45. De Maeseneer J, Boeckxstaens P. James Mackenzie Lecture 2011: multimorbidity, goal-oriented care, and equity. Br J Gen Pract. 2012;62(600):e522–4.
46. Roland M, Paddison C. Better management of patients with multimorbidity. BMJ. 2013;346:f2510.

Part III
Clinical/Health Fields for Person-Centered Care

Chapter 19
Person-Centered Family Medicine and General Practice

Ted Epperly, C. Ruth Wilson, and Michael Kidd

19.1 Introduction

The importance of family medicine and general practice as the backbones of primary care cannot be understated in the development of person and family centered health care. The role of family physicians and general practitioners is to integrate the complexity of health care and health needs. Health care is responsible for only about 10% of a person's overall health [1]. Conversely, patients' behaviors, their genetics, their environment, and their jobs are responsible for about 90% of their health. The important role of family physicians and general practice physicians is to be an integrator between individuals, families, the community, health care, and health. The process in which family physicians and general practice physicians achieve this integration of health and health care is through trusted relationships with people in a continuous and comprehensive manner over time. The skill of generalism and having a broad-based scope of practice that understands the complexities of the human body all age groups, both genders, and the context of family, community and peoples' jobs is the important ingredient in providing person-centered care. It is this generalist knowledge that allows the big picture to be seen and

---

T. Epperly (✉)
Full Circle Health, Boise, ID, USA

University of Washington School of Medicine, Seattle, WA, USA
e-mail: tedepperly@fullcircleidaho.org

C. R. Wilson
Department of Family Medicine, Queen's University, Kingston, ON, Canada

Presidency, North America Region, World Organization of Family Doctors (Wonca), Singapore, Singapore
e-mail: ruth.wilson@dfm.queensu.ca

M. Kidd
The Australian National University, Canberra, ACT, Australia

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_19

acted on. It is in the subtle nuances of knowing not only what to do for a person or family that is having health care and health related issues but perhaps even more importantly knowing what not to do. All these things become important to efficient and effective resource utilization of health care to impact health as an outcome. This wise and thoughtful approach will not only maximize health care expenditures and improve the quality of health care outcomes, but at the same time manage sky rocketing cost that can be associated with redundant, ineffective, and wasteful health care dollars. Family medicine and general practice physicians are at the heart of primary care. Health care must be built around this type of generalism as being foundational to any functioning and effective health care system.

19.2 Health Systems Must Become More Responsive to Person-Centered Needs

Five common shortcomings of existing health care delivery across the world include inverse care, impoverishing care, fragmented and fragmenting care, unsafe care, and misdirected care. Inverse care plays out in most nations as the richest people getting the most care while the poor get the least care and have the greatest burden of suffering [2]. Impoverishing care is when the cost of care is causing a financial hardship or even bankrupting individuals, communities, nations, and the world. It is estimated that 100 million people worldwide go bankrupt around health care cost every year [3]. In the United States this represents 1.5 million people per year and averages one every 30 s [4]. Health care systems around the world are becoming more sub-specialized and reductionistic in approach. This leads to fragmented and fragmenting care versus the generalized holistic approach of primary care. Unsafe care is a result of poor system design, leading to medication errors, hospital acquired infections, and leads to increased morbidity and mortality. Misdirected care may occur with intensive or futile services - such as treatment of cancer, stroke, heart attack, or kidney failure—that offer only modest gains in longevity and quality of life but come at great cost.

Conversely, effective person-centered primary care promote health and wellness, can prevent 70% of chronic disease burden, and can add 25–30 years to people's lives [3]. Universal and timely access to primary care is not available throughout much of the world. This results in considerable fragmentation in healthcare and magnifies disparities in care, with some receiving high quality care close to home while many more lack access to basic primary care services. These wide disparities in primary care access create significant disparities in health care outcomes and perpetuate inequities across the world. A person-centered approach ensures that these five health care system shortcomings are both mitigated against but dialed in for appropriate care at the person and family level.

19.3 Proactive Versus Reactive Approaches in Person-Centered Care

As the world continues to develop and progress, the focus of health care systems must also progress away from reactive disease-oriented systems to proactive health care services that improve the populations health. As populations age, become more urbanized, face climate change, and confront the social determinants of health such as obesity for many and food insecurity for others, there must be an organized effort to address these challenges from a proactive and comprehensive systems perspective instead of from a reactive and fragmented individual perspective.

The excessive focus on disease and curative procedural interventions distracts attention from the realities and values of people in the context of their families, lives, and communities. This disease centered approach has kept systems from being more equitable, effective, and efficient and people from better health. In many ways, the business of disease has trumped the profession of medicine and health [5]. Albert Einstein once famously said, “Insanity is doing the same thing over and over again and expecting different results” [6]. This speaks powerfully to a failing health care system needing a different health care systems solution and not a temporary remedy or bandage. The Commonwealth Fund determined that two things improve health care outcomes for populations the most. First, some type of universal health insurance coverage and secondly, access to a usual source of care [7]. It is through this usual source of care that a relationship can be developed which leads to mutual trust and respect between the provider and the patient which leads to behavior change which is the majority of the causes of premature deaths in the world [1, 8]. Primary care as manifested in family medicine general practice, general internal medicine, general pediatrics, and geriatrics serves as a primary care integrator and a hub of coordination. This coordination and integration, as the usual source of care, helps lead to the triple aim of better health, better health care, and lower costs [9]. Primary care is integrative in nature by possessing a broad knowledge of all sectors of healthcare and a strong understanding of community resources and other social and structural determinants of health. It is unfortunate that one’s postal code is more important than one’s genetic code in determining one’s health. Primary care through trusted and continuous relationships, through a person and family centered approach over time can start to achieve the required integration and coordination of care that can both start to understand but also diminish the impact of those social determinants of health.

19.4 Person Centered Approaches in Family Medicine and General Practice

Aspects of care that distinguish disease centered health care from person centered primary care can be seen in Table 19.1. The basic distinction as noted here is that a person and people centered primary care focus on people's health needs through comprehensive, continuous, and person-centered care in which people are partners in managing their own health. This leads to enduring and continuous personal relationships. The combination of continuity, comprehensiveness, and person-centered care produce better health for all people in the community as well as addressing the social determinants of health for better population health. Clarification of the key terms used in describing the various elements and layers of the complex healthcare system is essential. Primary care connotes health care professionals who act as a first point of contact and consultation for all people within the health care system. All people should have a primary care professional as their usual source of care. Secondary care involves health care services provided by medical specialists and other health professionals who provide limited access and services. Tertiary care is specialized consultative health care, usually provided in hospital or specialty clinics. Quaternary care is used sometimes to refer to services that are highly specialized and not widely accessed. Experimental medicine and some types of uncommon diagnostic or surgical procedures are considered quaternary care. Preventative care includes measures taken to prevent diseases or injuries before occurrence rather than curing them or treating them afterwards. End-of-life or palliative services involve care for those with terminal illnesses or advancing disease that is progressive an incurable.

Table 19.1 Aspects of care that distinguish disease-centered care from person-centered primary care

Disease-centered care	Person-centered primary care
• Reactive in approach • Focus on illness and cure • Relationship limited to the moment of service • Episodic curative care • Responsibility limited • Users are consumers of the care they purchase • Social determinants of health are most often not addressed	• Proactive in approach • Focus on health needs • Enduring and continuous personal relationship • Comprehensive, and timely, person-centered care • Responsibility and accountability over time • People are partners in managing their own health and that of their community • Social determinants are often addressed

Modified from Epperly et al. [10]

19.5 The Seven Shared Principles of Person-Centered Primary Care

The seven Shared Principles are listed in Table 19.2. They include the four classic Starfield Principles [12]: continuous, comprehensive, coordinated, and accessible—along with several other concepts.

1. **Person and Family Centered**

   The decision to replace "patient-centered" with the term "person and family centered" was a very intentional one, responsive to concerns expressed by consumer advocates that the word "patient" objectified individuals in a sick or dependent role. The principles sought to move beyond the narrow framework of a disease care system to one promoting health. This first of the Shared Principles affirms an empowered partnership role for individuals and families. For example, the principal asserts that "primary care is grounded in mutual beneficial partnerships among clinicians, staff, individuals and their families, as equal members of the care team. Care delivery is customized based on individual and family strengths, preferences, values, goals and experiences using strategies such as care planning and shared decision making. There are opportunities for individuals and their families to shape the design, operation, and evaluation of care delivery [12]."
2. **Continuous**

   This principle reiterates the long-standing concept that "dynamic, trusted, respectful, and enduring relationships between individuals, families and their clinical team members are hallmarks of primary care." The secret sauce of primary care is the ongoing trusting relationship between clinicians and the primary care team and individuals and families that is a healing process unto itself. This allows the importance of a sustained incremental approach over time to be foundational to dealing with acute, chronic and prevention-based health care problems and issues [13]. This process also allows a thoughtful approach to the integration of a person/family into the health care system [12].
3. **Comprehensive and equitable**

   This principle emphasizes important contemporary aspects of comprehensive primary care, such as behavioral and mental health as well as oral health. The

Table 19.2 The seven shared principles of primary care [11]

1. Person and family centered
2. Continuous
3. Comprehensive and equitable
4. Team-based and collaborative
5. Coordinated and integrated
6. Accessible
7. High-value

principle also ties comprehensiveness to emerging concepts in health equity, calling on primary care to "seek out the impact of social determinants of health and social inequities. Primary care practices partner with health and community-based organizations to promote population health and health equity, including making inequities visible and identifying avenues for solution." [12] Current research demonstrates that health care influences only approximately 10–20% of a person's health, a person's behaviors, environment, genetic makeup and social conditions being the most powerful determinants of health, illness and death [13].

4. **Team-based and collaborative**

   This principle affirms that individuals and families are critical members of primary care teams. In recognizing the multidisciplinary nature of team-based care, it also asserts that "health care professional members of the team are trained to work together at the top of their skill set, according to clearly defined roles and responsibilities [12]". This principle broadens the importance of relationships to include the entire primary care team. Many team members, from nurses, medical assistants, receptionists, as well as clinicians, form relationships with the persons and families cared for by the practice. All primary health care team members are important in delivery of team-based collaborative care [12].

5. **Coordinated and integrated**

   The Shared Principles largely reiterate the central emphasis on contemporary issues such as "transitions of care to achieve better health and seamless care delivery across the lifespan." The term "integrated" refers to how the individual's health data and records can inform care within the primary care team and with other health care professionals in the medical neighborhood. The term "coordinated" refers to how healthcare is seamlessly arranged with others participating with the individuals care outside of the primary care practice in the medical neighborhood. With the emergence of evolving health information technology new and dynamic ways of integrating and coordinating health care information and data can be performed both synchronously and asynchronously with individuals to optimize their health care and health [12].

6. **Accessible**

   This principle acknowledges the changing nature of access in a digital communication era, asserting that "primary care is readily accessible, both in person and virtually for all individuals regardless of linguistic, literacy, socioeconomic, cognitive or physical barriers. This accessibility goes far beyond the concept of face to face visit. Meeting patient's health and health care needs electronically, telephonically, and in other technologically empowered ways in both achieving person and family centered care but accessible care that is of high value. Primary care provides individuals with easy, routine access to their health information." Moreover, person and family centered access means that "clinicians and staff are available and responsive when, where, and how individuals and families need them [12]."

7. **High value**

   This principle goes further than most prior formulations by asserting that primary care has a responsibility for both the "numerator" (quality and patient experience) and "denominator" (cost) components of health care value, and once again highlights the importance of a person and family centered approach. “Primary care achieves excellence, equitable outcomes for individuals and families, including using healthcare resources wisely and considering cost to patients, payers, and the system. Primary care practices employ a systematic approach to measuring, reporting and improving population health, quality, safety and health equity, including partnering with individuals, families and community groups.” Additionally, you cannot place enough value on the importance of the trusting relationship to drive quality and patient safety into appropriately lower healthcare costs [12].

19.6 The Value of Person-Centered Primary Care

Countries with stronger primary care have better overall health care outcomes and reduce per capita health expenditures than countries with weaker primary care systems [14]. Studies in the United States show that as the number of primary care physicians increase per ten thousand people, the quality of care improves and health care cost per person decrease [15]. Conversely, as the number of specialists per ten thousand increases in the United States, quality scores are reduced and cost increase [15]. Evidence also demonstrates that person-centeredness contributes to quality care and better outcomes. This can be seen in the improved treatment intensity and quality of life [16], better understanding of the psychological aspects of a patient’s problems [17], improved satisfaction with communication [18], improved patient confidence regarding sensitive problems [19], increased trust and treatment compliance [20], and better integration of prevention and curative care [21]. Evidence similarly shows that comprehensiveness leads to higher quality care and better outcomes [22–24].This is seen by better health outcomes, increased uptake of disease focused preventative care [25], and fewer patients admitted for preventable complications of chronic conditions [26]. Continuity of care also shows clear evidence of improving quality of care and better outcomes. This can be seen through lower all-cause mortality [27–30], better access to care [31, 32], less re-hospitalization [33, 34], fewer consultations with specialist [35], less use of emergency services [33, 36], and better detection of adverse effects of medical interventions [37, 38]. Finally, a regular entry point of care as provided in person-centered primary health care contributes positively to quality of care and better outcomes. These include increased satisfaction with services [39–42], better compliance and lower hospitalization rate [24, 39, 43, 44], less use of specialists and emergency services [24, 43–46], fewer consultations with specialist [43, 46], more efficient use of resources [23, 31, 47, 48], better understanding of the psychological aspects of patient’s problems [17], better uptake of preventative care by adolescents [11], and protection against over-treatment [10]. In fact, people’s perceptions of a high-quality, person-centered primary health care has been recently studied and supported in 34 countries as to why it is important to invest in strong primary health care as practiced by family medicine and general practice physicians [49]. The evidence showing that primary care leads to higher quality of care and better outcomes is summarized in Table 19.3 below.

Table 19.3 Rational for the benefits of primary care for health [14]

1. Greater Access to Needed Services
2. Better Quality of Care
3. A Greater Focus of Prevention
4. Early Management of Health Problems
5. Cumulative Effect of Primary Care to more Appropriate Care
6. Reducing Unnecessary and Potentially Harmful Specialist Care
7. Decreased Morbidity and Mortality
8. More Equitable Distribution of Health in Populations
9. Lower Cost of Care
10. Better Self-Reported Health
11. Primary Care Physicians achieve Better Outcomes than do Specialists at Much Lower Costs

There are several large gaps in national health care systems that will need to be addressed to advance person-centered care. Primary care needs greater capacity in and integration with behavioral/mental health, public health, end-of-life care, telemedicine and health information technologies, community health services, and patient activation and community engagement. These areas represent targets for improvement that will drive forward better health care for people, communities, and nations. Engaging people in their own health care through shared decision making and empowering their involvement should not be only their right, but their duty in the participation of the planning, the choosing, and the implementation of their health care and their health. The person-centered engagement framework of "inform me, engage me, empower me, partner with me, and stay by me" becomes pivotal to person-centered care for the future and essential to helping achieve better health care, better population health and lower cost care [50].

19.7 The Outcome of the 2015 Geneva Declaration of Person-Centered Primary Healthcare

The 2015 Geneva Declaration on Person-Centered Primary Health Care calls for the following ten principles to be endorsed and acted upon by all nations of the world [10].

1. Timely access to quality healthcare is a fundamental human right to all people.
2. All health care systems in all nations be designed with the person and people at the center of the health care system.
3. That all health care systems in all nations be built on the foundation of person-centered, community-based primary care as the entry point of first contact and the usual source of people's care.

4. That all people have a relationship of trust with a person-centered primary health care professional, and their team, as that usual source of care.
5. That people are encouraged and empowered to be partners with their primary care professionals and their teams in their community in informed and shared decision making.
6. That people are educated to be engaged and responsible as partners in their own health care and in the design and development of health services so that their voice and view are always heard.
7. That persons' voices be heard and respected around the framework of "inform me, engage me, empower me, partner with me, and stay by me".
8. That nation's medical, nursing, and other health professional schools are held accountable for producing a future health care work force that meet these person-centered primary health care goals in sufficient numbers to ensure that all people have access to this type of person-centered care.
9. That resources and payment be aligned to person-centered primary health care providers and practices that allow them to integrate and coordinate a person's care that will produce the results of improved person-centered care, improved population health, and lower health care costs.
10. That health care leaders and health care policies are produced that support primary healthcare to provide person-centered and community/population-centered healthcare and achieve these goals.

19.8 The Rural Paradigm and Person-Centered Approach

There is no better place to understand the importance of family medicine and general practice in providing person and family centered primary care than in rural and frontier parts of our nations. This approach should be a five-step process with the following key attributes:

1. **Person and Family Centered**—In rural areas future health care should start by putting the people and their families and their communities at the center of the health and health care system that surrounds and serves them. By doing this we can focus on high value activities that meet the peoples, families, and communities' needs.
2. **Required services—**Once we have the conceptual reframing of putting people, families, and communities at the center of health care then we need to prioritize what primary care services are of value to them. By doing this we will ensure that we are preforming on the activities that the people of the community desire and not what the financial revenue generation of the health care system is intending to achieve.
3. **Team Based Care**—Once people and families have been put at the center of the system and appropriate primary care services are identified then integrated professional teams of people working together both in a practice and within the

community must meet these needs. It is by the team preforming these services that people's health and health care outcomes will be maximized. By doing this as well as a team-based activity it will decrease burnout and lesson the burden on any particular team member as long as all are working collaboratively to the tops of their professional licenses

4. **Interprofessional Team Based Education**—It should be a requirement that interprofessional team-based training and communication are taught at all professional schools. It is important that the team work effectively and efficiently work together to meet the people, families and communities primary care services needs in ways that are cost effective, high value and of high quality. In fact, this approach can bring great joy to the team members as they work together effectively and efficiently to produce these outcomes and to maximize population health.
5. **Payment Reform—**We must evolve the payment for health care and the acquisition of health to a different model. We must move away from fee for service payments to a value-based payment system that achieves health and health care outcomes as our goals. A combined payment system that is based on a per member per month capitation formula with quality outcomes and shared savings for health and health care outcomes must be at the center of this system. In that way these teams can be empowered to produce the results we want in a financially sustainable way to the practice and the community. This will move us away from reactive disease care to proactive health care and health maintenance. If the practices can move away from volume of patients seen as the currency of financial success, to the health of the people of their population as the health outcome success in a way that provides enough financial support to keep the teams intact then this should be the goal. This model of payment is within easy grasp and actually not only could be paid for in its entirety but would save the system billions of dollars.

These five things when taken together in the order listed would help transform both health and health care in rural sectors of our world as well as would reshape how health care is practiced in all areas of the world. Therefore, the rural paradigm is important to get right because in so doing it will create the model of how family medicine, general practice and primary care can be at the center of helping these five items be successful.

19.9 Key Factors for the Implementation of a Person-Centered Approach in Family Medicine and General Practice

Key factors for the implementation of a person-centered approach in family medicine and general practice can be seen in Table 19.4 below. These key factors are important when working with each other as outlined in the rural paradigm section

Table 19.4 Key factors for implementation of PCM approach

- Attitudinal
  - Rural paradigm model above
- Operational
  - Patient centered medical home
  - Team based
- Quality
  - Metrics
  - Health outcomes
- Educational
  - Interprofessional team based training models
- Financial
  - Advance payment models
  - Population health payment

above in achieving improved health care and health outcomes. All educational facilities teaching interprofessional team based care must focus on the interaction of these variables with graduates from their programs so that we can contribute interprofessional team members to help across silos within other members of the health care teams in ways that are truly meeting a person-centered, family-centered and community based population health need. By creating these teams not only will we be caring for ongoing chronic health care diseases but more importantly we will start to leverage the teams to move upstream to address in a proactive way the bigger factors that impact people's health. These factors such as personal behaviors, environment, social determinants of health and others can be proactively addressed in communities to decrease downstream bad health care outcomes. By so doing the finances of health care can be reframed and re-leveraged in manners to achieve these outcomes.

19.10 Conclusions

The most effective and efficient health care systems depend on a strong foundation of primary care as practiced by family medicine and general practice physicians. As health care systems become more complex, there is greater need for better integration and coordination. Now is the time to create and set in place the principles of high-quality, person and family centered primary care. Primary care is the glue that holds health care systems together and integrates their multiple complex parts. Providing all people foundation of accessible team-based primary care as the entry point into the health care system leads to improved coordination, continuity, and comprehensiveness of care. This process also leads to trusted relationships from which higher quality and safer person-centered care results. Primary care must be accessible, timely, and community based and is the main antidote to reduce disparities and inequalities of care. For all health care systems in the world, primary care must be valued, promoted, financed, and sustained in order to help deliver these benefits in uniform manner across all countries of the world. Only by working with people in a person-centered manner that reflects the wishes and desires of the people served will nations and communities create systems of quality health care for all people [10].

Acknowledgements and Disclosures The authors do not report any conflicts of interest in the preparation of this manuscript.

References

1. McGinnis JM, Foege WH. Actual causes of death in the United States. JAMA. 1993;270:2207–12.
2. Hart JT. The inverse care law. Lancet. 1971;297:405–12.
3. The World Health Report. Primary health care—now more than ever. 2008. http://www.who.int/whr/2008/en/.
4. The White House. Office of the Press Secretary. Remarks by the President at the Opening of the White House Forum on Health Reform. 2009. http://www.whitehouse.gov/the_press_office/Remarksby-the-President-at-the-Opening-of-the-White-House-Forum-on-Health-Reform.
5. Epperly T. Fractured: America's broken health care system and what we must do to heal it. 2012. http://fracturedhealthcare.com/about/.
6. Albert Einstein. BrainyQuote.com. n.d. http://www.brainyquote.com/quotes/quotes/a/alberteins133991.html. Accessed 25 June 2015.
7. Beal AC, Doty MM, Hernandez SE, Shea KK, Davis K. Closing the divide: how medical homes promote equity in health care: results from the Commonwealth Fund. Health Care Quality Survey; 2006–2007.
8. Mokdad AH, Marks JS, Stroup DF, Gereberding JL. Actual causes of death in the United States. JAMA. 2000;2004(291):1230–45.
9. IHI Triple Aim Measures. n.d. http://www.ihi.org/Engage/Initiatives/TripleAim/Pages/MeasuresResults.aspx.
10. Epperly T, Roberts R, Rawaf S, Van Well C, Mezzich J, et al. Person-centered primary health care: now more than ever. Int J Pers Cent Med. 2015;5(2):53–9.
11. Epperly T, Bechtel C, Sweeny R, Greiner A, Grumbach K, et al. The shared principles of primary care: a multistakeholder initiative to find a common voice. Fam Med. 2019;51(2):179–84.
12. Starfield B. Primary care: concept, evaluation, and policy. Oxford: Oxford University Press; 1992.
13. Institute for Healthcare Improvement. The IHI triple aim. 2018. http://www.ihi.org/engage/initiatives/Triple-Aim/Pages/default.aspx.
14. Starfield B, Shi L, Macinko J. Contribution of primary care to health systems and health. Millbank Q. 2005;83(3):457–502.
15. Medicare Claims Data. Area health resource file. Health Research & Services Administration, US Department of Health and Human Resources; 2003.
16. Ferrer RL, Hambidge SJ, Maly RC. The essential role of generalists in health care systems. Ann Intern Med. 2005;142:691–9.
17. Gulbrandsen P, Hjortdahl P, Fugelli P. General practitioners' knowledge of their patients' psychosocial problems: multipractice questionnaire survey. Br Med J. 1997;314:1014–8.
18. Jaturapatporn D, Dellow A. Does family medicine training in Thailand affect patient satisfaction with primary care doctors? BMC Fam Pract. 2007;8:14.
19. Kovess-Masféty V, et al. What makes people decide who to turn to when faced with a mental health problem? Results from a French survey. BMC Public Health. 2007;7:188.

20. Fiscella K, et al. Patient trust: is it related to patient-centered behavior of primary care physicians? Med Care. 2004;42:1049–55.
21. Mead N, Bower P. Patient-centeredness: a conceptual framework and review of the empirical literature. Soc Sci Med. 2000;51:1087–110.
22. Chande VT, Kinane JM. Role of the primary care provider in expediting children with acute appendicitis. Arch Pediatr Adolesc Med. 1996;150:703–6.
23. Forrest CB, Starfield B. The effect of first-contact care with primary care clinicians on ambulatory health care expenditures. J Fam Pract. 1996;43:40–8.
24. Starfield B. Primary care: balancing health needs, services, and technology. New York: Oxford University Press; 1998.
25. Bindman AB, et al. Primary care and receipt of preventive services. J Gen Intern Med. 1996;11:269–76.
26. Shea S, et al. Predisposing factors for severe, uncontrolled hypertension in an inner-city minority population. N Engl J Med. 1992;327:776–81.
27. Franks P, Fiscella K. Primary care physicians and specialists as personal physicians. Health care expenditures and mortality experience. J Fam Pract. 1998;47:105–9.
28. Regional Core Health Data Initiative. Washington DC: Pan American Health Organization. 2005. http://www.paho.org/English/SHA/coredata/tabulator/newTabulator.htm.
29. Shi L, et al. The relationship between primary care, income inequality, and mortality in the United States, 1980-1995. J Am Board Fam Pract. 2003;16:412–22.
30. Villalbi JR, et al. An evaluation of the impact of primary care reform on health. Aten Primaria. 1999;24:468–74.
31. Forrest CB, Starfield B. Entry into primary care and continuity: the effects of access. Am J Public Health. 1998;88:1330–6.
32. Weinick RM, Krauss NA. Racial/ethnic differences in children's access to care. Am J Public Health. 2000;90:1771–4.
33. Friedberg MW, Rosenthal MB, Werner RM, Volpp KG, Schneider EC. Effects of a medical home and shared savings intervention on quality and utilization of care. JAMA Intern Med. 2015;175(8):1362–8. https://doi.org/10.1001/jamainternmed.2015.2047.
34. Weinberger M, Oddone EZ, Henderson WG. Does increased access to primary care reduce hospital readmissions? For The Veterans Affairs Cooperative Study Group on Primary Care and Hospital Readmission. N Engl J Med. 1996;334:1441–7.
35. Woodward CA, et al. What is important to continuity in home care? Perspectives of key stakeholders. Soc Sci Med. 2004;58:177–92.
36. Gill JM, Mainous AGI, Nsereko M. The effect of continuity of care on emergency department use. Arch Fam Med. 2000;9:333–8.
37. Kravitz RL, Duan N, Braslow J. Evidence-based medicine, heterogeneity of treatment effects, and the trouble with averages. Milbank Q. 2004;82:661–87.
38. Rothwell P. Subgroup analysis in randomized controlled trials: importance, indications, and interpretation. Lancet. 2005;365:176–86.
39. Freeman G, Hjortdahl P. What future for continuity of care in general practice? Br Med J. 1997;314:1870–3.
40. Miller MR, et al. Parental preferences for primary and specialty care collaboration in the management of teenagers with congenital heart disease. Pediatrics. 2000;106:264–9.
41. Rosenblatt RL, et al. The generalist role of specialty physicians: is there a hidden system of primary care? JAMA. 1998;279:1364–70.
42. Weiss LJ, Blustein J. Faithful patients: the effect of long-term physician–patient relationships on the costs and use of health care by older Americans. Am J Public Health. 1996;86:1742–7.
43. Martin DP, et al. Effect of a gatekeeper plan on health services use and charges: a randomized trial. Am J Public Health. 1989;79:1628–32.
44. Parchman ML, Culler SD. Primary care physicians and avoidable hospitalizations. J Fam Pract. 1994;39:123–8.

45. Gadomski A, Jenkins P, Nichols M. Impact of a Medicaid Primary Care Provider and Preventive Care on pediatric hospitalization. Pediatrics. 1998;101:E1.
46. Hurley RE, Freund DA, Taylor DE. Emergency room use and primary care case management: evidence from four Medicaid demonstration programs. Am J Public Health. 1989;79:834–6.
47. Hjortdahl P, Borchgrevink CF. Continuity of care: influence of general practitioners' knowledge about their patients on use of resources in consultations. Br Med J. 1991;303:1181–4.
48. Roos NP, Carriere KC, Friesen D. Factors influencing the frequency of visits by hypertensive patients to primary care physicians in Winnipeg. Can Med Assoc J. 1998;159:777–83.
49. Schafer WLA, Boerma WGW, Murante AM, Sixma HJM, Schellevis FG, Groenewegen PP. Assessing the potential for improvement of primary care in 34 countries: a cross-sectional survey. Bull World Health Organ. 2015;93:161–8.
50. Patient Engagement Framework. Healthwise. n.d. http://www.healthwise.org/solutions/patientengagement.aspx.

Chapter 20
Person-Centered Internal Medicine

José Luis Calderón-Viacava and Herman Vildózola

20.1 Conceptual Bases of Person-centered Internal Medicine

Person Centered Medicine (PCM) is a fundamental clinical principle and a fundamental strategy. This follows the meaning of these terms in the Dictionary of the Royal Academy of the Spanish Language, where principle is the fundamental norm or idea that governs thought or behavior; and strategy is the art of guiding or managing a major issue or task [1]. Medicine centered on the person and public health centered on the community, are essential principles and strategies to carry out adequately health care, education of health personnel, ethics activities, biomedical research and the definition and implementation of public health policies.

Thus, person centered medicine is much more than basic and technical work focused on the diagnosis and treatment of diseases. Person centered medicine is aimed at caring for and optimizing the health and well-being of persons and the community. For this, it is essential to combine humanism, art, science and technology, in a systematic and holistic approach to health. This needs to be instrumentally educational and bidirectional establishing a symmetrical doctor-patient relationship in which two persons complement each other. The power of medicine needs to be achieved combining the power of evidence with the power of attending to the patient's values and preferences. This involves conducting a collaborative diagnosis as joint understanding of the clinical situation and then making care decisions engaging the views of patient, clinicians and family.

J. L. Calderón-Viacava (✉)
Cayetano Heredia Peruvian University, Lima, Peru

Corpac Medical Center, Lima, Peru

H. Vildózola
San Fernando Medical School, San Marcos National University, Lima, Peru

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_20

20.2 Health, Medicine and Professionalism

Around 1828, anatomopathologist José Letamendi de Manjarres proclaimed in Barcelona "He who only knows medicine, nor medicine knows". This speaks of the need for a broad knowledge of life, health and humanism in order to practice medicine well. Human health is arguably the most important part of the human condition, that must be understood a comprehensive manner: physical health (physical fitness), emotional health (psychological stability and strength), social health (effective relationships) and spiritual health (sense of transcendence and vocation of service). It is also a fundamental human value, a right and a responsibility.

Regarding the medical profession, medicine is a cultural institution and a social responsibility, concerned with caring for health, restoring and promoting it, alleviating suffering, enhancing functioning, and accompanying fellow human beings throughout their lives.

20.3 The Comprehensive Clinical Approach

The comprehensive clinical approach consists of recognizing the person as a bio-psycho-spiritual being, in a social environment. Therefore, it is necessary to consider a comprehensive causality, a comprehensive clinical condition, a comprehensive diagnosis and a comprehensive treatment. Regarding comprehensing causality, it is recognized that it is usually multifactorial and that the health/disease process can be initiated by any of its variables (biophysical, biochemical, psychological and social). In relation to comprehensive clinical condition, it must account for the symptoms and signs of disease, ailments and dysfunctions. Regarding comprehensive diagnosis, it should address the characteristics, conditions and circumstances of the person, in addition to diseases, risk factors, protective factors, the state of well-being, and the state of functionality, experience and expectations for care. Regarding comprehensive treatment, it is always pertinent to consider that non-pharmacological treatment is as important or more than pharmacological treatment and that the four levels of prevention must always be taken into account: primary, secondary, tertiary and quaternary that are necessary in each particular case.

Primary Prevention: Measures taken to avoid or eliminate the cause of a health problem, in an individual or population, before it occurs.

Secondary Prevention: Measures taken to detect a disease at an early stage in an individual or in a population (early diagnosis and treatment).

Tertiary Prevention: Measures taken to treat a disease or clinical problem thoroughly in an individual or population.

Quaternary Prevention: Measures adopted that deal with the sequalae or complications of a disease. It includes physical/emotional/mental/spiritual and social rehabilitation, and promotes full functioning and flourishing of the person, in an ethical manner and preventing overmedicalization [2].

Another major consideration to promote comprehensive care is attending to mental health, both in terms of psychiatry as a major medical specialty and as a major transversal factor in the health field. As former WHO Director General Gro Brundtland proclaimed, there is no health without mental health. This involves not only addressing mental problems, but pointedly promoting positive health, i.e., resilience, adaptive functioning, supports, well-being and quality of life [3, 4]. In addition, one must consider that health psychological variables play a determining role as sensitizing and triggering factors of a broad range of diseases.

20.3.1 Clinical Thinking

Medical thinking is a complex process that is made up of several components. The most important of these follow: analytical or reflective, intuitive or expert-based, holistic (integrative), preventive, critical, creative (playful), strategic, systemic, synthetic, the systematic, the historical, the axiological, the moral or ethical, the prospective, the heuristic (imaginative), the hermeneutical (interpretive) and the ontological. Clinical judgment allows the doctor to recognize a clinical picture, analyze it, interpret it, make a differential diagnosis, specify its course and its degree of severity; consider the characteristics, conditions and circumstances of the patient and the context of the health/disease process. Also pertinent is the cultivation of positive health discussed in the previous section, and the encouragement and guidance for the formulation of each person's life project.

20.3.2 Basic Clinical Skills

The two most important clinical skills are: taking the medical history and performing the physical examination. With the overwhelming advancement of technology and greater access to medical/scientific information, the basic clinical skills have lost visibility and their adherence from medical professionals. It is not possible, however, to do PCM and have the best results in health care if we do not carry out a complete, orderly, rigorously chronological and detailed medical history and a complete, orderly and rigorously systematic physical examination. Regarding the Clinical History, the classic structure is still valid at present: ancestry, current illness, personal history (physiological and pathological), family history and anamnestic review of systems. It is important to consider the proper assessment of biological and social functions. These encompass functions whose variation or alteration suggests the possibility, probability or certainty of the presence of disease. In this sense, it is necessary to evaluate appetite, urine, stools, sleep, sensitivity to cold, sweating, thirst, mood, physical activity, weight, family life, work life, social life and sexual life.

Regarding the performance of the physical examination, it must be complete, orderly and rigorously systematic, carried out with high standards, effectiveness, efficiency and deep respect for the integrity and privacy of the person. The well-performed physical examination, when the patient feels adequately approached and not handled, plays a tremendous role in building trust between the person and the physician. It is an indispensable and necessary element of diagnostic and therapeutic tasks. As for the case of the medical history, in the physical examination, vital functions must be meticulously evaluated. These are the functions whose alteration suggests the possibility, probability or certainty of the presence of disease, with the particularity that the significant alteration of them endangers the life of the person. Among such functions are heart rate and its characteristics, respiration rate and its characteristics, blood pressure, temperature and the state of consciousness (level, scope and content).

20.3.3 Primary Health Care and Person-Centered Medicine Considerations

Primary Health Care has its origin in the Declaration of Alma Ata [5] approved at the International Conference of WHO on September 6–12, 1978, in Alma Ata (now Almaty), in Kazakstan then part of USSR, with the participation of 191 countries and 67 international organizations. The Declaration is based "on the need for urgent action by all governments, all health and development personnel and the world community, to protect and promote the health of all the peoples of the world." This is a joint declaration encompassing ten agreements in order to achieve Health for All in the year 2000. David Rivero de Tejada, a Peruvian doctor and then Deputy Director General of the World Health Organization, specified the following to fully understand the meaning of Primary Health Care.

"At that time the term "Primary Health Care" was badly mistranslated distorting its genuine interpretation and complete understanding. On the one hand, the word "care" was positioned to mean a service, especially medical, where there are active providers and passive recipients (hangover of the Flexnerian model), instead of meaning caring for each other. On the other hand, the word "primary" leads to undervaluing the content of that service, identifying it with elementary, informal, cheap service for the poor. Actually, the meaning of this term adopted in Alma-Ata was to consider it as essential, nuclear, fundamental, substantive and prioritary, and, above all, applicable to all levels of health services, including institutions in other sectors and the homes, schools, work centers and institutions of the communities in general." "Integral health care for all by all" is the best way to express the genuine "primary health care" of Alma-Ata. It is a necessity not only in the field of health but for the future of the countries that aspire to remain sovereign nation-states in an increasingly unjust world [6].

Regarding individual health care, the strategic principle of PCM undoubtedly allows to have good results, because by practicing this centrality the Clinical History and the Physical Examination may be really useful, which allows to carry out the Diagnosis and Treatment with the highest precision and validity and also reduces doubt and confussion of health professionals, the persons who seek care and their families in the health care process.

20.4 Generic and Specific Clinical Professional Competences

These are essential to be able to practice a truly person centered medicine in which the objectives are: to take care of and improve health, cure the disease, rehabilitate the consequences and accompany a dignified death with the least possible pain and suffering.

The generic clinical professional competencies and the specific clinical professional competencies that must be taken into account to execute PCM are listed below.

20.4.1 Generic Clinical Professional Competences

1. Educate the person, their family members and the community in health and disease aspects, in order to achieve their responsible, voluntary and knowledgeable participation; in the promotion, prevention, diagnosis and treatment of their health problems.
2. Communicate effectively to achieve as a result a genuine and symmetrical doctor/patient relationship that allows a shared decision-making process.
3. Sensitize the person and family to create a framework of value, which allows developing the intrinsic motivations necessary to achieve appropriate decisions and actions.
4. Be responsible and prudent in everything you do or fail to do in professional practice, committing yourself to the rational and pertinent use of the best means for the diagnostic and therapeutic process.
5. Be respectful, so that the persons and their families perceive the feeling that the doctor is concerned for their dignity as human beings, generating the confidence and security essential to achieve the best results.
6. Be empathetic, making the persons and their family members feel that their doctor puts themselves in their circumstances, understanding their vital situation.
7. Be assertive, being able to defend your point of view without damaging the points of view of the persons and their families.

8. Be altruistic, healthy and warm, achieving an environment of tranquility and well-being, which conditions that the persons and their family members feel comfortable, allowing them to be good informants and good partners for health.
9. Be fair, patient and tolerant, maintaining a balanced state of mind under any unfavorable circumstances conditioned by the emotional state of the professional, the patient, or the family.
10. Understand and effectively use the Comprehensive Clinical Approach.
11. Know, understand and practice a relevant Code of Ethics and Deontology.
12. Understand, value and respect the rights of patients and encourage the fulfillment of their responsibilities
13. Understand, value and practice according to ethical codes that originated in the Hippocratic Oath, and adapted in the World Medical Association's Geneva Declaration
14. Understand, value and effectively use informed consent for treatment and research, including the World Medical Association' Helsinki Declaration for Ethical Medical Research.
15. Understand and practice Person Centered Medicine as fundamental principle and strategy
16. Understand and practice the Primary Health Care Strategy as integral health care
17. Understand and practice the strategy of Educational Medicine, based on the fact that health care is fundamentally a bidirectional educational process in which the aim is to achieve the least possible degree of uncertainty.
18. Understand and practice the Health Teamwork strategy, considering, respecting and valuing the contribution of other doctors and other health professionals.
19. Understand and practice the strategy of considering in decision-making the importance of economic costs in health care.
20. Understand and practice the strategy of cultural competence in health care. Being culturally competent means that clinicians consider and act each other's cultural perspectives.
21. Cultivate critical and creative thinking to use the best information for decisions made through the medical act, based on the strategy of evidence-based medicine and empirically proven practice.
22. Cultivating the necessary capacities to develop leadership in health care service, effectively managing to be an agent for change in individual and collective health.
23. Use digital tools to adequately carry out telemedicine: teleconsultation, teleinterconsultation, telemonitoring and teledata.

20.4.2 Specific Clinical Professional Competences

The medical internist must commit to:

1. Clinical judgment, preventive thinking and patient safety as transversal axes of the medical act.

2. Clinical History: to be complete, ordered and rigorously chronological and detailed.
3. Clinical Exam: to be complete, orderly and rigorously systematic.
4. Diagnosis: to be complete, orderly and rigorously precise.
5. Clinical and differential diagnosis as the essential intellectual activity in medical work.
6. Early diagnosis and timely and adequate treatment to limit damage and avoid complications and sequelae.
7. Prevention and early diagnosis of complications.
8. Prevention and early diagnosis of adverse drug reactions.
9. Treatment: complete, orderly and rigorously rational.
10. Consider both non-pharmacological and pharmacological treatments.
11. Prophylactic treatments.
12. Psychotherapeutic and sociotherapeutic treatments.
13. Rational use of medication.
14. Work plan: Complete, orderly and rigorously relevant.
15. Evolution parameters: complete, ordered and rigorously useful.
16. Prognosis: complete, orderly and rigorously prudent.
17. Early identification of the patient of medium to severe complexity.
18. Early identification of the patient who requires special help.
19. Avoid iatrogenesis.
20. Avoid intrusion.
21. Attenuate hospitalism.
22. Critical attitude towards propaganda about medical information and health professionals.

20.5 Practical Implications for the Implementation of Person-Centered Clinical Care

20.5.1 Key Factors in Internal Medicine Useful to Evaluate the Implementation of Person-Centered Medicine

Medicine centered on the person as a philosophy of caring for patients has a solid doctrinal and historical support, as can be seen from the conclusions of the International College of Person Centered Medicine's Geneva Conferences Geneva, including the following: (1) A broad biological, psychological, social, cultural and spiritual theoretical framework, (2) Care for both sick health and positive health, (3) Person-centered research and education around clinician-patient-family communication, diagnosis, treatment, prevention, and health promotion and (4) Respect for the autonomy, responsibility and dignity of every person involved [7], which allows us a very high quality medical care of the person as well as involving the family and the community. However, its application to daily practice in hospitals, clinics or health centers encounters difficulties of various kinds, so its analysis and solution proposals to face these difficulties, becomes a challenge for those of us who believe of its benefits. As a way of humanizing medicine and maximizing satisfaction not only for the patient treated under this perspective but also for the full development of the doctor by raising the quality of care and above all, fully recovering the trust of patients.

Internists by training have the broadest understanding of health-disease problems of patients and thus has the specialty to easily adopt the postulates of Person-Centered Medicine. The complexity of clinical situations, which frequently occur in medical practice, allows the internist to develop skills and dexterity that other medical specialties do not have for a holistic approach to sick persons. This peculiar characteristic makes Internal Medicine one of the specialties with more possibilities of success to lead the training strategy of this new and enduring form of high-quality person centered medical care, also taking into account that their solid preparation will facilitate their role as trainers of first-level care physicians. By training doctors at the first level of care, they will raise their self-esteem by offering patients better quality care and at the same time regain their confidence, solving the vast majority of problems addressed at this level and consequently reducing the demand on hospital centers in large cities, which will result in better care and ultimately greater patient satisfaction and health fulfillment.

20.5.2 The Degree to Which Current Clinical Care Is Person-Centered

In this case, an important starting point is the statement by Miles et al. [8] about the profound crisis that modern medicine is going through internationally, expressed in different aspects as a knowledge crisis, (uncertainty about what counts as "evidence" for making decisions), a crisis of care (deficit in sympathy, empathy, compassion, dignity and autonomy), a crisis of patient safety (negligence, iatrogenic damage, malpractice, excess mortality), a crisis of economic costs (which threatens bankruptcy of health systems worldwide), a crisis of clinical and institutional management (a failure in both basic and advanced management and inspirational and transformative leadership).

This crisis situation has generated in the popular imagination the idea of a dehumanization of medicine, which even though its causes are multifactorial, nevertheless, the doctor is unfairly attributed to being the cause. The logical answer is to humanize medicine, but for that we must be aware that humanizing implies reaching the essence of the human being, who is the protagonist of all health processes, transforming it, creating a personal commitment, facing professional and personal challenges. To humanize is to reposition oneself in life as a person, to assume a humanist stance, to make one's own existence a focus of effective humanization in medicine and in life [9].

In relation to this opaque present of health in the world, especially in developing countries, and in relation to the implementation of person-centered medicine as a work policy in the health sector, there are also other critical situations such as the training of doctors and health professionals in general in universities. This adds to fragmented health systems, the scarce economic support from governments that is expressed in deficit budgets for the health sector, the subjugation to technology, distorting its important role as the physician's ally, by competing with him by minimizing the insurmountable value of the physician-patient relationship in its most human expression, which is ultimately the essence of person-centered medicine. On the other hand, there is a permanent and old deficit in the supply of health services in the face of growing demand, coupled with the weakness of the first level of care that has been little attended by governments for a long time, both in the budgetary and infrastructure aspects. There is a lack of basic technological support and especially of health professionals primarily due to a little motivating panorama to develop oneself professionally and personally. All these factors have had a very negative impact on the confidence of patients to go to this level, replacing it by seeking specialized care in urban hospital centers, where the collapse of these institutions has occurred. The response of the health authorities to this situation has been to reduce the time given to each consultation in order to increase the offer but with a worrying reduction in the quality of care and at the same time becoming an obstacle to the implementation of person-centered medicine. From a practical point of view, this is probably one of the main obstacles to the implementation of the provision of medical services through the strategy of person-centered medicine.

20.5.3 Obstacles for the Implementation of Person-Centered Care (Skills, Workload, Financial Aspects, Organization of Services)

As can be seen from what has been said in the previous paragraphs, the reasons why these levels of dehumanization of medicine have been reached high levels are political, economic, institutional (health systems), legal, sociocultural, but we believe that the educational factor is one of the most important.

The strategy to promote the implementation of person-centered care begins with the analysis for curricular change in medical schools to replace the reductionist biological model with a more comprehensive model such as the one that offers person-centered medic care.

It is important that national ministries of health and academic institutions develop training programs for medicine focused on the person, as an institutional policy, in order to establish the knowledge and skills required to develop person-centered care. This has to be associated with a reorganization of health services, accompanied by greater budgetary resources, better salaries for doctors, an optimal infrastructure, with basic technological support, with the aim of covering the vast majority of these users. As a developing illustration, a current Comprehensive Health Insurance (SIS) in Peru, is emerging as a free insurance subsidized by the government and with a coverage that currently reaches 17 million people in this country.

20.5.4 What Would Have to Change for the Implementation of Person-Centered Clinical Care

Given the current situation of medical training worldwide having a reductionist biological approach, the practical implementation of Person-Centered Medicine is urgently needed. Universities will have to modify their curricula in the sense of establishing person-centered training, taking into account an important factor that has to do with medical specialization. This is exemplified by the offer in Peru that seems to reach approximately 40% of the graduates of Medical Schools, which means that 60% will not be able to specialize, and those doctors are the ones who will occupy the positions in the first level of care. For this reason, among others, this 60% is strategically the most available professional population for training in Person Centered Medicine.

In reference to this reality, it is pertinent to summarize the history of the evolution of international medical teaching models, which formally began in 1910 with the Flexner report, which emphasized the role of the doctor in the treatment of disease. This was a clearly individual and curative biomedical model. In the following years it went through a problem-based teaching, a community-based curriculum (Alma Ata), in the 1960s and 1970s respectively. Then emerged the Edinburgh model in the late 1980s that incorporated the concept that health should be promoted for the entire population and a later one in the 90s that emphasized deepening of the social sciences, the recognition of the rights of patients and the prioritization of primary care, prevention and health promotion. In the meantime, came to force the movement started by Paul Tournier [10] emphasizing the concept of attending to the whole person in his biological, psychological, social and spiritual aspects.

Biological reductionist training brought educational deficiencies to medical students, such as poor communication between different health professionals, neglect of the positive aspects of health, failure to comply with ethical imperatives such as respecting the autonomy, responsibility and dignity of each person and the rigid application of evidence-based medicine. Thus, to overcome this eminently biomedical model, it is necessary to orient it towards one or more centered on the person (and on society), for which the curriculum will have to be more complete and comprehensive, with the incorporation of community aspects, integration of the clinical and interpersonal skills dimensions [11].

At Western Ontario University in Canada, the positive impact of patient-centered communication on the doctor-patient relationship and clinical outcomes was investigated. In this sense, the conceptualization of disease and illness is very important, because it allows the comprehensive understanding of the patient in their biopsychosocial aspects.

The Francisco de Vitoria University (Madrid) [12, 13] emphasizes that, in order to train students in clinical skills, in addition to medical knowledge, communication skills must be developed as an essential component of this, which requires training with simulated patients under the supervision of trained teachers.

The application of this medical training to our reality would imply implementing reforms in the health system in our country, strengthening the first level of care, which represents the ideal setting for the practical application of a person-centered medical training. On the other hand, the current reality clearly indicates that doctors trained with the biological reductionist model may have difficulties in applying the person-centered care model, which is why an intense training program in this care model cannot be postponed, such as a health policy, so that the doctors who work in all the institutions that make up this fragmented health system can participate actively. This will not be easy and requires a political decision at the highest level of the country's government, which will only be achieved if universities modify their medical training curricula to one centered on the person.

In other words, a strategy is necessary that involves the university by modifying the medical studies curriculum intensifying the general practitioners training at the same time that modifying the health system. In summary, we could say that from the point of view of the training of doctors to apply person centered medicine, we consider two levels:

20.5.4.1 Training Level

Changes in the medical training curriculum, emphasizing the ethical-communicational and changing the biologist approach to a biopsychosocial-spiritual one. In this sense, the most important changes in the curriculum refer to:

- Emphasize work in and with the community, from the first year
- Promote the active participation of the sick person in diagnosis and treatment
- Reinforce the first level of care during training, to regulate the referral system for specialists
- Promote research at the university on the type of care patients receive and what would be the alternative involving person-centered care.
- Establish coordination at the highest level of the Ministries of Health and Social Security with the university to improve the working conditions of doctors at the first level of care.
- Apply the fundamentals of comprehensive training and pillars of medical professionalism, which would include altruism, tolerance for diversity, social sensitivity, adherence to the ethical principles that regulate medical practice and the ability to establish relationships.

20.5.4.2 Professional Level

Rethink the reductionist biological approach of training in health care toward one that understands all aspects of person-centered care, in terms of knowledge, skills, attitudes and values based on the seven key concepts of medical professionalism from an international group of medical organizations gathered in the United States under the title of Medical Professionalism in the New Millennium. In its Physician Charter, three principles were established: the primacy of the well-being of the patient over any interest of the doctor or of the health system; the autonomy of the patient in making decisions related to state of health and the obligation of the doctor to guarantee the application of the criteria of social justice, including the equitable distribution of the resources available for this purpose and the elimination of any form of discrimination in health care [14].

Among the professional responsibilities of the doctor are the following:

- Commitment to professional competence
- Honesty with the patient
- Respect for confidentiality
- Maintaining an adequate relationship with the patient
- Continuous improvement of the quality of care
- Guaranteeing equitable access to health services
- Adequate distribution of the resources available in the system.
- The integrity and appropriate use of scientific knowledge and technology
- The resolution of conflicts of interest and individual and collective self-regulation of the profession.

20.5.4.3 Proposed Solution

- Change the curricula of undergraduate studies in the Faculties of Medicine, emphasizing work in and with the community, from the first year
- Promote during training the need for the patient to participate protagonically in diagnosis and treatment
- Reinforce the first level of care through permanent training to regulate the referral system for specialists.
- Promote research at the university on the type of care patients receive and the option of person centered care.
- Establish coordination at the highest level of the Ministry of Health and Social Security with the university to improve the working conditions of doctors at the first level of care.
- For physicians originally trained with the reductionist biological curriculum, develop an intensive training program on Person Centered Medicine.

20.6 Conclusions

Quoting Jorge Lazo Manrique [15], in his book The Spiritual Crisis of Medicine, the most important factors that have contributed to the current health crisis are the weakness of humanism, the rise of technology, the deterioration of the doctor-patient relationship, and neglect of the human values and personality characteristics of the physician. Along with the above, in different publications a series of problems of modern medicine are identified, such as hyperbolic focusing on diseases and organs, fragmentation of services, patient objectification, weakness of the doctor-patient relationship and the commercialization of health.

Three historical variables should be added to promote a comprehensive approach to health care, namely, the articulation between Clinical Medicine and Public Health; the coordination between Clinical Medicine and Mental Health and the strengthening of the Conceptual Bases of Medicine in a person-centered manner.

For these reasons a proposal of clinical care and public health centered on persons (at the individual and community levels) and emphasizing primary health care as integral of all by all constitute the essential training elements for health professionals that would allow the development of a health system with a strong first level of effective and efficient care and which is person-centered throughout all the levels of care and forms of service, and in which person centered medicine is carried out at real cost by competent professionals, based on effective communication, active empathy, informed by evidence, experience and values, committed to quality of care, to patient safety, to patient rights and responsibilities, to collaborative diagnosis and shared care decision-making, to achieving a satisfactory care experience for the patient and family, and ensuring attention to both ill- and positive-health at individual and community levels and thorough evaluation of processes and outcomes.

Acknowledgement and Disclosures The authors do not report conflicts of interest in the preparation of this chapter.

References

1. Dictionary of the Royal Academy of the Spanish Language. Twenty-second edition, vol. 5, p. 679, second meaning; vol. 8, p. 1244, eighth meaning; 2001. Barcelona: Editorial Espasa (Planeta).
2. Jamoulle M. Quaternary prevention, an answer of family doctors to overmedicalization. Int J Health Policy Manag. 2015;4(2):61–4.
3. Cloninger CR, Salloum IM, Mezzich JE. The dynamic origins of positive health and wellbeing. Int J Pers Cent Med. 2012;2:179–87.
4. Mezzich JE. Person centered medicine, well-being, and quality of life. Int J Pers Cent Med. 2019;9:9–17.

5. Pan American Health Organization. Declaration of Alma-Ata 1978. https://www.paho.org/hq/dmdocuments/2012/Alma-Ata-1978Declaracion.pdf. Accessed 31 Mar 2021.
6. Rivero de Tejada D. What a primary health care is: some considerations after almost thirty five years of Alma-Ata. Rev Peru Med Exp Salud Publica. 2013;30(2):283–28.
7. Mezzich JE, Snaedal J, van Weel C, Heath I. The International Network for Person Centered Medicine: background and first steps. World Med J. 2009;55:104–7.
8. Miles A, Asbridge JE, Caballero F. Towards a person-centered medical education: challenges and imperatives. Educ Med. 2015;16(1):25–33.
9. Gonzales P. Mundo da Saude. Sao Paulo. 2010;34(3):357–67.
10. Tournier P. Medecine de la Personne. Neuchatel: Delachaux et Nestle; 1941.
11. Brailovsky C, Centeno A. Some actual trends in medical education. J Univ Teach. 2012;10:23–33.
12. Ruiz Moral R. Comunicación clínica: principios y habilidades para la práctica. Clinical communication: principles and skills for practice (Original in Spanish). Madrid: Médica Panamericana; 2014.
13. Sox H. Medical professionalism in the new millennium: a physician charter. Ann Intern Med. 2002;136:243–6.
14. Ruiz R, Caballero F, García C, Monge D, Cañas F, Castaño P. Enseñar y aprender habilidades de comunicación clínica en la Facultad de Medicina. La experiencia de la Francisco de Vitoria (Madrid). Med Educ. 2017;18(4):289–97.
15. Lazo-Manrique J. La crisis spiritual de la Medicina/The spiritual crisis of medicine. Rev Soc Peru Med Interna. 2001;14(4):220–6.

Chapter 21
Person-centered Women's Health and Maternity Care

C. Ruth Wilson, José Pacheco, and Petra ten Hoope-Bender

21.1 Introduction

21.1.1 Why a Chapter on Women's Health?

Why would a textbook on person centered medicine include a chapter on women's health? Are women not persons and thus included in all other chapters of a book exploring this topic? The legal status designating women as persons is surprisingly recent; in Canada, women were only formally declared as persons in 1929, enabling them to sit as Senators. In Peru, literate women were not allowed to vote and to be elected until 1955. Early feminists in the suffrage movement felt that they needed to affirm that women were persons, so that they could be declared citizens eligible to vote. In 1873 Susan B Anthony said "The only question left to be settled now is: Are women persons? And I hardly believe any of our opponents will have the hardihood to say they are not. Being persons, then, women are citizens; and no state has a right to make any law, or to enforce any old law, that shall abridge their privileges or immunities." It is worth recalling this debate over the legal personhood of women in a consideration of person centered medicine, as societal views of the status of women also affect how medicine has viewed women.

C. R. Wilson (✉)
Department of Family Medicine, Queen's University, Kingston, ON, Canada

Presidency, North America Region, World Organization of Family Doctors (Wonca), Singapore, Singapore
e-mail: ruth.wilson@dfm.queensu.ca

J. Pacheco
Universidad Nacional Mayor de San Marcos, Lima, Peru

P. ten Hoope-Bender
Sexual and Reproductive Health and Rights, UNFPA, Geneva, Switzerland
e-mail: tenhoope-bender@unfpa.org

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_21

21.2 Objectives

This chapter will examine the historical context and current thinking on women's health. It offers a definition of women's health, differentiating between sex and gender. We describe women's participation in the health workforce, where they are the majority of providers but not generally the leaders. Turning to the concept of person centered medicine, we offer the principles of such an approach as applied to women. We examine the concept of safe maternity care as an example of the promise of this approach. Finally, we describe some obstacles to the implementation of person centered women's health and suggest how these may be overcome.

21.3 Women as Persons in Medicine: Historical Context

Historically, the male body was illustrated as the default for normal in the study of medicine. Images in textbooks predominantly did and still do portray the male body as the exemplar of normal anatomy, usually only differentiating male from female in urogenital illustrations [1].

Manifestations of disease were typically described as they affected men. In the past it was assumed that organs such as the heart and kidney would produce the same symptoms in either sex, as they are not reproductive organs. For many conditions common to both men and women, such as renal disease and cardiovascular disease we are now aware of different patterns of symptoms and signs in men and women [2] (see Table 21.1). Evidence also shows that for the same medical condition, women may be less likely than men to be referred for diagnostic testing and may be less likely to receive evidence-based interventions [1].

Similarly, new therapeutic agents were and are commonly tested first in humans in young males. This was partly based on a legitimate concern about teratogenic effects on the fetus, made more acute in public consciousness following on the thalidomide scandal. This reticence has had the effect of drugs coming on the market which may not have been adequately tested in women [3]. It has also led to some drugs, which may be effective for women during pregnancy not having been adequately studied. An example of this is the use of selective serotonin reuptake inhibitors for the treatment of depression in pregnancy. Because these medications have not been tested in randomized trials of pregnant women, doctors and their patients are left balancing possible risks to the fetus as against the danger to the health of the pregnant women who has untreated depression [4]. The medical community has acknowledged the need for research in pregnancy in its main ethical declaration on research involving human subjects, the Declaration of Helsinki. In the chapter on research on vulnerable populations it is stated in par. 28 that "Medical research with a vulnerable group is only justified if the research is responsive to the health needs or priorities of this group and *the research cannot be carried out in a non-vulnerable group*. In addition, this group should stand to benefit from the knowledge, practices or interventions that result from the research [5]."

Table 21.1 Publications with sex and gender differences in the most frequent clinical entities

Cardiology	Rheumatology/ Immunology	Pneumology	Nephrology	Gastroenterology/ Hepatology	Neurology	Endocrinology	Oncology	Haematology
Hypertension (414)	Lupus erythematosus (68)	Asthma (140)	Renal failure (27)	Hepatitis B (22)	Multiple sclerosis (65)	Diabetes mellitus (447)	Skin carcinoma (45)	Anaemia (44)
Myocardial infarction (275)	Rheumatoid arthritis (41)	Lung cancer (116)	Diabetic nephropathy (11)	Hepatitis C (26)	Stroke (129)	Obesity (349)	Gastric cancer (25)	Leukaemia (49)
Heart failure (153)	Systemic sclerosis (3)	Chronic obstructive pulmonary disease (36)	Glomerulonephritis (9)	Hepato-cellular carcinoma (37)	Alzheimer's disease (104)	Osteo-porosis (123)	Renal cell carcinoma (17)	Lymphoma (34)
Atrial fibrillation (38)	Fibromyalgia (15)	Pulmonary hypertension (12)	Polycystic kidney disease (12)	Inflammatory bowel disease (13)	Epilepsy (56)	Hypothyroidsm (33)	Bladder cancer (22)	Thrombocytopoenia (6)
Coronary heart disease (207)	Sjögren's syndrome	Pulmonary embolism (110)	Renal artery stenosis (0)	Colorectoral cancer (24)	Parkinson's disease (69)	Hyperthyroidsm (16)	Thyroid carcinoma (16)	Purpura (2)
Cardiomyopathy (41)	Ankylosing sponylitis (11)	Sarcoidosis (6)	IgA Nephropathy (2)	Autoimmune Hepatitis (2)	Muscular dystrophy (11)	Morbus Addison/ Cushing disease (5)	Pancreatic carcinoma (10)	Agranulocytosis (0)

And yet medicine has not always ignored aspects of women's reproductive biology. Medicalization of normal biological life course events such as menopause has led to the creation of new so-called diseases, amenable to dubious pharmaceutical interventions. Menopause was seen as a condition of estrogen deficiency, and was commonly treated with "replacement" estrogen, with no randomized controlled trials to support this intervention (Interestingly, the only double-blind study of estrogen in the treatment of cardiovascular disease before the 1990s was carried out in men.) [6]. The history of attitudes towards pregnancy and childbirth is equally mixed. On the one hand, unacceptably high rates of maternal mortality globally cry out for skilled birth attendants and better prenatal care. On the other hand, the medicalization of childbirth has led to situations such as Brazil, where 55% of women are delivered by Caesarean section [7].

In epidemiology women and men were too often considered together. Only in April 2019 were WHO statistics for the first time disaggregated by sex [8]. Research into the major conditions affecting women has been hampered by this failure to analyse data for women and men separately.

21.4 Definition of Women's Health

Defining women's health goes beyond simply describing the biology and pathophysiology of conditions affecting women. One commonly accepted definition of women's health states "Women's health involves women's emotional, social, cultural, physical and spiritual wellbeing and is determined by the social, political, cultural and economic context of women's lives, as well as by biology. This definition of women's health recognizes the validity of women's life experiences and women's own beliefs about and experiences of health." [9]

Crucial to a discussion of women's health is to distinguish the concepts of sex, which is biologically based, from gender, which is a socially constructed concept. Sex refers to biological characteristics of human beings, and is usually characterized as being male or female, although there may be some variation in how biological attributes are expressed. Gender refers to the socially constructed roles and identities, usually expressed as male and female. There is considerable variation in how gender is identified and expressed (see Table 21.2).

Table 21.2 Definitions of sex and gender

Sex
Sex refers to the biological characteristics that define humans as female or male. These sets of biological characteristics are not mutually exclusive, because there are individuals who are born with physical or biological sex characteristics who do not fit the traditional definitions of female or male (intersex)
Sex differences can be observed at the level of chromosomes, gene expression, hormones, immune system and anatomy (e.g. body size, and sexual and reproductive anatomy)
Examples of sex-specific conditions
• Cervical cancer (women)
• Prostate cancer (men)
• X-linked immune regulators may enhance immune responses in female children, resulting in reduced mortality among girls aged under 5 years in most settings
Gender
Gender refers to the socially constructed norms, roles and relations of and among women, men, boys and girls. Gender also refers to expressions and identities of women, men, boys, girls and gender-diverse people. Gender is inextricable from other social and structural determinants shaping health and equity and can vary across time and place
Gender differences and inequalities influence exposure to risk factors, health-seeking and risk-taking behaviours, access to and use of health information, and promotive, preventive, curative, rehabilitative and palliative health services, experience with health care, including in terms of access to and control over resources and power relations
Examples of gender-related factors resulting in differential health outcomes
• Early pregnancy, including as a result of child marriage, increases girls' risk of adverse health outcomes
• Due to the gender-based division of labour, men and women may be exposed to different risks for workrelated injuries or illnesses
• Gender norms related to masculinity promote smoking and alcohol use among men, while gender norms associating smoking with women's freedom and liberation are being targeted to young women by the tobacco industry
• Women's access to health services may be limited by lack of access to and control of household financial resources, caregiving roles, and restrictions on their mobility; whereas men's use of health services may be influenced by masculinity norms in which seeking health care is not seen as manly
• In addition to gender norms and roles, intersecting discrimination based on gender identity contributes to transgender people experiencing high rates of stigma and discrimination including in health care settings, and lack appropriate services responding to their needs

21.5 Women Live Longer but Suffer More

The definition of women’s health takes into account a paradox in women’s health. Although women live longer than men, they suffer more. Despite a longer life expectancy (about 6–8 years on average) they have a lower quality of life. The longer life expectancy is likely due to inherent biological differences and may also reflect behavioural influences such as smoking rates. The gap between mortality rates for men and women is lessening in countries where smoking rates increase [10]. The claim that women suffer more is partly based on their gender-related roles in society, but also on increased burden of illness in almost every disease category [11]. In other words, women live longer but experience more years of ill health during that life.

Women globally experience higher rates of poverty, food insecurity, and illiteracy compared to men. Lack of safe cooking fuel and access to clean water place a disproportionate burden on women’s health. Most victims of human trafficking and sex exploitation are women. These disparities related to gender explain why ensuring healthy lives and promoting well-being for women is one of the seventeen sustainable development goals of the United Nations [12]. Violence, gender-based harassment, power differentials and discrimination are of particular concern because women are more adversely affected by some of these determinants [13].

The health behaviours and ways in which men and women seek out health care varies by context and is highly influenced by gendered roles. Women may lack access to health care because of prohibitions against contraception and abortion by community or religious leaders or conservative health care providers. They may lack transportation or funds to access health care. Conversely, they are often seen as the custodians of the health of their children, families and parents and may have a key role in defining gendered rituals such as female genital mutilation.

21.6 The Health Workforce Is Predominantly Female

The health workforce is largely made up of women, but in general is led by men. According to the WHO 2019 report “Delivered by Women, Led by Men: A Gender and Equity Analysis of the Global Health and Social Workforce”, 24 million of the 28.5 million nurses and midwives globally are women [14]. Overall women are about 70% of health workers globally.

Historically most doctors have been men. In Peru the first woman who graduated as a physician in 1900 had to study anatomy behind a screen because it was not proper that women see naked bodies. Although this is changing (about 45% of United Kingdom doctors are women) still the leadership positions in academic and organized medicine are male dominated [15]. In Canada, since 1995, more women than men have entered medical education, yet they represent only 38% of full-time faculty members in Canadian medical schools [16]. A sex difference in pay persists, and according to the same WHO Health Workforce report, women in the health care sector earn on average 28% less than men. In Peru woman doctors represent about 27% of all doctors, and 68% earn less than their male partners [17].

Women are also the majority of informal caregivers; health systems rely on the unpaid labour of women to function. This hierarchy of pay and status in the medical workforce affects women's health in several ways. Women in the health workforce experience discrimination and violence as well as pay inequity. The social construction of women's roles in health care, both paid and unpaid, may devalue the contributions of women and affects the health of both women in the workforce and the persons they care for.

21.7 Person Centered Women's Health

Person-centered medicine for women is possible if health care is responsive to the needs and expectations of women as persons, and as community members. Health care that enhances women's health needs to be:

- Of women: addressing physical, mental, social and spiritual needs—as a person and as a member of a community—including strengths and vulnerabilities, while caring for illness and promoting positive health.
- For women: empowering women to fulfil aspirations for their own health and personal life projects and their role in the community.
- With women: expressing mutually respectful and assertive relationships in which there is co-active communication and joint understanding between the health workers and women served, including the promotion of autonomy and self-care.
- By women: recognizing that most of the health workforce is comprised of women, who must be supported and empowered to take leadership roles in the delivery of health care.

21.8 Towards Person Centered Women's Health Care: Safe Maternity Care

Achieving health for all women includes an emphasis on reproductive health. The Sustainable Development Goals call for the reduction of the global maternal mortality rate to less than 70 per 100,000 births by 2030. Over eight hundred women die every day in childbirth, an improvement in mortality rates, but still an unacceptable rate of loss. Every 11 s, a pregnant woman or newborn dies somewhere around the world, most of them due to preventable and treatable reasons [18].

Safe motherhood is more than the prevention of death and disability. It is respect for every women's humanity, individuality, feelings, choices, and preferences. All childbearing women need and deserve respectful care. This includes especially protecting the mother-baby pair. Disrespect and abuse during maternity care are a violation of women's basic human rights. Those who speak out and demand respectful care make it safe for women everywhere to do so. The impact of respectful care on mothers and newborn should be measured in both medical and non-medical outcomes such as ownership, autonomy, increase of control and the strengthening of agency in women. However, a recent study shows that more research is needed 'on how outcomes and quality of care differ by the degree to which childbirth facilities adopt and sustain respectful maternity care culture'. [19]

21.9 Obstacles and Costs for the Implementation of Person-centered Care

What are the obstacles to implementing person-centred medicine for women? First is the appreciation that sex and gender are determinants of health just as genetics and poverty are. Biology determines some conditions specific only to women, such as reproduction and sex specific cancers. Many medical conditions present differently in men and in women as noted above. Women have not been included in some major pharmacologic trials and so the therapeutic effect on women is not as well known. Medical educators and researchers need to work to overcome these inequities.

Similarly, there must be recognition that gender is a determinant of health. The context of women's lives may include sexual harassment, illiteracy, poverty, violence and discrimination, all of which affect their health outcomes. The sustainable development goals provide targets, which all countries must strive for in order to improve the status of women and thus their health.

Next, the health workforce must be reshaped to be more equitable. Both men and women should be represented in the makeup of the health professional workforce. This includes the necessity of more women in positions of power in academia and professional organizations. Informal unpaid caregivers must be recognized for what they are—people, generally women, who are subsidizing the health care system. Pay equity and working conditions which take account of women's needs (for example, paid maternity leave) are essential to achieving a more balanced workforce.

Women must be involved in the design of the health care system. Nowhere is this need more urgent than in the provision of safe maternity care. As conditions for women improve in the health workforce, and more women take leadership positions, this will contribute to women having their voices heard. Equally important is to involve women who are not health professionals in designing responsive and socially accountable heath care systems, which are designed not for the convenience of health care professionals but for those who seek care. This is particularly the case in the push for universal health coverage based on strong primary health care systems.

A further barrier is the lack of a research base on person-centered medicine, particularly as applied to women's health. A clear set of measurable characteristics of person-centred women's health care would allow characterization of such a method of care both at an individual and system level, and would contribute to an understanding of how such systems can be implemented. A review of research in patient centred care for women showed that there were no studies of the type of interventions, which promote or support patient centred care [20].

21.10 Considerations in Implementing Person Centered Women's Health

Clinical areas and methods of implementing person centered women's health should be at the heart of any person-centred care programme.

- Person centered women's health should include the life span of woman, from infanthood, adolescence, reproductive age, menopause, through to aging and end -of-life.
- The relationship between health care professional and woman/patient should take account of women's biological attributes, autonomy, human rights, ethics, and dignity.
- Attention to women includes recommendations for health preservation (emotional, psychosocial, biological and other), prevention of diseases (balancing personalized medicine and personalized care [21] and life-expectation (aged person-centred care) [22].

Person-centeredness in healthcare should be incorporated in all health systems, including family-centered care, person-centered care, child-centered care, women-centered care. It should contemplate the ethnicity, history, location, literacy, customs and traditions of all care seekers.

- Person-centred care should address food insecurity, housing instability, utility needs, transportation needs, interpersonal violence [23].
- The concept and practice of person-centered medicine should be implemented in the education and training of all health care professionals, and mentoring should be provided regularly once in active service.
- The need for and positive impact of person centered medicine should be reinforced when negotiating with governmental and political authorities and health managers about women's health needs and programmes.
- Universal health coverage should focus on people-centred care with special attention to women and children.
- Medical institutions, societies, federations should guide members on women centered medicine.
- Include participation of mass media in promoting person centered medicine.

- Encourage research on gender difference, women's anatomy and physiology and difference with men, disparity of health care quality, appropriate health-care settings and facilities, women's autonomy, sexual and reproductive rights, the pregnancy context, unintended pregnancy [24], and dignity [25]. Particular research on all aspects of patient-centered reproductive care including assisted reproduction and maternity care, pregnancy complications, preparation for delivery, depression, and family planning must be encouraged [26].
- Person centered medicine must be integrated into telemedicine and telehealth on women-centered care, including virtual communication in distance provision of health care [27], advanced technology procedures such as robotic surgery, artificial intelligence with regards to WCM.

21.11 Conclusions

True person centered medicine will promote the flourishing of individual women and girls, and women in communities and society. Practitioners of this renewed holistic healing will need to understand the historical and current context of women's lives as well as their biologic determinants. The values and preferences of women need to be considered along with scientific evidence when co-designing treatment plans. Person-centred care practitioners, many of whom will be women, must work to overcome power differentials between providers and persons seeking care, and support co-designing health care systems, so that the dignity of women is respected and affirmed.

Acknowledgements and Disclosures The authors do not report any conflicts of interest concerning the preparation of this paper.

References

1. Morgan S, Plaisant O, Lignier B, Moxham BJ. Sexism and anatomy, as discerned in textbooks and as perceived by medical students at Cardiff University and University of Paris Descartes. J Anat. 2014;224:352–65.
2. Regitz-Zagrosek V. Sex and gender differences in health. EMBO Rep. 2012;13:596–603.
3. Liu KA, Dipietro Mager NA. Women's involvement in clinical trials: historical perspective and future implications. Pharm Pract. 2016;14:708.
4. Reefhuis J, Devine O, Friedman JM, Louik C, Honein MA. Specific SSRIs and birth defects: bayesian analysis to interpret new data in the context of previous reports. BMJ. 2015;351:h3190.
5. WMA Declartion of Helsinki. 2013. Available from: https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/
6. Coronary Drug Project Research Group. The Coronary Drug Project. Findings leading to discontinuation of the 2.5-mg day estrogen group. JAMA. 1973;226:652–7.
7. Lopes, M. Caesarean sections in Brazil are an audience spectacle, with wedding-style parties - The Washington Post June 12 2019. https://www.washingtonpost.com/world/the_americas/c-sections-are-all-the-rage-in-brazil-so-too-now-are-fancyparties-to-watch-them/2019/06/11/8d2533ac-7bfc-11e9-b1f3-b233fe5811ef_story.html. Accessed 2022-10-06.

8. International Alliance of Patients' Organizations. World health statistics 2019 disaggregated by sex for the first time [Online]. 16 April 2019. Available from: https://www.iapo.org.uk/news/2019/apr/16/world-health-statistics-2019-disaggregated-sex-first-time [Accessed 29 Nov 2019].
9. Women's Health Office, MU. 1991. Available from: https://fhs.mcmaster.ca/women/office.html [Accessed 29 Nov 2019].
10. World Health Organization. Female life expectancy [Online]. 2019. Available from: https://www.who.int/gho/women_and_health/mortality/situation_trends_life_expectancy/en/ [Accessed 29 Nov 2019].
11. Buvinić M, Medici A, Fernández E, et al. Gender differentials in health. In: Jamison DT, Breman JG, Measham AR, et al., editors. Disease control priorities in developing countries. 2nd ed. Washington (DC): The World Bank; 2006.
12. United Nations. Progress on the sustainable development goals. The gender snapshot 2019 [Online]. 2019. Available from: https://www.unwomen.org/-/media/headquarters/attachments/sections/library/publications/2019/progress-on-the-sdgs-the-gender-snapshot-2019-single-pages-en.pdf?la=en&vs=5813 [Accessed 29 Nov 2019].
13. World Health Organization. Uneven access to health services drives life expectancy gaps [Online]. 4 April 2019. Available from: https://www.who.int/news-room/detail/04-04-2019-uneven-access-to-health-services-drives-life-expectancy-gaps-who [Accessed 2019].
14. World Health Organization. Female health workers drive global health [Online]. 2019. Available from: https://www.who.int/news-room/commentaries/detail/female-health-workers-drive-global-health [Accessed 29 Nov 2019].
15. Medical Women's Federation. Women play an increasingly important role in the medical workforce [Online]. 2019. Available from: http://www.medicalwomensfederation.org.uk/about-us/facts-figures [Accessed 29 Nov 2019].
16. Association of Faculties of Medicine of Canada. Women in academic medicine [Online]. September 2019. Available from: https://ct.enews.afmc.ca/core/web/hjmiaabogdgabakfcjkhdh [Accessed 29 Nov 2019].
17. Taype-Rondan A, Torres-Roman JS, Herrera-Añazco P, Diaz CA, Brañez-Condorena A, Moscoso-Porras MG. Ingresos Económicos En Médicos Peruanos Según Especialidad: Un Análisis Transversal De La Ensusalud 2015. [Economic income in peruvian physicians according to the specialty: a cross-sectional analysis of the ensusalud 2015]. Rev Perú Med Exp Salud Publica. 2017;34(2):183–91.
18. UNICEF. Surviving birth: Every 11 seconds, a pregnant woman or newborn dies somewhere around the world [Online]. 2019. Available from: https://www.unicef.org/press-releases/surviving-birth-every-11-seconds-pregnant-woman-or-newborn-dies-somewhere-around
19. Morton CH, Simkin P. Can respectful maternity care save and improve lives? Birth. 2019;46(3):391–5.
20. Gagliardi AR, Dunn S, Foster A, et al. How is patient-centred care addressed in women's health? A theoretical rapid review. BMJ Open. 2019;9:e026121. https://doi.org/10.1136/bmjopen-2018-026121.
21. Cornetta K, Brown CG. Balancing personalized medicine and personalized care. Acad Med. 2013;88:309–13.
22. Chouvarda IG, Goulis DG, Lambrinoudaki I, Maglaveras N. Connected health and integrated care: Toward new models for chronic disease management. 2015;82:22–7.
23. Fraze TK, Brewster AL, Lewis VA, Beidler LB, Murray GF, Colla CH. Prevalence of screening for food insecurity, housing instability, utility needs, transportation needs, and interpersonal violence by US physician practices and hospitals. JAMA Netw Open. 2019;2:e1911514.
24. French VA, Steinauer JE, Kimport K. What women want from their health care providers about pregnancy options counseling: a qualitative study. Womens Health Issues. 2017;27:715–20.
25. Rubashkin N, Warnock R, Diamond-Smith N. A systematic review of person-centered care interventions to improve quality of facility-based delivery. Reprod Health. 2018;15(1):169.
26. Callegari LS, Aiken ARA, Dehlendorf C, Cason P, Borrero S. Addressing potential pitfalls of reproductive life planning with patient-centered counseling. Am J Obstet Gynecol. 2017;216:129–34.
27. Woodward JT. Third-party reproduction in the Internet Age: the new, patient-centered landscape. Fertil Steril. 2015;104:525–30.

Chapter 22
Person-centered Neonatal Health Care

Ornella Lincetto, Saverio Bellizzi, Silke Mader, Arti Maria, John Cox, and Nathalie Charpak

22.1 Introduction

Neonatal health care has evolved over the years with progressive recognition of the burden of disease represented by neonatal conditions [1, 2], growing evidence on key interventions to improve survival and human capital [3], and new opportunities offered by infant and family-centered care approaches to respond to the special needs of newborns too small or sick and their families in all settings [3]. Globally,

---

O. Lincetto (✉)
Department of Maternal Newborn Child and Adolescent Health and Ageing, World Health Organization, Geneva, Switzerland

S. Bellizzi
World Health Organization, Amman, Jordan
e-mail: bellizzis@who.int

S. Mader
European Foundation for the Care of Newborn Infants, EFCNI, München, Germany
e-mail: silke.mader@efcni.org

A. Maria
Department of Neonatology, Atal Bihari Vajpayee Institute of Medical Sciences and Dr. Ram Manohar Lohia Hospital, New Delhi, Delhi, India

J. Cox
World Psychiatric Association, Geneva, Switzerland

International College of Person Centered Medicine, New York, NY, USA

Keele University, Keele, UK

Royal College of Psychiatrists, London, UK

International Marce Society, Brentwood, TN, USA

N. Charpak
Kangaroo Foundation and Integral KMC Program, San Ignacio Teaching Hospital, Javeriana University, Bogotá, Colombia

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_22

48% of under-five deaths occur during the neonatal period [2], and the proportion of under–five deaths due to neonatal causes continues to increase [2]. Neonatal conditions bring about 2.5 million neonatal deaths every year and represent an important cause of childhood morbidity and long-term disability [3]. Newborn babies, particularly when born preterm or low birth weight or sick in many parts of the world are not receiving the care they need. Their immediate needs, love and care from mother, father, family and health professionals in the form of dignity and respect, warmth, freedom from infection, good nutrition and support for breathing too often are not met. It has been estimated that of the 30 million newborns requiring inpatient care every year half don't have access to care and a considerable proportion of those who have access receive poor quality of care [3].

Poor-quality care is now a bigger barrier to reducing mortality than insufficient access [4]; it impacts on mortality, morbidity, growth and brain development; and affects parents' experience of care for themselves and their baby. The WHO defines quality as "the extent to which health care services provided to individuals and patient populations improve desired health outcomes. In order to achieve this, health care needs to be safe, effective, timely, efficient, equitable, and people-centered" [5]. This definition encompasses three key components of quality: clinical (safe and effective), interpersonal (people-centered) and contextual (timely, efficient and equitable) [6].

Challenges to ensure quality of neonatal services in low and middle-income countries (LMICs), and at times in high-income countries (HICs), include lack of infrastructure, medicines and supplies, insufficient number of skilled health providers, and limited family involvement in the care of the baby [3]. Specifically, infant-parents separation in the neonatal period affects optimal brain development, limits the bidirectional development of physical, emotional, and psychological bonds between parents and their infants and is detrimental to parents' mental health [7]. Person-centered models of care built on newborn and family needs and rights, such as non-separation immediately after birth and during the care process (e.g. Mother-NICU care and Kangaroo Mother Care method for preterm and low birth weight babies), are very promising and can address the complex needs of the newborn, family and health system. This chapter describes what person-centered approach means when applied to newborn care for infants, families, communities, health systems; what is the evidence in support of it; and how it can be implemented within a health system approach for achieving better short and long-term outcomes.

22.2 Approaches to Fulfill the Objectives

Evidence for this review was collected iteratively, beginning with pertinent systematic reviews and WHO an UNICEF relevant documentation. Bibliographic search of articles published in international journals as well as research unpublished and material like country reports, fact sheets, policy statements and bulletins were used to complement the under-study review. Searches of both peer-reviewed and grey literature were undertaken to address the following questions: "*What does a person-centered approach mean for neonatal care*"; "*how it is implemented and what could* *be done to make neonatal services more person-centered*?". The resources were to be facility based, clinically focused and documenting models of person-centered care applied to newborn health and newborn service provision from both High-Income Countries (HIC) and Low- and Middle-Income Countries (LMIC).

The literature search was conducted using MEDLINE (including ePub ahead of print, in process and other non-indexed citations), CINAHL, EMBASE and PSYCHInfo databases. Additional sources for information included the websites of Global Organizations, National Governments and National/International Associations. The search terms "family-centered care", "family participatory care", "family-integrated care", "Kangaroo Mother Care", "Skin-to-skin", "Rooming-in", "Mother Neonatal Intensive Care Unit" were applied and complemented with the terms "newborn/neonatal care", "small and sick newborns", "preterm newborns". Studies were not restricted by study design and reference lists of all retrieved articles were screened for additional potentially eligible studies. All searches were limited to English language publications and reports from 1990 to 2019 (Fig. 22.1).

We reviewed the definitions, the application and the benefits of different models of person-centered care in healthy and small and sick newborns. The status of implementation, the challenges and specific health system requirements, based on the evidence and country experience, to implement and scale-up newborn and family-centered care approaches were analyzed and discussed.

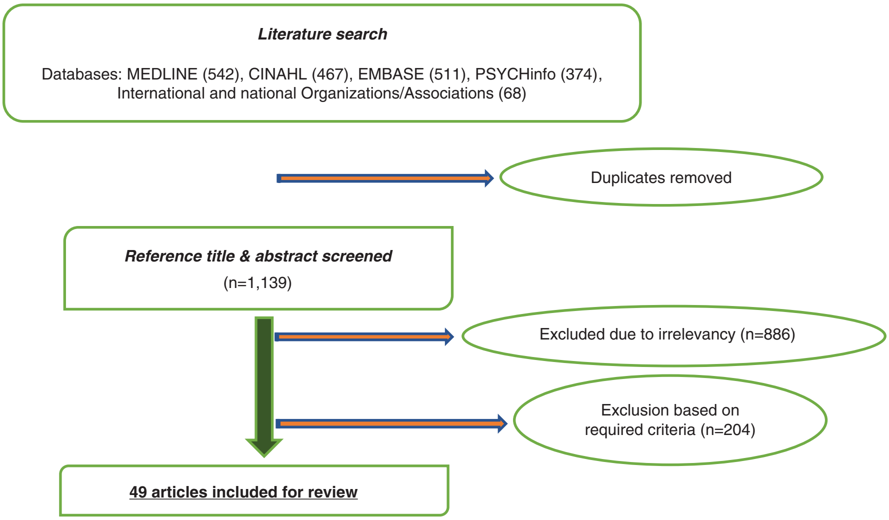


Fig. 22.1 Flowchart of screened and retained articles for this review

22.3 Conceptual Frameworks

This chapter was conceived in line with the WHO framework on integrated people-centered health services [5], which incorporates the Universal Health Coverage (UHC) principles and calls for comprehensive multisectoral action, and the WHO Quality of Care (QoC) for maternal and newborn health Framework that defines the critical health system dimensions [8].

The concept of person-centered care, people-centered care and person-centered medicine means considering people's needs and preferences at the center, prioritizing health care services as close as possible to the community, and co-production of health [5]. It encompasses a vision of medicine informed by evidence, experience and values, and oriented to health restauration and health promotion for the total contextualized person [5].

The QoC Framework conceptualizes QoC for maternal and newborn health by identifying eight domains of QoC, which should be targeted to assess, improve and monitor care within the health system context. Health systems create the structure, which enables access to quality care and allows for the process of care to occur along two important and inter-linked dimensions of provision (#1–3) and experience of care (#4–6) [8]. Based on this framework, QoC for pregnant women and newborns in facilities requires competent and motivated human resources (#7) and the availability of essential physical resources (#8) to impact on individual and facility-level outcomes.

These concepts are critical when applied to the neonatal period, given the long-life impact of the caring environment and quality of care on infant health and development, on family experience of care, and infant parents attachment (Fig. 22.2).

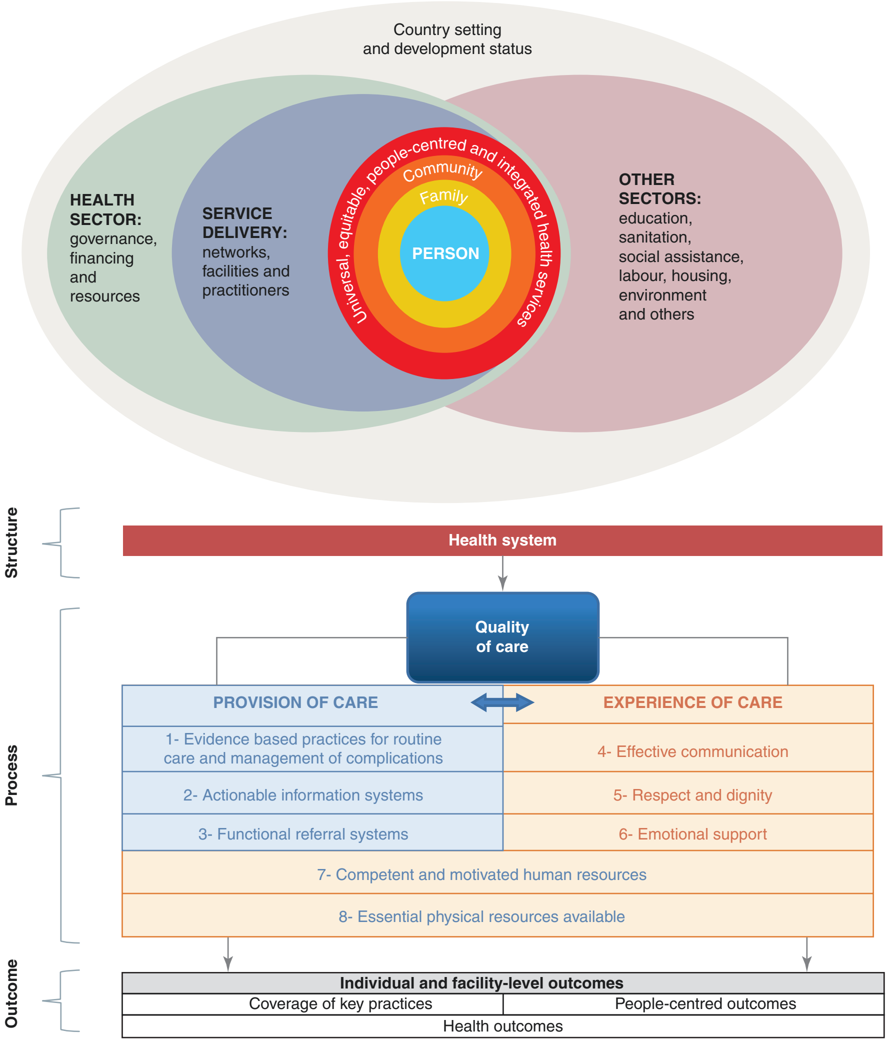


Fig. 22.2 Conceptual frameworks

22.4 Knowledge Base

In this chapter both healthy and sick newborns that require individualized care and receives treatment from health-care providers, mother, father, other caregivers, or a combination of these are at the center of care. However, particularly when prolonged hospitalization is needed, like in case of preterm birth, the newborn is seen in the family context, as a unit together with family members. Mothers play the central role as the main caregivers because of breastfeeding and are critical for attachment and immediate and long-term care. Fathers need to be included too, they can greatly contribute particularly if the mother is unwell, but also to support the mother, and for their own emotional wellbeing and attachment. Siblings are affected by the birth of preterm or sick baby and need to be part of the care process. Therefore, everyone in the family unit, being the newborn, the mother and father and at times the siblings may be considered at the center and should receive care according to their respective needs.

Different definitions and approaches exist of person-centered care applied to neonatal health care reflecting the evolution of newborn care. These include immediate skin-to-skin contact and rooming-in for healthy newborns, Kangaroo Mother Care for preterm and low birth weight infants, Family-Centered Care, Family-Integrated Care, and Mother-NICU care among others (Table 22.1). All have in common the participation of the mother and at times other family members in the care of the baby. These approaches differ from more conventional models of newborn care which separate the newborn from the mother and family for variable time, due to a variety of considerations, and may look at the newborn as a passive recipient of care disconnected from mother in which womb he/she began to develop up to the delivery and from the family and the community in which the infant will develop after discharge from the hospital.

Based on decades of evidence, the WHO and UNICEF [9] recommend that all healthy mothers and babies, irrespective of feeding preferences and method of birth, have uninterrupted skin-to-skin care beginning immediately after birth for at least one hour, and until after the first feeding, for breastfeeding women. Skin-to-skin care consists of placing dried, unclothed newborn on the mother's bare chest, and entails that all routine maternal and newborn procedures, including assessment, are conducted during or after this sensitive period immediately after birth [10].

The benefits of early mother-infant contact for preterm babies were first recognized in the 1970s in Bogota, Colombia, where few incubators were available to care for low-birth-weight infants [11, 12]. Research conducted during the same period in the United States confirmed the positive effects for healthy babies [12]. Specifically, the immediate and uninterrupted skin-to-skin care facilitates a series of critical processes for newborns, parents and health system (Table 22.1), including breastfeeding initiation and exclusivity rates, reduced incidence of post-partum depression [12–14], and prevention of infection and hospitalization [13] (Fig. 22.3).

The practice of rooming-in, introduced between the 70s and 80s, is defined by the WHO and UNICEF as a “hospital practice where postnatal mothers and normal infants stay together in the same room for 24 h a day from the time they arrive in their room after delivery” [15]. Rooming-in is often connected to skin-to-skin care, therefore associated with the above-mentioned series (Table 22.1) of benefits [16].

As far as the small and sick babies are concerned, parents often report distress, frustration, and alienation if they are excluded from taking care of their neonates. Preterm birth throws parents in a situation they are not prepared for, the experience of loss and putting life on hold force them to block emotions and brings feeling of alienation of being a parent [17]. Acute stress disorders, depressive symptoms and symptoms of psychological trauma are common in these situations. Clinical experience suggests that depressive disorders ranges from 13% to over 30% in poorly

Table 22.1 Benefits for infants, parents and health system by different types of newborn-centered care

		Benefits for infant	Benefits for parents	Benefits for health system
Healthy babies	Immediate SSC	Thermoregulation, colonization with maternal flora, early neurobehavioral self-regulation, improved breastfeeding outcomes and cardio-respiratory stability.	Enhanced affective response to baby, decreased incidence of post-partum depression and reduced salivary cortisol levels	Prevention of infection and reduced hospitalization
	Rooming-in	Improved breastfeeding outcomes	Better detection of infants' hunger cues and better bonding	Prevention of infection and reduced hospitalization
Small and Sick babies	Open NICU, FCC and FIC	Improved clinical outcomes and weight gain	Reduced stress and anxiety	Decreased length of stay in neonatal intensive care unit, improved staff satisfaction, decision making, employment of resources and quality of care
	KMC	Reduced mortality at discharge, severe infection/sepsis, hypothermia, severe illness, and lower respiratory tract disease. Increased weight, length, and head circumference gain. Improved breastfeeding outcomes, sleep organization, brain maturation and long-term outcomes	Enhanced maternal-infant bonding and decreased anxiety levels	Decreased length of stay, hospital re-admission, and cost of care
	M-NICU	Early initiation of breastfeeding and skin-to-skin care, improved weight gain	Enhanced maternal-infant bonding and breastfeeding outcomes. Decreased anxiety levels	Shortened duration of incubator care

resourced communities and have an increased prevalence in the NICUs due to the stressful and unexpected environment [18]. Possible causes include separation from the baby, lack of opportunities to establish early bonding and the institutional environment [19]. Limited or no role in care and decision making may result in lack of self-confidence and guilt. Additionally, most risk factors for prematurity are also risk factors for mental health problems [18]. However, if parents are provided with

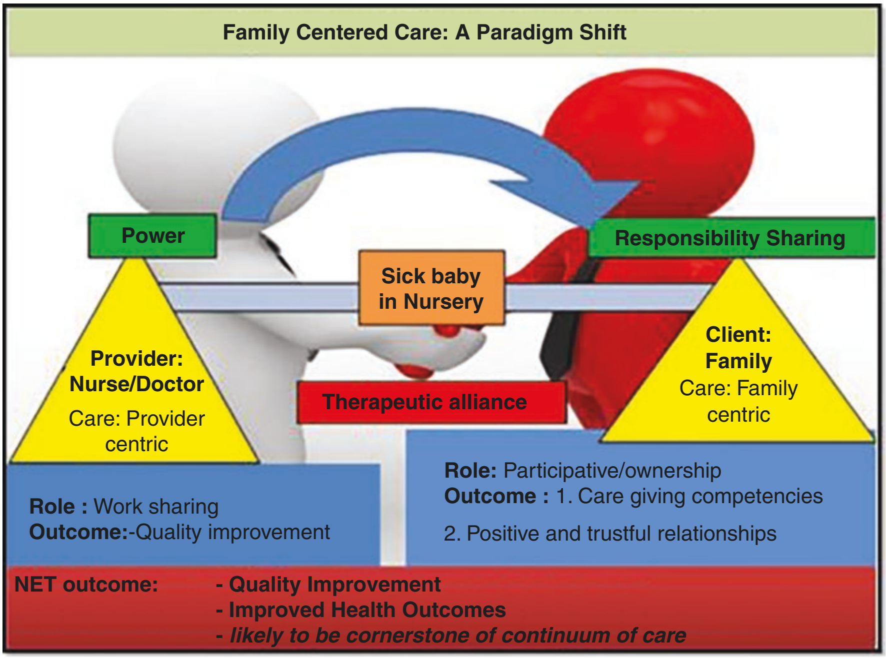


Fig. 22.3 Family centered care: a paradigm shift

the opportunity to be involved in care, receive clear communication about their newborn's status from health care providers, and establish rapport with providers, they experience satisfaction and reduced stress [20]. These experiences support neonatal care approaches that promote parental participation such as Kangaroo Mother Care, Family-centered care (FCC), Family Participatory Care (FPC), Family Integrated Care and Mother-NICU care.

Family-Centered care (FCC), which represents a significant shift for health care providers by involving parents in the planning and delivery of pediatric and neonatal care [21], is based on the principles of information sharing, respect and honoring differences, partnership and collaboration, negotiation and care in context of family and community [22]. Specifically, within the FCC approach, families are acknowledged to be integral members of the care team and are considered to be primary decision makers for their infants [22].

Benefits of FCC have been highlighted in different circumstances and comprehends improved clinical outcomes and weight gain for the child, reduced stress and anxiety for parents, as well as lower hospital re-admission [23].

Family-Integrated Care, a very similar concept to FCC but with major emphasis on family participation in inpatient newborn care, showed additional benefits on the health system such as increased staff satisfaction, improved decision making, resources more efficiently employed and higher quality of care [24].

As previously mentioned, the creation of the Kangaroo Mother Care (KMC) model programme in Colombia in 1978 [25, 26] represents a critical moment for newborn care. This low-cost revolutionary technique promoting skin-to-skin contact between premature and low birth weight newborns and family members, exclusive breastfeeding, and early discharge with follow-up, was launched to address overcrowding, insufficient human resources and other limitations related to newborn care [25, 26]. KMC is today recommended standard of care for preterm and low birth weight infants [3] and is in phase of expansion all over the world.

Despite the slow global uptake, the benefits of KMC have been extensively explored and confirmed by the scientific community in the last 30 years [11, 25, 27]. Among low birth weight newborns, KMC compared to conventional care is associated with several benefits (Table 22.1), from lower mortality to higher oxygen saturation [28–30], and improved brain maturation [31–33]. Better bonding with infant [34–36] and lower hospital re-admission [28, 29] are among the fundamental benefits of KMC respectively for parents and the health system. KMC seems to have significant, long-lasting social and behavioral protective effects 20 years after the intervention [25].

Mother-Neonatal ICU (M-NICU) is a relatively new concept which goes in parallel with the open NICU model or the Breastfeeding Initiative in NICU. This is an expansion of the Baby-Friendly Hospital Initiative, where no separation starts in the delivery room and the mother has her bed inside the NICU by the side of baby's warmer/incubator with the opportunity of practicing KMC as long as she desires. Mother as a resident of M-NICU becomes an active caregiver, and is involved in continuum of neonatal care, from routine baby hygiene to monitoring the babies on intravenous fluids and providing skin-to-skin contact [37].

The open neonatal unit, intended as unrestricted access to the newborn by the parents, is a concept difficult to implement especially in the developing countries. Parents who have the possibility to remain with their infants in open neonatal units state that this allows for active participation in the care of their newborn, especially Kangaroo Mother Care, and activities such as changing diapers, tube feeding and bathing. In addition, parents acquire the confidence to perform these tasks without supervision. Parents also highlight the importance of events such as eye contact, direct contact, the first time the baby receives breast milk and the first time they can stay with their child without being disturbed [38–42].

Among the descriptions from parents on the effect of practicing KMC are: the mutual feeling of having one another (mother-baby), establishing a relationship with their son or daughter, feeling close or creating a unique connection, loving their baby, mothers being fully concentrated on their baby during skin-to-skin contact, provides the best bonding experience, superior to even breastfeeding or other kind of support, the baby can smell and touch their mother/father and therefore get to know them and finally parents report that, once skin-to-skin contact is established, mothers recognize that babies prefer to remain in skin-to-skin contact with their parents, rather than being left alone in the crib.

The postnatal mother-child relationship (or father-child) is the pillar that supports the physical and psychological development of the human being. Attachment guarantees the survival of the human species. In this sense, the main outcome measures correspond to an approximation of the measurement of the mother's behaviors and perceptions in the first weeks of life which will favor the development of an attachment to the baby. In the systematic review of Anderzén-Carlsson et al., the bonding experience was a central element in the qualitative studies of the parents' perception of the Kangaroo Mother Care method [43].

Thanks to the close contact of the kangaroo position or skin-to-skin contact, parents recount becoming more and more familiar with their baby, easily establishing a relationship [44]. Such practices are therefore in line with the needs and rights of the newborn as well as preferences of parents.

Impact on early attachment, bonding and continued positive influence of mother-infant interaction due to opportunity of parental participation in care of their small and sick newborn at facility and continued at home in community after discharge are likely to have positive impact on early childhood development [45].

22.5 Practical Implications

Ideally, as stated in the European Standards of Care for Newborn Health, parents must be members of the caregiving team and, with individualized support, assume the primary role in the provision of care for their infant, and be active partners in decision-making processes [46].

To make this possible, three simple rules could guide a progressive transformation of maternity and neonatal services towards better quality and people-centeredness. First rule: minimizing or avoiding the separation of the mother from her baby; second rule: involving the father in the care of his baby when available; and third rule: being a support and not replacing the mother and father but empowering them to take care of their baby since the beginning. Context specific adaptations will be required along the continuum of care depending on newborn's needs.

22.5.1 Around the Time of Birth in the Delivery Room

General trends indicate an increase in institutional delivery with professionalization of care. However, quality of childbirth care has been questioned [4]. To make services more person-centered requires improvement in the preparation of delivery, comfort of the mother, respect for her choices, and presence of the father or a companion of choice. Immediate care of the newborn at birth should include the WHO recommended interventions for essential newborn care [3]. Skin-to-skin care should be ensured for at least the first hour after birth for all newborns [47] with early breastfeeding, including in preterm babies whenever possible. The specific purpose of starting KMC in the delivery room is to avoid the separation of the mother and the newborn and the stress it may cause to the premature newborn.

It is easy to implement skin-to-skin contact in the delivery room as long as precise parameters (Table 22.2) exist. It should not be an option but a well-defined routine when implemented. The placement of the infant in the kangaroo position should be supervised and the supervision of the newborn cannot be the responsibility of the mother in postpartum; the initiation of skin-to-skin should be reconsidered if there is no monitoring of the mother-child dyad, unless a family member is present to fill this role. The need to support the position of the newborn with a spandex girdle should also be considered since the mother can fall asleep and endanger her baby if the baby slips.

Table 22.2 Parameters prior to implementation of skin-to-skin in the newborn unit, delivery room or mother-infant ward

Areas	Components
Infrastructure	Comfortable chairs
	Support of the baby in an adequate kangaroo position, as with lycra bands
	Food and drinking water for the mother
	Privacy screens
	Water and soap
Protocols	Open neonatal unit protocol
	Skin-to-skin and KMC initiation protocol in the NICU as soon as possible when physiological stability is obtained
	Skin-to-skin and KMC initiation protocol in intermediary care for stable infants even the late preterm from 34 to 37 weeks of gestational age
	Registration protocol for kangaroo practice including breastfeeding the premature infant for all the premature infants and LBWI
	Protocols for pain (KP) Protocols for minimal manipulation (all the blood sample in the same time when the baby is awake and in KP) Protocols for modification of the macro environment (light, noise, nests) and the micro environment (KP as soon and as long as possible) Protocols for nutrition
	Protocol for parental participation and stay in the unit
	Protocol for family visits
	Protocol for social worker
	Protocol for other visits (No formula gratis) Protocol for infection prevention and control
Human resources	Previous training of personnel in the skin-to-skin, KMC and FCC Training on education and support of parents
	Regular staff support meetings in case of difficulty
Parents	Education and training materials adapted for parents
	Preparation for discharge in kangaroo position in a skin-to-skin/KMC ward if the mother is living far or at home if the mother is living in the city and willing to come back in the ambulatory skin-to-skin/KMC follow up clinic.
Monitoring	Systems for monitoring the infants, parents and staff

22.5.2 Transportation from Delivery Room to Neonatal Unit and Referral

Postnatal transportation with KMC of the infant on the mother's or other caregiver's chest bears some analogy to in utero transport and might ameliorate several of the risks associated with incubator transport [48, 49]. Similarly, referral from health facility to another on the mother's or other caregiver's chest represent a life-saving intervention in contexts with low availability of emergency vehicles like ambulances.

22.5.3 Neonatal Unit: Intermediate and Minimal Care Unit

FCC for the mother means no separation according to her health status, but the father can and must participate. As listed in Table 22.2, a series of logistic and procedural requirements must be in place, such as lycra band or support to be able to carry the baby and trained professionals for supporting breastfeeding and KMC.

22.5.4 Neonatal Intensive Care Unit

FCC is aligned to the previously mentioned neonatal units. For preterm infant there is evidence on the importance of decreasing stress and pain with KMC [30] and manipulations, stimulating the permanent presence of the mother with her voice, her smell, her heart and her colostrum and milk [50].

22.5.5 Mother-Infant Ward and Kangaroo Mother Care Ward

Mother-infant ward for term infant and stable preterm infant is important especially when the hospital stay is very short (less than 48 h) to teach the mother and the family the danger signs (jaundice, hypoglycemia), how to breastfeed her baby or when there are many infants in the NICU. The KMC ward is also where the mother and the preterm infant will stay when the baby is stable, but not filling the eligibility criteria to be discharged home in kangaroo position. Other situations include the mother that did not achieve a successful kangaroo adaptation, baby still with treatment or oxygen or feeding tube, and staff not certain if the mother (caregiver) and infant come back to daily consultations. The KMC ward is de-medicalized and the KMC training allows for gradual transfer of the responsibilities of physical and emotional care of the infant from the healthcare personnel to the infant's family, particularly the mother (and to any other KP provider accepted by the family such as the father, grandparents, amongst others). The treating pediatrician is the person who decides the discharge of the infant from the neonatal unit to a KMC ward or to home based on neonatal conditions and family situation, including supportive systems in the community.

The preterm infant is considered eligible to leave the neonatal unit, whether for a kangaroo ward for the mother-infant dyad or for the home, independently of their weight or gestational age, when the conditions listed here are met (Table 22.3). Once at home, preterm infants should be maintained in the kangaroo position 24 h until they refuse it.

22.5.6 Ambulatory Program for all High-Risk Newborns, Including Preterm Infant or Low Birth Weight (LBW) Infants: An Integral FCC Unit up to 40 Weeks and in a Second Step from Term to up 1 or 2 Years of Corrected Age

High-risk babies, such as those who were born preterm or who have suffered severe infections, carry risk in terms of somatic growth and in neurologic and developmental aspects. Knowing for instance that insufficient weight gain and growth predisposes to neurologic and developmental sequelae in the long term, and rapid growth predisposes to morbidity in adulthood, it is fundamental to emphasize the importance of follow-up of somatic growth [51]. Mental retardation, cerebral palsy, behavioral problems and learning difficulties are observed frequently in babies born with a gestational age below 28 weeks and the importance of multidisciplinary follow-up should be specifically emphasized at each visit [51]. Linkages with social and community-based support systems are equally important to smooth transition of high-risk babies from health facility discharge to their first years of life.

A community study on assessment of Implementation of Family Participatory Care (FPC) in Special Newborn Care Units in Three States of India revealed that FPC appears to be a winning strategy to increase compliance with KMC in facility as well as continuing KMC rates post discharge in community [52]. This study also revealed operational feasibility of implementation in Indian public health system.

After the home discharge from the hospital in kangaroo position, preterm and LBW infants should be assessed daily with weight monitoring until they reach a daily weight gain at least two or three consecutive days of 15 g/kg/day if they have less than 37 weeks of gestational age, and then 8–11 g/kg/day until full-term. When this gain is achieved, weekly assessments are carried out until the infant reaches full term (40 weeks of gestational age) and 2500 g. This constitutes the KMC ambulatory care equivalent to the minimal intrahospital care and can be named “minimal neonatal ambulatory care” or “hospital day care”. After 40 weeks (presume term) the kangaroo infant will be followed up to one or 2 years of corrected age in the

Table 22.3 Eligibility criteria for home discharge of preterm and low birth weight infants from the hospital

Eligibility criteria for the infant's discharge	The infant has had a successful intrahospital kangaroo adaptation, especially in that he/she regulates his/her temperature in the kangaroo position and has an adequate suction-swallowing-respiration coordination
	The infant has an adequate weight gain in the neonatal unit with the kangaroo position plus incubator during at least two consecutive days if he/she is more than ten days old
	The infant has finished the medical treatment, if applicable
	If the infant receives oxygen through the nasal cannula, this must be less than ½ L/min. (This is for practical reasons, as on average the journey from the home to the Kangaroo Mother Program takes an hour. As such, the oxygen tank must last the distance there and back and still have enough for an emergency visit). Only few KMC programs have the experience of discharging infant in kangaroo position with ambulatory oxygen
	The infant must have an ambulatory Kangaroo Mother Program able to provide adequate follow-up if home discharge is considered
Eligibility criteria for the mother's discharge	She has accepted to take part in the Kangaroo Mother Program. For this, she must receive the necessary education in the Kangaroo Mother Method
	She feels capable of caring for her infant using the Kangaroo Mother Method (position and nutrition) at home if home discharged is considered
	She has had a successful intrahospital kangaroo adaptation and in particular she knows how to breastfeed her infant (direct suction from the breast) and the milk extraction techniques
	There is a family commitment and capacity to participate in ambulatory kangaroo monitoring controls
	She is physically and mentally capable of caring for her infant
	The concept of a multidisciplinary team is favorable for the ambulatory follow-up, in particular for high social risk cases such as adolescent, single mother with an infant using portable oxygen, with twins, or with more infants, with infants that have health problems, and in the case of alcoholism or drug addiction or other social problems
Eligibility criteria for the discharge of the family/support network	They must want to support or accompany the mother and be part of the program that applies the Kangaroo Mother Method
	Understand the method well and feel capable of helping the handling of the infant in KP at their home
	Have sufficient time and family collaboration in care to achieve the objectives of the KMC and guarantee the safety of the infant
	Support the mother in duly attending appointments, respecting lactation hours until 40 weeks of gestational age (and afterwards continue with maternal lactation on free demand), follow application instructions for medications and carry out the special exams ordered
	To be able to adapt to the transitory changes implied by the adoption of the Kangaroo Mother Method at home. Provide support for maintaining the kangaroo position 24 hours a day and redefine the cooperation roles between members of the family which must be adopted to support the principal caregiver
	Be physically and mentally capable to help care for the infant at home

same KMC program (KMCP) for a high risk follow up. It includes the monitoring of the growth, the evaluation of the neuro, psychomotor and sensorial development to be able to detect any deviation from the normal development and to do an opportune intervention.

The justification for this approach is that kangaroo infants clearly belong to the high biological risk category due to risk of inadequate somatic growth and the risk of presenting neuro-psychomotor and sensory problems. The KMCP represents, as such, an opportunity for high risk monitoring and continuity of care for these infants during at least the first two years of life.

22.5.7 Obstacles to Person Centered Care and Potential Solutions

Multiple factors influence the uptake of more person-centered clinical approaches [53, 54]. The fact that conventional work in neonatal services in not so person-centered could be attributed to several reasons, which stretch from the lack of supportive political commitment to poor understanding of the benefits especially of breastfeeding, which is time consuming at the beginning. Limited demand from parents, perceived lack of economic advantage for providers, not yet being seen as a standard of care and confusing guidelines both complement and confuse the current landscape.

There are substantial barriers to put the family-centered newborn model of care in practice, especially service delivery and financing [55]. KMC is low-cost but not without cost; funding should consider creation of suitable environments, including the provision of meals and drinking water to the mother, the availability of soap to wash hands, comfortable chair and a lycra band.

Studies on typology of rooms and separation show different gradients of parents' involvement in relation to the environment. This varies from (a) complete separation with parents as visitors, separation at birth, parents visits allowed few hours a day, very limited facilities; (b) frequent separation with staff-dependent parent, separation at birth, possibility of visits during day time, but limited facilities; (c) part-time with staff dependent parents, separated at birth, parents rooming-in part of the day and some facilities making easier to feel closer and have attuned relationship; (d) full time and zero separation when parent can stay with the baby from birth to discharge, thus enabling attuned relationship and complete ownership of the care process. Adequate space for the performance and monitoring of KMC can be addressed conducting advocacy, creating policies, and making KMC follow-up a part of existing postnatal services [54]. Policies would also facilitate participation of the father in the delivery room, open neonatal unit to parents 24 h, follow up in a specific program and not in particular pediatrician consultation [53].

Specifically, primary policies are no separation of newborn from mother/father from birth, skin-to-skin and KMC as early as possible and reorganization of services to allow full participation of the parents in the care and decision-making process. Reducing burden of transport costs to mothers, home visits by community health workers, and training parents to perform KMC as independently as possible, and offering psychosocial support to parents of high-risk newborns, should be promoted and facilitated through policies, guidelines, education, and monitoring systems [55]. Buy-in from policy-makers is fundamental to promote family-centered care, specifically through policies like maternity and paternity leave [55].

Clear explanation of the benefits of person-centered care with practical examples and stressing the importance of a safe and sensory adjusted environment for optimal development of the infant, is needed to overcome barriers due to sociocultural norms. Behavioral change via engagement of fathers in childcare and creation of a community among parents, caregivers and health-care workers can help deal with contextual factors. Shifting social norms around skin-to-skin contact while avoiding stigmatization of KMC provision requires engagement of all the community, including cultural, religious, and community leaders [54].

In an Indian study, the delivery of care was forthcoming by fathers, grandfathers while two thirds of primary care providers were males [56]. Care delivery did not matter irrespective of age, gender, relationship or literacy level. Hence, the implementation was feasible and well accepted by families. Till such time that mother could be available to provide care, fathers and grand-parents capitalized on this unique opportunity to establish early bonding with their small and sick infant while being engaged in care [56].

Providers knowledge, attitudes and practices, and availability of staff competent in KMC and breastfeeding of the premature infant is another key aspect and might be solved through in-service training, use of quality improvement processes and by teaming specialized nurses and midwives with unexperienced human resources [55]. Also, the creation of national newborn health training curricula that include KMC as a priority intervention is crucial to ensure sustainability [54].

A series of barriers to a more person-centered approach are strictly connected with the mindset of the providers, including: accepting parents as co-partner in care, perceived diminished authority, uneasiness because of being constantly assessed by the parents (Watch Dog effect), tendency to delegate clinical tasks to parents (task-shift), and expectations on standards of care by empowered and well-aware parents. Initial and periodic sensitization and training of provider teams followed by constant supervision and monitoring represent the most important solution to overcome the above-mentioned challenges [20].

Successful implementation FCC implies well trained and supported healthcare professionals who receive counselling and regular clinical supervision in communicating with and providing emotional support for parents [57]. As perinatal mental disorders commonly arise in the days immediately following childbirth (the *postnatal Blues* are particularly prominent on the sixth day post-partum, when the mother has marked lability and crying spells), their impact on the work of the Neonatal Intensive Care Unit is considerable, and they may complicate the provision of

Family-Centered Care outlined in this chapter [58]. Perinatal mental disorders may also be exacerbations of a pre-pregnancy mental disorder, such as a chronic psychosis, bipolar disorder, prolonged anxiety or alcoholism. Each may trigger a pre-term delivery and the birth of a vulnerable infant. Family-Centered Care is adversely affected by these disorders because of their adverse effect on bonding, an increased reluctance to breast feed, or the unwanted effects of medication [58]. The aphorism *No Neonatal Health without Mental Health* is an expression of integrative holism, which emphasizes the need for education in Perinatal Mental Health as well as the need for closing the gap between the Maternal and Child Health services and perinatal mental health expertise [59]. At the heart of Neonatal Health there are family and professional relationships, and the various health professionals like perinatal psychiatrists, mental health nurses, midwives, neonatologists, developmental psychologists, paediatricians, reproductive health professionals, as well as service managers, have a lot to learn from each other [59].

Studies have highlighted how, despite the initial hesitation, health professionals revealed a favorable attitude to FCC after realizing its importance in: (a) building attachment between newborn and caregiver; (b) mitigation of potential conflicts with relatives of newborns who have an adverse outcome; (c) empowerment of parents, whose caregiving skills were enhanced, potentially ensuring better continuity of care at home [20].

22.6 Conclusions

Newborn services should be designed to support the best start in life with the newborn and the family at the center of care. Person-centered models of care such Mother-NICU, Family-Centered Care and Kangaroo Mother Care have substantial potential to benefit newborns, families and health system, but require a transformation of neonatal care services and of follow-up services. To improve neonatal outcomes and reach universal health coverage, quality services for the small and sick newborn should be built up from person-centered needs and rights considering the individual infant, the mother, father and the wider family in the context of the local community and based on a shared vision of health care providers and the community.

All over the world a paradigm shift is highly required to ensure the provision of person-centered neonatal health care services. This can be adapted to countries differences in resources, development and demand for services and should be supported by political commitment and a favorable legal and policy framework that recognizes the value of investing in early start of life for the individual and the society. While working in the neonatal ward can be perceived by neonatal staff as easier without parents, neonatal health professionals are in the best position to teach the parents how to be the best providers of care for their infants and must be prepared to change their role in the neonatal unit.

Family-centered newborn care, whose operational feasibility and acceptability seem promising, is indeed a family's right to a respectful care that we need to protect, support and promote.

Infant and family-centered model of care fits with WHO quality of care framework and will advance universal health coverage, equity, efficiency and responsiveness of the health system. This will greatly contribute to increase neonatal survival, health and human capital.

Acknowledgements and Disclosures Authors do not report any conflicts of interest.

References

1. Liu L, Oza S, Hogan D, Perin J, Rudan I, Lawn JE, Cousens S, Mathers C, Black RE. Global, regional, and national causes of child mortality in 2000–13, with projections to inform post–2015 priorities: an updated systematic analysis. Lancet. 2015;385:430–40.
2. UN IGME. Levels & trends in child mortality: report 2018. Estimates developed by the United Nations interagency group for child mortality estimation (UN IGME). New York: United Nations Children's Fund; 2018.
3. WHO. Survive and thrive, transforming care for every small and sick newborn. Geneva: World Health Organizations; 2019.
4. Kruk ME, Gage AD, Arsenault C, Jordan K, Leslie HH, Roder-DeWan S, Adeyi O, Barker P, Daelmans B, Doubova SV, English M, Garcia Elorrio E, Guanais F, Gureje O, Hirschhorn LR, Jiang L, Kelley E, Tekle Lemango E, Liljestrand J, Malata A, Marchant T, Precious Matsoso M, Meara JG, Mohanan M, Ndiaye Y, Norheim OF, Reddy KS, Rowe AK, Salomon JA, Thapa G, Twum-Danso NAY, Pate M. High-quality health systems in the sustainable development goals era: time for a revolution[Published correction appears in Lancet Glob Health. Sep 18]; [Published correction appears in Lancet Glob Health. 2018 Nov;6(11):e1162]. Lancet Glob Health. 2018;6(11):e1196–252.
5. WHO. Framework on integrated people-centred health services. Report by the secretariat. A67/39. Provisional agenda item 16.1. 15 April 2016. Geneva: World Health Organization; 2016. Available from: http://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_39-en.pdf?ua=1&ua=1
6. Austin A, Langer A, Salam RA, Lassi ZS, Das JK, Bhutta ZA. Approaches to improve the quality of maternal and newborn health care: an overview of the evidence. Reprod Health. 2014;11(Suppl 2):S1.
7. Gooding JS, Cooper LG, Blaine BA, Franck LS, Howse JL, Berns SD. Family support and family centered care in the neonatal intensive care unit: origins, advances, impact. Semin Perinatol. 2011;35:20–8.
8. Tunçalp Ö, Were WM, MacLennan C, Oladapo OT, Gulmezoglu AM, Bahl R, Daelmans B, Mathai M, Say L, Kristensen F, Temmerman M, Bustreo F. Quality of care for pregnant women and newborns-the WHO vision. BJOG. 2015;122(8):1045–9.
9. World Health Organization, United Nations Children's Fund. Baby-friendly hospital initiative: revised, updated, and expanded for integrated care. Geneva: World Health Organization; 2009. Available from: http://whqlibdoc.who.int/publications/2009/9789241594967
10. Johnston M, Landers S, Noble L, Szucs K, Viehmann L. Breastfeeding and the use of human milk. Pediatrics. 2012;129(3):e827–41.
11. Charpak N, Ruiz G, Zupan J, Cattaneo A, Figueroa Z, Tessier R, Cristo M, Anderson G, Ludington S, Mendoza S, Mokhachane M, Worku B. Kangaroo Mother Care: 25 years after. Acta Paediatr. 2005;94(5):514–22.

12. Cleveland L, Hill CM, Pulse WS, DiCioccio HC, Field T, White-Traut R. Systematic review of skin-to-skin care for full-term, healthy newborns. J Obstet Gynecol Neonatal Nurs. 2017;46(6):857–69.
13. Crenshaw JT. Healthy birth practice #6: keep mother and baby together—it's best for mother, baby, and breastfeeding. J Perinat Educ. 2014;23(4):211–7.
14. Stevens J, Schmied V, Burns E, Dahlen H. Immediate or early skin-to-skin contact after a caesarean section: a review of the literature. Matern Child Nutr. 2014;10(4):456–73.
15. Baby-Friendly USA. The ten steps to successful breastfeeding. 2012. Available from: http://www.babyfriendlyusa.org/about-us/baby-friendly-hospital-initiative/the-ten-steps.
16. Barrera CM, Nelson JM, Boundy EO, Perrine CG. Trends in rooming-in practices among hospitals in the United States, 2007-2015. Birth. 2018;45(4):432–9.
17. Henderson J, Carson C, Redshaw M. Impact of preterm birth on maternal well-being and women's perceptions of their baby: a population-based survey. BMJ Open. 2016;6(10):e012676.
18. Cox J. Perinatal mental health around the world: a new thematic series. BJPsych Int. 2020;17:1.
19. Guillaume S, Michelin N, Amrani E, Benier B, Durrmeyer X, Lescure S, Bony C, Danan C, Baud O, Jarreau PH, Zana-Taieb E, Caeymaex L. Parents' expectations of staff in the early bonding process with their premature babies in the intensive care setting: a qualitative multicenter study with 60 parents. BMC Pediatr. 2013;13:18.
20. Sarin E, Maria A. Acceptability of a family-centered newborn care model among providers and receivers of care in a public health setting: a qualitative study from India. BMC Health Serv Res. 2019;19(1):184.
21. Mirlashari J, Brown H, Fomani FK, de Salaberry J, Zadeh TK, Khoshkhou F. The challenges of implementing family-centered care in NICU from the perspectives of physicians and nurses. J Pediatr Nurs. 2019;50:e91–8.
22. Committee on Hospital Care and Institute for Patient- and Family-Centered Care. Patient- and family-centered care and the pediatrician's role. Pediatrics. 2012;129(2):394–404.
23. Ding X, Zhu L, Zhang R, Wang L, Wang TT, Latour JM. Effects of family-centred care interventions on preterm infants and parents in neonatal intensive care units: a systematic review and meta-analysis of randomized controlled trials. Aust Crit Care. 2019;32(1):63–75.
24. O'Brien K, Robson K, Bracht M, Cruz M, Leu K, Alvaro R, da Silva O, Monterrosa L, Narvey M, Ng E, Soraisham A, Ye XY, Mirea L, Tarnow-Mordi W, Lee SK. Effectiveness of family integrated care in neonatal intensive care units on infant and parent outcomes: a multicenter, multinational, cluster-randomised controlled trial. Lancet Child Adolesc Health. 2018;2(4):245–54.
25. Charpak N, Ruiz JG. Latin American Clinical Epidemiology Network Series–Paper 9: the Kangaroo Mother Care method: from scientific evidence generated in Colombia to worldwide practice. J Clin Epidemiol. 2017;86:125–8.
26. Rey-Sanabria E. À l'autre bout du monde, accueillir le prématand volontary uré. In: Hillier J, editor. Cahiers du nouveau-né, vol. 6. Paris: Stock; 1983. p. 197–203.
27. Chan GJ, Valsangkar B, Kajeepeta S, Boundy EO, Wall S. What is Kangaroo Mother Care? Systematic review of the literature. J Glob Health. 2016;6(1):010701.
28. Boundy EO, Dastjerdi R, Spiegelman D, Fawzi WW, Missmer SA, Lieberman E, Kajeepeta S, Wall S, Chan GJ. Kangaroo Mother Care and neonatal outcomes: a meta-analysis. Pediatrics. 2016;137(1)
29. Charpak N, Ruiz-Peláez JG, Charpak Y. A randomized, controlled trial of Kangaroo Mother Care: results of follow-up at 1 year of corrected age. Pediatrics. 2001;108(5):1072–9.
30. Conde-Agudelo A, Diaz-Rossello JL. Kangaroo Mother Care to reduce morbidity and mortality in low birthweight infants. Cochrane Database Syst Rev. 2016;8:CD002771.
31. Dey R, Maria A, Shukla A, Vallamkonda N. Neurodevelopmental outcomes in NICU graduates at one year of age who received family centered care in NICU: a prospective observational study. GGSIP University, Delhi, India. 2019 (Thesis Work).

32. Scher MS, Ludington-Hoe S, Kaffashi F, Johnson MW, Holditch-Davis D, Loparo KA. Neurophysiologic assessment of brain maturation after an 8-week trial of skin-to-skin contact on preterm infants. Clin Neurophysiol. 2009;120:1812–8.
33. Schneider C, Charpak N, Ruiz-Peláez JG, Tessier R. Cerebral motor function in very premature-at-birth adolescents: a brain stimulation exploration of Kangaroo Mother Care effects. Acta Paediatr. 2012;101(10):1045–53.
34. Shorey S, Ang L. Experiences, needs, and perceptions of paternal involvement during the first year after their infants' birth: a meta-synthesis. PLoS One. 2019;14(1):e0210388.
35. Tessier R, Cristo M, Velez S, Giron M, de Calume ZF, Ruiz-Palaez JG, Charpak N. Kangaroo Mother Care and the bonding hypothesis. Pediatrics. 1998;102(2):e17.
36. Tessier R, Cristo MB, Velez S, Giron M, Nadeau L, de Calume ZF, Ruiz-Palaez JG, Charpak N. Kangaroo Mother Care: a method for protecting high-risk low-birth-weight and premature infants against developmental delay. Infant Behav Dev. 2003;26(3):384–97.
37. Chellani H, Mittal P, Arya S. Mother-Neonatal Intensive Care Unit (M-NICU): a novel concept in newborn care. Indian Pediatr. 2018;55(12):1035–6.
38. Baylis R, Ewald U, Gradin M, Hedberg Nyqvist K, Rubertsson C, Thernström BY. First-time events between parents and preterm infants are affected by the designs and routines of neonatal intensive care units. Acta Paediatr. 2014;103(10):1045–52.
39. Flacking R, Thomson G, Ekenberg L, Löwegren L, Wallin L. Influence of NICU co-care facilities and skin-to-skin contact on maternal stress in mothers of preterm infants. Sex Reprod Healthc. 2013;4(3):107–12.
40. Pierrat V, Coquelin A, Cuttini M, Khoshnood B, Glorieux I, Claris O, Durox M, Kaminski M, Ancel PY, Arnaud C, EPIPAGE-2 Neurodevelopmental Care Writing Group. Translating neurodevelopmental care policies into practice: the experience of neonatal ICUs in France-The EPIPAGE-2 Cohort Study. Pediatr Crit Care Med. 2016;17(10):957–67.
41. Raiskila S, Axelin A, Rapeli S, Vasko I, Lehtonen L. Trends in care practices reflecting parental involvement in neonatal care. Early Hum Dev. 2014;90(12):863–7.
42. Reynolds LC, Duncan MM, Smith GC, Mathur A, Neil J, Inder T, Pineda RG. Parental presence and holding in the neonatal intensive care unit and associations with early neurobehavior. J Perinatol. 2013;33(8):636–41.
43. Anderzén-Carlsson A, Lamy ZC, Tingvall M, Eriksson M. Parental experiences of providing skin-to-skin care to their newborn infant—Part 2: a qualitative meta-synthesis. Int J Qual Stud Health Well-being. 2014;9:24907.
44. Santos LM, Morais RA, Miranda JOF, Santana R, Oliveira V, Nery F. Maternal perception of the skin to skin contact with premature infants through the Kangaroo position. Revista de Pesquisa: Cuidado é Fundamental Online; 2013.
45. Maria A. India case study on family participatory care: A gateway to nurturing care for small and sick newborn included for launch of nurturing care framework launch for early childhood development at 71st World Health Assembly, May 2018, Geneva. Available from: http://nurturing-care.org/wp-content/uploads/2018/05/nurturing-care-case-study-india.pdf
46. EFCNI. European Standards of Care for Newborn Health. Munich: European Foundation for the Care of Newborn Infants; 2018.
47. Moore ER, Bergman N, Anderson GC, Medley N. Early skin-to-skin contact for mothers and their healthy newborn infants. Cochrane Database Syst Rev. 2016;11(11):CD003519.
48. Hennequin Y, Grevesse L, Gylbert D, Albertyn V, Hermans S, Van Overmeire B. Skin-to-skin back transfers provide a feasible, safe and low-stress alternative to conventional neonatal transport. Acta Paediatr. 2018;107(1):163–4.
49. Sontheimer D, Fischer CB, Buch KE. Kangaroo transport instead of incubator transport. Pediatrics. 2004;113(4):920–3.
50. Picciolini O, Porro M, Meazza A, Gianni ML, Rivoli C, Lucco G, Barretta F, Bonzini M, Mosca F. Early exposure to maternal voice: effects on preterm infants development. Early Hum Dev. 2014;90(6):287–92.

51. Acunaş B, Uslu S, Baş AY. Turkish Neonatal Society guideline for the follow-up of high-risk newborn infants. Turk Pediatri Ars. 2018;53(Suppl 1):S180–95.
52. Kumar H, Bhat A, Alwadhi V, Maria A, Khanna R, Neogi SB, Khera A. An assessment of implementation of family participatory care in special newborn care units in three states of India. Indian Pediatr. 2021;58(4):349–53.
53. Charpak N, Gabriel R-PJ. Resistance to implementing Kangaroo Mother Care in developing countries, and proposed solutions. Acta Paediatr. 2006;95(5):529–34.
54. Vesel L, Bergh AM, Kerber KJ, Valsangkar B, Mazia G, Moxon SG, Blencowe H, Darmstad GL, de Graft J, Dickson KE, Ruiz Pelaez J, von Xylander S, Lawn JE, KMC Research Acceleration Group. Kangaroo Mother Care: a multi-country analysis of health system bottlenecks and potential solutions. BMC Pregnancy Childbirth. 2015;15(Suppl 2):S5.
55. Chan GJ, Labar AS, Wall S, Atun R. Kangaroo Mother Care: a systematic review of barriers and enablers. Bull World Health Organ. 2016;94(2):130–141J.
56. Verma A, Maria A, Pandey RM, Hans C, Verma A, Sherwani F. Family-centered care to complement care of sick newborns: a randomized controlled trial. Indian Pediatr. 2017;54(6):455–9.
57. Hall SL, Phillips R, Hynan MT. Transforming NICU care to provide comprehensive family support. Newborn Infant Nurs Rev. 2016;16(2):69–73.
58. Cox J. Conceptual and treatment approaches for a revitalized health service and renewed Person Centered Perinatal Psychiatry. Int J Pers Cent Med. 2012;1:14–9.
59. Ganjekar S, Thekkethayyil AV, Chandra PS. Perinatal mental health around the world: priorities for research and service development in India. BJPsych Int. 2020;17:2–5.

Chapter 23
Person-centered Pediatrics

W. James Appleyard, Manuel Hernán Izaguirre-Sotomayor, Lucy Gait, and Ian Sinha

23.1 Objectives

Children must be considered as biological, psychological and social beings, in context of the environment where they live. Pediatric care cannot be focused exclusively on the biomedical aspects of disease to achieve this, the pediatrician must attempt to humanize pediatric care by focusing on the care of the person, for the person, by the person and with the person of the child and adolescent [1]. They must collaboratively elaborate the state of a child's health, with its contributing, convergent and triggering factors, and the experiences and expectations of the patient.

Pediatric care must satisfy the child's moral, ethical and scientific foundations, and promote their autonomy, responsibility and dignity [2]. It must be based, jointly, on clinical examination of the disease and the understanding of the patient, and focused on empathic dialogue between the paediatrician, the child and their family. Therefore, according to the patient-centered clinical method, the physician when

---

W. J. Appleyard
Presidency 2013–2017, International College of Person Centered Medicine, New York, NY, USA

Presidency 2003–2004, World Medical Association, Ferney-Voltaire, France

St George's University School of Medicine, Grenada, Grenada

Kent and Canterbury Hospital, Canterbury, UK

M. H. Izaguirre-Sotomayor (✉)
San Fernando Faculty of Medicine, San Marcos National University, Peruvian Association of Person-Centered Medicine, Lima, Peru
e-mail: mizaguirres@unmsm.edu.pe

L. Gait · I. Sinha
Alder Hey Children's Hospital, Liverpool, UK
e-mail: lucy.gait@alderhey.nhs.uk; ian.sinha@alderhey.nhs.uk

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_23

addressing the disease must do so taking into account the complexity of the pediatric patient, considering him or her biologically, psychologically, socially, and spiritually, in order to perceive their needs, desires, and expectations. By integrating their ideas in their health, and promoting self-care, healthy children and adolescents with positive lifestyles will be achieved.

23.2 Approaches

The central axes of paediatric care centered on the person of the child and adolescent, in the family and in the community, are not only the disease that afflicts the child and the adolescent, but also how the patient lives it and how it affects both their value system as well as its environment. The pediatrician must share power, and responsibility, with the child and family. Furthermore, understanding the pediatric patient as a whole improves the doctor-patient relationship, and leads the pediatrician to recognize the family impact. Therefore, the paediatric patient's approach must include family, social, labour, cultural and economic aspects [3]. Consequently, the new approach to paediatrics must be circumscribed around the person of the child and adolescent, the family and the environment, and there must be symbiosis with science and humanism. Ethical training, communication, the appropriate use of technology and scientific evidence must be at the service of the person of the child, the adolescent and the family. Science must be the essential instrument, and humanism the essence, of paediatrics. This is opposed to the reductionist approach that focuses exclusively on the biological, the technological and the genetic—the pediatric patient must be considered as a person, recognizing complexity, autonomy, dignity and rights.

23.3 Body of Knowledge

23.3.1 Respect the Human Rights of Children

Human rights are internationally agreed standards, which apply to all human beings—including children. They encompass civil, cultural, economic, political and social rights of individual persons as set out in the Universal Declaration of Human Rights [2]. Their aim is to safeguard the inherent dignity and equal worth of each person—each right being interdependent, interrelated and indivisible with the others. These 'rights' include the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. "The *right to health* is not to be understood as a *right to be healthy*." Instead, the right to health is expressed as a set of both freedoms and entitlements, which accommodate the individual's biological and social conditions as well as the available resources. Article 25 of the UDHR states that everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection. Unfortunately, children are not always afforded these rights [4].

23.3.2 Convention on the Rights of the Child 1989

The Convention comprises 52 articles—all important and interconnected—of which six fundamentally underline the need for a person-centred approach [5].

Article 1

For the purposes of the present Convention, a child means every human being below the age of 18 years unless under the law applicable to the child, majority is attained earlier.

Article 2

States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.

Article 6

States Parties recognize that every child has the inherent right to life.

States Parties shall ensure to the maximum extent possible the survival and development of the child.

Article 12

States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

Article 23

States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

Article 24

States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

Article 27

States Parties recognize the right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social development.

23.3.3 The Ethics of Paediatric Practice

Within paediatric professional practice, the ethical and legal responsibility to the child and their family obliges the paediatrician with their teams to comply with the international and national legal requirements and deontological regulations of their professional college.

Paediatricians must therefore be guided by the values of autonomy, responsibility and professional competence, in their decision-making. The child is a person with Rights and societies' moral and legal protection, which requires recognizing this moral authority in therapeutic decisions and maintain their commitment to the well-being and best interest of the child patient at all times. Ethic needs to be learnt as part of the development of institutional values within medical academia and health systems [6].

This ethical responsibility to the child patient and with society obliges the paediatrician to maintain updated professional skills to provide quality care, effective, based on scientific evidence, acting in accordance with his moral responsibility, especially in cases of urgency, prioritizing the health and life of the unborn, neonates, children and adolescents, as well as those unable to make decisions for themselves [7].

23.3.4 Sustainable Developmental Goals

The concept of child well-being is rooted in the Convention on the Rights of the Child [5]. The Sustainable Development Goals (SDGs) agreed by the international community in 2015 represent an ambitious effort to set a global agenda for development that is both equitable and sustainable, in social, economic and environmental terms [8]. The earlier Millennium Development Goals (MDGs) prioritized the reduction of poverty, as well as progress in related social indicators. The 17 goals of the SDGs add a wider perspective with outcomes associated with inequality, economic development, the environment and climate change, as well as peace and security.

The stronger focus of the SDGs on equitable development also demands attention to inequalities along multiple dimensions—of income and wealth, health and educational opportunity, as well as voice and political participation—both within and between countries. Addressing rising inequality and its related problems requires a focus not just on the conditions of the poorest, but also on the consequences of wealth accumulation by the richest. As countries seek to meet the SDGs, so the changing political landscape will require new approaches to ensure inclusive and sustainable outcomes [9].

Long-term, inclusive and sustainable social goals are best met through attention to the needs of children. Ensuring the well-being and realizing the rights of all children (including migrants and refugees) is not only a commitment made by those states that have signed the CRC but is also an essential condition for achieving long-term development goals.

23.3.5 The Value of Children

Some insight can be found in a study based in Turkey about 30 years ago on the views of 20,000 **mothers** in nine different countries about the value of their children [10]. Their responses were classified under three headings—utilitarian, social and psychological. The utilitarian group included those who rated the economic and material benefits arising from children both when they are of child age and when they grow up to be their security in old age. The social group valued the general social acceptance that normal adults are given when they have children and their desires for the continuation of the family. The psychological group was those mothers who valued their children for the love, joy, pride and companionship that the fulfilment of the children themselves brought. The children in the 'utilitarian' group who had their children to meet the perceived needs of themselves and their families rather than the needs of the children themselves had the greatest number of children and the highest death rate, whereas those mothers who value their children as individuals in their own right had fewer children and fewer died. It is interesting that those values of love joy and companionship are more part of a person's 'spirit' difficult to measure, usually discounted in health care but actually found to be very important.

23.3.6 The Importance of Early Development

John Bowlby and others found that a child's first relationship, the one with the mother acts as a template that permanently moulds the individual's capacity to enter into all later emotional relationships [11]. The crucial elements are early attunement or essentially what we understood as 'bonding' and the development of empathy [12]. Attunement takes place when the parent and child are emotionally functioning 'in tune' with each other and where the emotional needs of love acceptance and security are met. Without satisfactory early attunement to the primary care giver, the development of empathy can be greatly impaired.

Babies who are healthily attached to their carer can regulate their emotions as they mature because the cortex, which exercises rational thought and control, has developed properly. However, when early conditions result in underdevelopment of the cortex, the child lacks 'an emotional guardian'. Small children look to a parent's facial expressions and other non-verbal signals to determine how to respond and feel in a strange or ambiguous situation.

An example of the long-term effects of impaired early relationships on children's long-term development is the effect of maternal depression on infant development. Relative to control mothers, depressed mothers express less positive and more negative affect, are less attentive and engaged with their infants, and, when engaged, are more intrusive and controlling and fail to respond adaptively to their infants' emotional signals [13].

Their infants have shorter attention spans, less motivation to master tasks, elevated heart rates, elevated cortisol levels, and reduced EEG activity in the right frontal cortex, all of which correlate with the experience of negative affect in adults. Longitudinal data on infants of depressed mothers indicate that elevated heart rates and cortisol can persist and may represent a functional programming of the child's autonomic set point [14].

23.3.7 Empathy

Through empathy the child's emotional needs for love, acceptance and security are met. Empathy entails the ability to step outside oneself emotionally and be able to suppress temporarily one's own (selfish) perspective on events to take another's. It is present when the observed experiences of others come to affect our own thoughts and feeling in a caring fashion. When a parent consistently fails to show any empathy with the child's expression of particular emotions, the child can drop those emotions from his or her repertoire. Because the infant's cortical and hippocampal emotional circuits require significant time and experience to mature, the child must regulate its inner world primarily through attachment relationships with primary caregivers.

The sensitive 'window' for emotional sensitivity and empathy lies within the first 18 months **of life** and these skills are shaped by the primary care giver Children's brains greatest capacity to be change or be rewired is in the first three years [15].

Coleman maintains that empathy builds on self-awareness first and that the more aware children are of their own feelings then more skilled they will be at reading the emotions of others [16].

Children need love and boundaries within which to feel secure. As children develop their cognitive or general thinking skills there is an expectation that they will start to conform to the morals set within the family and wider society. Some insights can be gained from the differing perspectives of three psychological theories [17].

Freud claims that the quality of relationship the child has with his/her parent/s greatly affects the way the child develops morally.

Whereas, the Social Learning theory states that children initially learn how to behave morally through modelling (imitating appropriate adult behaviour).

Cognitive-developmental theories promoted by Piaget and Kohlberg claim that a child's ability to reason morally depend on his/her general thinking abilities.

Coles widens the practical issues building a narrative in which a child is shaped at the very start of life by the values of certain adults. Even before a boy or girl is born, his or her parents are already giving expression to their values that will matter to their son or daughter. A woman tries to think of others, not only of herself, so she watches what she eats and drink and does not smoke not only out of concern for herself but with her future child in mind. A man takes an interest in the woman who is carrying his child offering affection comfort and reassurance. Both parents are concerned for the third person to arrive. This leads up to what Coles describes as a 'golden rule'—a respect for others, a commitment of mind heart and soul to one's family, local community and nation!

Moral intelligence isn't acquired by 'dictate' or by the memorization of rules but as a consequence of learning to be with others and taking to heart what we have seen and heard. The child is a witness of 'grown up morality and looks for clues as to how one ought to behave from parents and teachers making choices, talking to people showing in action our basic assumptions, desires and values and thereby telling these young observers more than is frequently realized. These concepts need to be woven into the support that is given to families in their children's journey from infancy through adolescence. Failure to do so comes at a very heavy price [18, 19].

The cost of intervening when everything has broken down is so much more—by a factor of between 10 and 20 times depending on the study [14].

23.3.8 Longitudinal Studies

The Adverse Childhood Event (ACE) study [20] provides retrospective and prospective analysis of the effect of early traumatic life experience on later wellbeing, social function, health risks, disease burden, healthcare costs, and life expectancy. It was found that there is a strong relationship between ACE Score and self acknowledged chronic depression and later suicide attempts. It appears that depression is common and has deep roots, usually going back to the developmental years of life. The higher the ACE Score the greater the likelihood of later smoking, alcoholism, intravenous drug use, obesity, and high-level promiscuity. The authors of the study conclude that 'all told, it is clear that adverse childhood experiences have a profound, proportionate, and long-lasting effect on well-being,' whether this is measured by depression or suicide attempts, by protective unconscious devices like overeating and even amnesia or by what they refer to as 'self-help attempts', the use of street drugs or alcohol to modulate feelings. The study points to a credible basis for a new paradigm of primary care medical practice and advocate that treatment should begin with a comprehensive biopsychosocial evaluation of all patients. After such an evaluation was administered to 200,000 patients there was a 35% reduction in visits to doctors' offices during the following year.

The work of David Barker and his colleagues pointed to the importance of early life factors in the programming of risk for chronic disease in adults during critical periods [21]. Using historical cohort designs, Barker's group analysed birth weight data and measures of development in the first years of life and found extensive evidence that adult somatic response patterns were programmed in early life. Birth weight, placenta size, and weight gain and growth in the first year of life were found to be associated with cardiovascular disease, diabetes, and hypertension in the fifth and sixth decades.

.

23.3.9 Integrated Support Throughout Childhood

Allen and Duncan Smith have proposed a system of integrated support throughout Childhood based on a 'virtuous 'circle from the experience in the City of Nottingham [3]. A scheme of a Prenatal Package, Post Natal Support, Preschool Sure Start Children's Centres, and Primary School follow on programmes, and at Secondary School ante drug and alcohol and pre-parenting skilling.

Being both socially well-adjusted and employed lead to:

Lower levels of addictive behaviour
Lower like hood of being trapped in poverty and low-quality housing
Greater likelihood of having only the number of children people can parent effectively and afford to support without sliding into dependency
Greater likelihood of people being naturally good parents to their own children and thereby feeding into a positive rather than negative generation cycle [22]

This needs underpinning by a 'spiritual (concepts of love) and moral (what is right or wrong) approach.

In the development of medical care for children all these concepts need to be applied locally at individual and community level starting with the child as a person.

Physician led primary care has important attributes to make such integrated care possible in all health systems. Family practice provides access by unselected health problems. It is comprehensive, coordinated, collaborative and local community orientated with key personal longitudinal support for children and their families [23].

23.4 Practical Implications for Person Centered Practice

23.4.1 Preventive Strategies for the Child

In the development of medical care for children, all these concepts need to be applied locally at individual and community level starting with the child as a person. Primary prevention means reducing the incidence of disorders and diseases, the most effective of which are ensuring adequate nutrition, a comprehensive immunization programme tailored to the local needs, anticipatory guidance of advice and support for parents and children, accident prevention and dental prophylaxis. Secondary prevention aims at reducing the prevalence of disease and poor health by early detection and prompt and effective intervention. Awareness and screening are some of the means through which prevention can be achieved. The first three criteria of Wilson and Junger's 1968 WHO criteria for the evaluation of screening programmes are that there should be a potential health gain and acceptable treatment, or intervention and facilities should be available, the latter raising local issues [24]. Tertiary prevention aims to minimize suffering and reduce impairments and disabilities caused by disease. Many acute and chronic diseases come under this area.

The great advantage on the Integrated Child development Schemes within primary care are that they encompass all three elements of prevention as well as the acute childhood diseases [25]. Schemes need to be grown up from the local community with locally trained lead health workers supported by more specialised paediatric care. Essential nutrition should be covered with a full immunization programme and guidance including family planning. Each individual child is important; each needs their own meticulously kept health record.

23.4.2 Person Centred Paediatric Care

The doctor needs to consider the paediatric patient is a whole integrated into the family and society [6]. This makes it easier to identify and understand their expectations and the setting in which they live, while continuing to consider the spiritual component, especially their faith, and the beliefs and values that are professed within the family. Likewise, when analysing the family life cycle and the patient's response to the disease, such insights serve to shed light on the possible evolution of the problems that are affecting the paediatric patient. The illness of the child and adolescent imbalances the family harmony and can lead to a crisis, in addition to having an impact on the economy, education, employment and family stability.

In addition, it is important that agreements are reached between the patient and/or responsible family member and the pediatrician, especially when establishing goals and treatment priorities for which the patient, if his age and state of health allows, must understand, internalize and participate in its formulation. Also, it is important that the pediatrician assigns roles both for himself and for the patient, if he is in a position to do so, motivating him towards self-care of his health based on the information given by the pediatrician and the previous information stored in his memory, valuing their appreciation, opinion and emotion, as a strategy to achieve an adequate doctor-patient relationship and to understand the patient's suffering, making pediatric medicine more humane by being centered on the patient as a person considering him as a biological, psychological and social being [7].

23.4.3 Prenatal and Postnatal Care Centered on the Person, the Family and the Community

The uniqueness of prenatal and postnatal care is expressed in absolute dependence on the foetus in the womb and the new-born postnatally. The foetus must be considered potentially a human person, whose life and wellbeing needs protecting and valued in the same way as the new-born. with the right to life, to be born and to become a person with all the rights that the law recognizes, without any discrimination.

Therefore, it is imperative to integrate parents, family and community as protagonists of the care of the pregnant mother and the new-born, achieving the humanization of comprehensive prenatal and postnatal care, by reaffirming their dignity, autonomy and life project.

23.4.4 Person-centred Care and Empowerment in Practice

The United Nations Convention on the Rights of the Child (1991) [26] outlined the need to enable children to participate in making decisions across their life, including being part of their health care. Such empowerment has been defined as 'the discovery of one's inherent capacity to be responsible for one's own life' [27]. To become empowered, individuals require sufficient knowledge and understanding to make informed decisions, alongside having the ability and resources to implement their decisions and evaluate the effectiveness of these decisions [28]. Tailoring care and promoting self-management can reduce crises; prevent illness and hospital admissions, thereby reducing costs to the National Health Service (NHS) [29]. Empowerment not only relies on the individual being provided with the opportunity to become involved in decision making about their care but that each individual is considered within their wider social context, including their culture and values; their knowledge; their experience of ill health and the structural barriers that impact on their self-management [30, 31].

Wong et al. [32] proposed the 'TYPE pyramid', with the belief that young people did not necessarily always want to be completely in control and that this did not necessarily mean they did not feel empowered. Thus, within their model, there was an assumption that 'youth driven' is not always ideal or wanted by the young person, with adult control and youth control falling at two ends of a scale, and shared control falling in the middle. Empowering individuals at a younger age will allow them to make more informed health care decisions, to improve their health and overall wellbeing, reduce their reliance on services and thus leading to more effective and appropriate service use later in life [33]. Traditional consultation models in the UK'S NHS tend to be professional led, with the use of directive language with less perceived control from the individual's perspective. This often leads to higher levels of non-adherence [33].

Adolescence is a time of great complexity as young people are transitioning from childhood to adulthood and go through significant physical maturational changes. In terms of their brain development, as the prefrontal lobes mature, adolescents develop executive functions which allow them to move from relying on concrete reasoning skills to being able to apply abstract reasoning skills. Adolescents are striving to develop their identity and autonomy from their parents; seeking to be socially accepted; aiming to achieve and succeed in their endeavours; and beginning to make their own choices. Managing a health condition alongside navigating this challenging landscape can be difficult as it may not always be compatible with their personal or social motivations. Therefore, engaging young people requires the acknowledgement of what is important to them at that time in their life. For young people with physical health problems, treatment related behaviours can also be hard to adopt, often conflicting with current behaviours and priorities of adolescence, as found in diabetic populations [34, 35]. Working alongside adolescents, hearing their opinions and recognising their beliefs and values can enable collaborative and realistic goal setting and health care decisions. Thereby health care appointments can provide an opportunity for professionals to educate young people allowing them to make informed choices and develop their self-efficacy. In this way, professionals can act as advocates for empowerment [36].

23.5 Barriers to Empowerment

Whilst empowering individuals can positively influence care and services more generally, there have been barriers to understanding and implementing the concept in practice ([27, 33, 37]). In terms of understanding the concept it requires the development of a unified definition. In order to implement empowerment in practice requires a paradigm shift at the organisational level as traditional approaches to care are grounded in the models adopted in health care professionals training [38]. Evaluative studies have highlighted that whilst a number of outcome measures have been developed to capture empowerment and change in this, these have appeared to lack in quality [39]. Thus, there is a need for the development of better-quality measures in order to evidence empowerment in health care settings.

23.5.1 Empowerment Interventions

Empowering children has three key components: to enable people to contribute to decisions about their health, self-manage as much as possible without relying on other people, and tailor their condition around their life, with minimum impact on their overall well-being and ambitions.

Cradock and Skinner [40] outlined an empowering consultation in which clinicians promoted acceptance around health, explored feelings, promoted autonomy (i.e. encouraged the individual to be responsible for consultation content), encouraged alliance and working together, and engaged in active participation and listening. Overall, they reinforced the idea of health care professionals working alongside the individual, without making assumptions around what it is they might want. Anderson and Funnell [38] added to this by suggesting an empowering approach should include personally meaningful and realistic goals, with the individual being internally rather than externally motivated. This was suggested in order to ensure the individual makes decisions and choices are important and personal to them, and thus is not responding for the benefit of others.

An empowering approach or young people is said to be when both the medical professional and the parent facilitates the child's participation, with them becoming an active participant during a Clinical Consultation.

23.6 Framework for Paediatric Consultation

Parents bring their children to visit physicians for help with their 'problems' in many settings whether in primary care or in hospital emergency rooms and clinics [41]. A child as a person's story recounted by the child, parent or carer is the key to the physician finding out what may be right and what may be wrong during a consultation with someone who seeks his or her help. A narrative approach encompasses an awareness of health and disease within a storied structure from which the meaning and purpose in both an illness and the experience of recovery emerge. Diagnostic 'labels' become secondary to the life of the person.

During a consultation when a person as a "patient" meets a physician a story is recounted in a complicated narrative of illness told in words, silences gestures and physical observations, overlain not only by the objective findings but also with the fears, hopes and implications associated with it [42]. The narration is a therapeutic central act because to find the words to contain the disorder and its attendant worries gives shape to and control over the uncertainties of the illness. As the physician listen to the child and their parents or carers, he or she follows the narrative thread of the story in all its existential cultural, familial biological social psychological and spiritual dimensions In order to facilitate a constructive dialogue children and their parents have a right to the physician's felicitous Attention, Attitude, Attire and Accurate records

23.6.1 Listening

The act of listening so essential to the process enlists the physician's interior resources—memories, association curiosities creativity interpretive powers and allusions to other stories by the person and others to identify meaning.

Only then can the physician hear and confront the person's narrative questions „what is wrong with me? Why is this happening to me? And what will be the result? [1]

Only through an understanding of how these problems developed within the social and environmental circumstances that impact on the family and following a comprehensive examination of the child can decisions be made about what the matter is, what it is due to and what can be done about it.

It is essential on the one hand to listen the child and his/her parent's or carer's worries in an open way and on the other hand to work within a semi structured framework that allows the identification of the individual problems and any pattern of symptoms and signs can be analysed.

A medical 'problem' is an unresolved clinical issue. It is not a diagnostic label even if a diagnosis may be suggested. It is important to avoid jumping to conclusions about the cause of any symptoms without a full analysis of the facts uncovered while listening to the child's and parent's narrative and following the physical examination.

The concerns of the child and his or her parents need to be recognized, respected and recorded.

Social issues and environmental factors including financial worries, housing, bullying at school or family bereavements may be particular problems that need to be highlighted in a list of problems.

Parents who are anxious about their baby or child may not be able to immediately recall the necessary information in a precise timeline. Their immediate concerns will be uppermost. They may withhold certain sensitive information until trust between the physician is fully established. Time and patience are required. It is essential to differentiate between a factual account of the events and a parent's interpretation of the child's symptoms and signs.

23.6.2 Attention

Children and their parents need to be given confidence as people, greeted by name with eye contact and a friendly smile. There can be fewer more inhibitory postures that that of a physician or another health professional with his or her eyes focused on the computer screen.

Shake hands with the parent and say hello to the child by his or her first name and if possible, gently touch the child's hand as well and acknowledge any other accompanying children.

Sit the parents down to the side of the desk so they are not confronted across the barrier of the desk.

Familiar toys on the top of the desk provide a welcoming sight to the young child and provide something to occupy them.

23.6.3 Attitude

Observe the young child on his parent's or carers lap and listen to the child as well as the parents.

An open, concerned and empathic manner is needed, not one blinkered by any diagnostic label applied by a referring physician or by the parent's immediate interpretation of the child's symptoms.

Parents may have secret fears that their child may have an underlying serious illness.

Mothers are usually right until they are proved wrong. Even the most inexperienced mother will know most about their own child.

The child or parents will not be reassured without an explanation of the clinical findings. If the simplistic reassurance of 'don't worry' is given only the second word 'worry' is likely to be retained by the parents!

23.6.4 Attire

White coats should be avoided if at all possible. They are an unnecessary status symbol and tend to frighten children. They also give little protection against a well-directed stream of urine during an examination of a baby!

23.6.5 Accurate Records

The essential data set needs to be recorded in an orderly way—a special proforma is helpful as it enables background information to be found quickly in the medical records. But such information should be acquired during the consultation by allowing the parents first to talk freely about their child's problems and their own anxieties. Direct questions about background data should be asked later.

Children from the age of 4 or 5 may also answer some points of detail and when they are a little older, they may be able to give more of the history. Older children should be offered to be seen on their own with a nurse for a few minutes to increase their self confidence.

23.6.6 Profile

Each child as a person has a range of physical, psychological, mental, emotional, social, cultural and spiritual needs.

During the clinical encounter(s) information should be sought about the child's general health status. Any illnesses, disorders and disabilities and their burden on the child and the family and their experience of illness and suffering as well as their understanding and meaning of illness, what biological, social and psychological factors have contributed to the illness. How the child and family normally feel with regard to their well-being, contentment and fulfilment and the intrinsic and extrinsic biological psychological and social contributors to their health [43].

From the information obtained, a profile of the child and the family should be constructed, and a list of problems identified.

An active medical 'problem' is an unresolved clinical issue. It should not be used as a diagnostic 'label' even if a specific diagnosis may be suggested.

These problems then need to be drawn together as a summary 'diagnoses' starting with the age and identity of the child as a person, the key findings and a shared decision plan of action.

23.7 Barriers to a Change Towards a Fully Person-centred Service

Children are valued more for their social and utilitarian worth rather than loved as individual persons in their own right.

Children's services are afforded a lower priority in public services in resource allocation as compared to adults.

Reductionist Health system culture putting population targets a higher priority than personal services.

Lack of understanding of the importance of the individual growth, development and maturation of children in the life cycle.

The Opinion that the implementation of a person centered approach would need more time and be more expensive than current system.

The perception that current practice already includes the concept.

23.8 Conclusions

Improving the well-being of all children is essential for achieving both equity and sustainability. Reducing the gaps in material well-being, health and education among children today enable a reduction in inequalities in adult life and contribute to the well-being of future generations of children.

There is need to foster common professional values, respect for the Human Rights of Children and develop a shared person-centred vision for the future child health services.

The integration of perspectives and services is crucial for all aspects of health and well-being, whether they are economic, physical, mental, social, intellectual, or spiritual as they are all highly intertwined with one another as complex adaptive systems.

Science must be the basic instrument and humanism the essence of both paediatrics and perinatology as opposed to the contemporary paternalistic and reductionist approach that focuses exclusively on the biological and genetic, by not fully including family, social, employment, cultural, environmental and economic aspects.

Listening to a child's story recounted by their parent[s] and by themselves is the key to the physician finding out what matters during a consultation. The narrative encompasses an awareness of health and disease from which the meaning and purpose in both an illness and the experience of recovery emerge.

Engaging young people requires the acknowledgement of what is important to them at that time in their life. Working alongside adolescents, hearing their opinions and recognising their beliefs and values can enable collaborative and realistic goal setting and health care decisions.

Acknowledgments and Disclosures The authors do not report any conflicts of interest concerning the preparation of this paper.

References

1. Appleyard WJ. A personal approach to person centered paediatric care. J Eval Clin Pract. 2011;17(2):376–8.
2. Appleyard WJ. The rights of children to healthcare. J Med Ethics. 1998;24(5):292–3.
3. Allen G, Smith ID. Early intervention—good parents, great kids, better citizens. London: The Centre for Social Justice; Smith Institute; 2008.
4. United Nations Children's Fund. The state of the world's children. New York: UNICEF; 2009.
5. UN General Assembly. Convention on the Rights of the Child 1989, A/RES/44/25.
6. Izaguirre M. Importancia de la formación ética de los estudiantes de medicina. An Fac Med. 2019;80(4):507–10.
7. Izaguirre M, Vera M, Podestá L, Córdova D. Actitud hacia la ética profesional en estudiantes de postgrado de medicina. An Fac Med. 2020;81(1):52–7. https://doi.org/10.15381/anales.v81i1.16972.
8. Sachs JD. From millennium development goals to sustainable development goals. Lancet. 2012;379(9832):2206–11.
9. Cloninger CR, et al. A time for action on health inequities: foundations of the 2014 Geneva Declaration on Person- and People-centered Integrated Health Care for All. Int J Pers Cent Med. 2014;4:69–89.
10. Kagitcibasi C. The value of children: a key to gender issues. Int Child Health. 1998;9(1):15–24.
11. Bowlby J. Attachment and loss. London: Hogarth Press; 1969.
12. Shore R. Rethinking the brain—new insights into early development. New York: Families and Work Institute; 1997.
13. Department of Health, UK. Children and young people in mind: the final report of the National CAMHS Review. London: UK Department of Health; 2008.
14. Carlson M, Earls F. Psychological and neuroendocrinological sequelae of early social deprivation in institutionalized children in Romania. Ann N Y Acad Sci. 1997;807:410–28.

15. Crittenden PM. Raising parents: attachment, parenting and child safety. Abingdon: Taylor & Francis; 2011.
16. Coleman D. Emotional Intelligence. New York: Bantam Books; 1998.
17. Coles R. The moral intelligence of children. London: Bloomsbury; 1997.
18. Greenough WT, Black JE, Wallace CS. Experience and brain development. Child Dev. 1987;50(3):539–5.
19. Hall MB. Health for all children. 3rd ed. Oxford; 1996.
20. Felitti V, Anda RF. The relationship of adverse childhood experiences to adult health, wellbeing, social function and healthcare. In: Lanius R, Vermetten E, editors. The hidden epidemic: the impact of early life trauma on health and disease. Cambridge: Cambridge University Press; 2008.
21. Barker DJP. Mothers, babies, and health in later life. Edinburgh: Churchill Livingstone; 1998.
22. Cunha F, Heckman JJ, Lochner L, Masterov DV. Interpreting the evidence of life cycle skill formation. NBER Working Paper. Cambridge: National Bureau of Economic Research; 2005.
23. Improving health systems: the contribution of family medicine. World Organization of Family Doctors 2000.
24. Wilson JMG, Jungner G. Principles and practice of screening for disease. Geneva: World Health Organization; 1968.
25. WHO. Integrated management of childhood illness. Geneva: World Health Organization; 2018. Available from: http://www.who.int/child_adolescent_health/topics/prevention_care/child/imci/en/index.html.
26. United Nations Convention on the Rights of the Child (1991); https://www.unicef.org.au/united-nations-convention-on-the-rights-of-the-child.
27. Bravo P, Edwards A, Barr PJ, Scholl I, Elwyn G, McAllister M. Conceptualising patient empowerment: a mixed methods study. BMC Health Serv Res. 2015;15(1):252.
28. Funnell MM, Anderson RM, Arnold MS, Barr PA, Donnelly M, Johnson PD, Taylor-Moon D, White NH. Empowerment: an idea whose time has come in diabetes education. Diabetes Educ. 1991;17(1):37–41.
29. Kings Fund (2012) King's Fund - Leadership and engagement for improvement in the ...; https://www.kingsfund.org.uk/sites/default/files/field/field.
30. Lawn S, McMillan J, Pulvirenti M. Chronic condition self-management: expectations of responsibility. Patient Educ Couns. 2011;84(2):e5–8.
31. Morsy M, Abd Al Moniem II. Diabetes self-management education to empower adolescents with Type I Diabetes. Am J Nurs Sci. 2011.
32. Wong NT, Zimmerman MA, Parker EA. A typology of youth participation and empowerment for child and adolescent health promotion. Am J Community Psychol. 2010;46(1-2):100–14.
33. McAllister M, Dunn G, Payne K, Davies L, Todd C. Patient empowerment: the need to consider it as a measurable patient-reported outcome for chronic conditions. BMC Health Serv Res. 2012;12(1):157. https://doi.org/10.1186/1472-6963-12-157. PMID: 22694747; PMCID: PMC3457855.
34. Aujoulat I, d'Hoore W, Deccache A. Patient empowerment in theory and practice: polysemy or cacophony? Patient Educ Couns. 2007;66(1):13–20.
35. Thompson SC, Schlehofer MM. Perceived control. In: Gerrard M, McCaul KD, editors. Health behavior constructs: theory, measurement, and research. National Cancer Institute; 2007. Available from: http://cancercontrol.cancer.gov/constructs.
36. Hennessy-Harstad EB. Empowering adolescent with asthma to take control through adaptation. J Pediatr Health Care. 1999;13(6):273–7.
37. Anderson, B. and Funnell, MM (2005) The art of empowerment: stories and strategies for diabetes educators. American Diabetes Association, Alexandria. https://www.scirp.org/reference/referencespapers.aspx?referenceid=1693792.
38. Anderson RM, Funnell MM. Patient empowerment: myths and misconceptions. Patient Educ Couns. 2010;79(3):277–82.
39. Herbert RJ, Gagnon AJ, Rennick JE, O'Loughlin JL. A systematic review of questionnaires measuring health-related empowerment. Res Theory Nurs Pract. 2009;23(2):107–32.

40. Craddock S, Skinner T. Empowerment: what about the evidence. Pract Diabet. 2000;17:91–5.
41. Appleyard WJ, Shurz AM. A paediatric handbook. Kigezi International School of Medicine; 2003.
42. Cloninger CR, Salloum IM, Mezzich JE. The dynamic origins of positive health and wellbeing. Int J Pers Cent Med. 2012;2:1–9.
43. Cloninger CR, Zohar AH. Personality and the perception of health and happiness. J Affect Disord. 2011;128(1-2):24–32. https://doi.org/10.1016/j.jad.2010.06.012. Epub 2010 Jun 26. PMID: 20580435.

Chapter 24
Person-centered Geriatric Medicine

Jon Snaedal and Mariarí Uzcátegui

24.1 Historical Account

There are many solitary accounts of treatment and care in old age in many parts of the world before 1900 but the Austrian Ignatz L. Nascher coined the term "geriatrics" in 1909 [1]. The origin of systematic geriatric medicine is however attributed to Marjory Warren in UK in 1936 [2]. In the mid thirties, she worked at old workhouse wards in Middlesex, an area that now is almost entirely within greater London. She started to systematically review cases of the several hundred inmates, many of them old and infirm and matched care to their needs. This was done systematically through a classification system Dr. Warren was able to discharge many of them through rehabilitation and by providing necessary assistance [2] and her work was duly person centered. She advocated for creation of a medical specialty of geriatrics with special units in general hospitals and for teaching medical students about care for elderly people [3].

The National Health Service (NHS) in United Kingdom was established in 1948 and very soon afterwards, the first consultant in geriatric medicine was appointed. In the early years, geriatricians worked primarily in rehabilitation units (geriatric rehabilitation) but soon they realized that many of the patients admitted to these wards for a prolonged rehabilitation had not received proper medical treatment before being admitted. Subsequently, geriatricians started to move their field closer to acute wards, creating true geriatric medicine [2]. In United States, the vision of

---

J. Snaedal (✉)
Presidency 2017–2021, International College of Person Centered Medicine,
New York, NY, USA

Landspitali University Hospital, Reykjavík, Iceland

Presidency 2007–2008, World Medical Association, Ferney-Voltaire, France
e-mail: jsn@mmedia.is

M. Uzcátegui
El Cedral Clinic, Caracas, Venezuela

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_24

geriatric medicine evolved slower but after the establishment of the National Institute of Ageing in 1974, research and care accelerated significantly [4]. As there is no real national health service in US (with exception of the veterans system), the geriatric medical service is more fragmented than in UK. Primary care physicians provide the bulk of medical care for the elderly in US and geriatricians are mainly stationed in hospital settings [4]. In Sweden, the University of Gothenburg was very early in epidemiology studies on the elderly population with the H70 study starting in 1971, ongoing for three decades. Many cohorts were studies intensively, the first one on twelve occasions, the last one when participants had reached the age of 100. Valuable information on normal and abnormal physical and cognitive health was collected as well as providing evidence of differences in health between age cohorts, the younger cohorts being healthier than the older at the same age [5].

In the first decades of geriatric medicine, the main challenges can be described by the concept of the “geriatric giants”, coined by Bernhard Isaacs in 1965: Instability, Immobility, Incontinence and Impaired cognition [6]. Very soon a fifth geriatric giant was added, Iatrogenesis, as it was realized that many of the problems experienced by the elderly were unintentionally caused by therapeutic intervention or suboptimal care. During the subsequent fifty years, geriatrics has developed, and today, the understanding of the modern “geriatric giants” has evolved to encompass three additional syndromes of Frailty, Sarcopenia and Anorexia. These conditions are causing many of the acute conditions in old age such as falls, fractures and delirium [6] described in more detail in the following sections.

24.2 Person Centered Medicine in the Elderly

The main purpose of Person Centered Medicine is to promote the medicine *of* the person, *for* the person, *by* the person and *with* the person [7]. As will be discussed in this chapter, this theoretical framework has in reality been the fundament of geriatric medicine from its origin, both in comprehensive geriatric assessment, which is the basis for in-hospital geriatric medicine, as well as in its specific sub-sections such as in dementia [8]. The concept of person centeredness has however not been very prominent in the literature, but recently, a literature review on person centered medicine for older adults with chronic conditions and functional impairment has been published [9]. A method for systematic evaluation of person centeredness has recently been developed [10]. The following key concepts underlying person centered medicine were elucidated: (1) Ethical Commitment, (2) Cultural Sensitivity, (3) Holistic scope, (4) Relational Focus, (5) Individualized Care, (6) Common Ground for Collaborative Diagnosis and Care, (7) People-centered Systems of Care, and (8) Person-centered Education and Research. This method has been used in several fields but primarily in psychiatry but recently, the method has been evaluated in medical service for older people [11]. It showed particular relevance of four of these concepts in the conceptual profile of elderly centered medicine; ethical commitment, holistic scope, relational focus, and person-centered health education and research.

24.3 Comprehensive Geriatric Assessment

Comprehensive geriatric assessment (CGA) is at the core of Geriatric Medicine In 1987; Epstein et al. highlighted the concept as an important procedure to improve the health of the geriatric population [12]. During that decade, several different projects on the benefit of CGA were published and in 1993, Stuck et al. published a much cited meta analysis of CGA showing the usefulness of not only the procedure but also of the benefit of special wards implementing CGA as its main tool [13]. This is now a widely accepted procedure exemplified with a recent Cochrane review [14]. The authors found 29 relevant trials from nine countries that recruited 13,766 people. These studies compared CGA with routine care for patients over 65 years of age who were admitted to hospital. Most trials thus evaluated CGA provided in a specialised hospital ward or across several wards by a mobile team. The review shows that older people who receive CGA rather than routine medical care after admission to hospital are more likely to be living at home and are less likely to be admitted to a nursing home at up to a year after hospital admission [14]. The importance of CGA is increasing as older people are the majority of users of health and adult social care services internationally and the proportion of the elderly in the population is increasing [15]. All tools that increase the likelihood of the elderly to recuperate from disease and to be able to live an independent living are therefore of great importance.

But what are the ingredients of CGA and how does it relate to person centered medicine? When looking at the whole picture, individual differences generally increase with age. Social difference through life, life styles and struggles of life in general make their mark on each individual in addition to physical and psychological age related changes. Multi morbidity and polypharmacy amongst the elderly complicate the clinical picture. Add to that a weaker social structure of the individual and we have the typical geriatric patient. It was shown early on that in order to succeed in helping the old patient to better health and to independent living, all the aspects had to be taken into account. It is not enough to treat heart failure in an old patient in the emergency room when arthritis and poor musculature hampers mobility, cognition is impaired and social support is lacking. The approach of CGA must therefore be holistic and include not only individual assessment but also interventions that are based on the holistic assessment. The physical and psychological symptoms as well as social situation are evaluated but for success, the possible strengths and aspiration of the person must be taken into account as these forms the most important basis for the therapeutic plan. This is obviously not a task for one profession and therefore, the geriatric assessment differs from a typical medical evaluation by including nonmedical domains; by emphasizing functional capacity and quality of life; and, often, by incorporating a multidisciplinary team including a physician, a nurse, nutritionist, social worker, and physical and occupational therapists [16].

Geriatric medicine has evolved not only by increasing the number of geriatric giants [6] but also by a more focused approach to different problems. By this, geriatric medicine is stretching the boarders towards other specialties; in early days towards rehabilitation medicine, later towards internal medicine and its many subspecialties and in the last decades towards psychiatry and neurology in dementia treatment and care. Classically, specialists work in silos such as in a specialist clinic with one specialty dominating. This is changing as multi-specialised clinics, not least in ambulatory work involves many specialties as well as non-medical professions. Geriatrician thus work alongside different specialists based on the field in question and geriatric medicine has therefore become more sub-specialized and intertwined with other professions.

The common theme in all of this work is person centeredness as problems in old age, medical conditions involved tend to be complicated and need to be addressed in a comprehensive, holistic way. In the coming sections, different sub-sections of geriatric medicine will be discussed.

24.4 Falls and Fractures

Mobility problems in old age such as poor balance and weak musculature in addition to osteoporosis are the main causes for the increasing number of fractures. To combat this, special sections have been established, either inside geriatric services, or in collaboration with other specialties with input from geriatricians, mainly in hospital settings. These services mirror the path of the problem, as some of them are primarily intended for prevention such as ambulatory clinics for osteoporosis and/or special falls and fracture clinics but others are aiming at medical attention and rehabilitation following a fracture. Clinics aiming at osteoporosis are often run by endocrinologists but are typically multi professional. This can be exemplified by the Johns Hopkins Metabolic Bone and Osteoporosis Center that is providing multiprofessional care as the team includes endocrinologists, geriatricians, orthopaedists, neurosurgeons, nutritionists, physical therapists, occupational therapists and physical medicine and rehabilitation physicians (www.hopkinsmedicine.org/metabolic_bone_center/). Comprehensive, holistic work in falls clinics have been advocated [17] and a recent publication from Australia using this approach, showed that multidisciplinary falls and fracture clinic can provide substantial reductions in falls and fractures for high-risk older people, even over a relatively short 6-month time period [18]. In addition of being holistic and person centered this work also makes use of different technical measures for evaluation of osteoporosis and balance problems with many medical and non-medical professions working together.

At the other end of the spectrum, when a fall has occurred leading to a fracture, typically on the hip, in-patient ortho-geriatric clinics have been established where the philosophy of comprehensive geriatric assessment are used [19]. This approach needs close cooperation between the orthopaedic surgeon and his team and the geriatric team. For optimal outcome, different requirements are suggested [20]. One of them is to keep the waiting time for surgery short and another is to start rehabilitation as soon as possible but primarily, the holistic, person centered approach is a key to success. A carefully conducted trial on CGA in these patients was published in Lancet in 2015 [21] showing that this approach was superior to the conventional post-surgery treatment generally used.

24.5 Sarcopenia and Frailty

These related problems occur typically among the oldest (>80 years) but as this aged population is increasing more rapidly than any other, frailty and sarcopenia is gaining increased interest.

Sarcopenia is a syndrome characterized by progressive and generalized loss of skeletal muscle mass and strength and it is strictly correlated with physical disability, poor quality of life and death [22]. Although it is primarily a disease of the elderly, it may be associated with conditions in younger adults. This is quite a new concept as it was proposed in 1989 [23]. The term is coming from the Greek words ‘sarx’ meaning “flesh” and ‘penia’ meaning “poverty”, to describe decreasing muscle mass. As there are many conditions leading to sarcopenia, not only medical but also psychological and social, a comprehensive approach is needed to address the problem. Typically, a patient with sarcopenia is lean almost to the extreme but it has been acknowledged that this may also be associated with increased body fat so that despite normal weight there is marked weakness; a condition called sarcopenic obesity [22]. Depending on some difference in definition for sarcopenia in the literature, the prevalence in 60–70-year-olds is reported as 5–13%, while the prevalence ranges from 11 to 50% in people >80 years. Because of these high proportions in the elderly fulfilling the criteria of sarcopenia, the condition has been the focus of the World Health Organization and is included in its work on ageing and life course [24]. In 2010, the European Geriatric Medicine Society along with other associations published a paper from a working group on a consensus on definition and diagnosis [25]). Sarcopenia has been seen by many as an integral part of the ageing process in the old but there are however some treatment possibilities [26, 27]. Those must be based on a holistic, person centered approach due to the complicated causes.

Frailty has many synonyms in English such as infirmity, debility, fragility and weakness and is more or less considered to be a condition of old age [28]. In an attempt to define frailty as a syndrome of the aged, the frail elderly person was considered as those in whom the assets maintaining health and the deficits threatening health are in precarious balance. In practical terms this definition includes those who depend on others for the activities of daily living or who are at high risk of becoming dependent [29]. This is thus a definition based on functional ability while many consider this in more biological terms as synonym with biological ageing in contrast to chronological ageing [29]. Frailty is a common clinical syndrome in older adults and carries an increased risk for poor health outcomes including falls, incident disability, hospitalization, and mortality [28]. Sarcopenia and frailty are not synonyms but have many things in common. Frailty is more closely linked to the ageing process but for the same reasons as for sarcopenia, frailty has gained increased attention as shown in a recent article published in Lancet [30]. In its summary it is stated “Frailty is an emerging global health burden, with major implications for clinical practice and public health. The prevalence of frailty is expected to rise alongside rapid growth in the ageing population.” In a systematic review and meta-analysis a consistent inverse association between frailty/prefrailty and quality of life among community-dwelling older people was demonstrated [31]. In this work, the term pre-frailty is used to describe a condition that is leading to full blown frailty as it is defined if no intervention is implemented. Another important lesson is that frailty is compromising quality of life among our oldest population and for that, there is an urgent need for effective interventions [31]. As for the closely related syndrome of sarcopenia, assessment and intervention needs to be person centered as the reasons for these conditions are complex.

24.6 Delirium and Dementia

These related but different concepts were among the first “geriatric giants” according to the terminology in the earliest years of geriatric medicine and are found under the original umbrella term of “Impaired cognition” [6].

Delirium is primarily a medical problem, most often arising in an unfamiliar environment with different external and internal influences such as in patients in a post-op state in an intensive care unit. Delirium is a common and serious acute neuropsychiatric syndrome, primarily in the elderly, with core features of inattention and global cognitive dysfunction [32]. Even though primarily a medical condition, the success of recovery is based on a comprehensive approach to the problem by addressing not only the medical status per se but also the environmental factors enhancing the state. During the recovery phase, other and broader approaches are needed based on information from family members on how the cognitive status was before the acute episode as delirium can be superimposed on dementia. For successful outcome, the concepts of CGA need to be used [12, 32] focusing on the whole of the person as in proper person centered medicine.

Dementia on the other hand is a condition that is slow in progression in contrast to the acute development of delirium. The global extent of dementia is already huge but is nevertheless estimated to double until 2050 when around 115 million people are estimated to live with dementia in the world. Almost two-thirds are living in low and middle-income countries where the increase will also become biggest [33]. As this is the only top ten killer in the world with no effective prevention, treatment or cure, the extent of the problem will rise immensely [34].

The current, recently updated version of the international classification of diseases from WHO (ICD-11) describes dementia in this way: “Dementia is an acquired brain syndrome characterized by a decline from a previous level of cognitive functioning with impairment in two or more cognitive domains (such as memory, executive functions, attention, language, social cognition and judgment, psychomotor speed, visuoperceptual or visuospatial abilities). The cognitive impairment is not entirely attributable to normal aging and significantly interferes with independence in the person's performance of activities of daily living" [35]. This updated diagnostic definition has not been accepted quietly and has been criticised from different angles [36]. The field of dementia is situated at the boarder of three different medical specialties; psychiatry, neurology and geriatric medicine. This can be clearly seen by the fact that the service for dementia is provided in all three specialties depending on traditions of a particular region. However, the fourth discipline of primary health care is in fact responsible for the greatest part of the service, a fact quite often overlooked. It can be argued that the holistic approach as seen in geriatric medicine (and in general practice) is best suited for dementia work-up, treatment and service as dementia is truly imposing threats to the person in question and must be approached in a comprehensive and holistic manner. Therefore, the person centered approach in dementia treatment and care has been adopted by all the specialties and therefore the difference in treatment and thus service is less based on the profession providing for the service.

Dementia service has adopted person centered approach as a specific ideology to greater extent than in most other types of medical services. Three decades ago, Professor Tom Kitwood used the term "person-centred approach" in relation to long-term care for people living with dementia [37, 38] and in several publications, he laid the ground for a psychosocial approach to dementia in contrast to the medical approach that is focusing primarily on symptom relief. These ideas were brought together in his influential book; "Dementia reconsidered: the person comes first" [39]. His pioneer work has had immense influence in dementia care but in different ways based on the context and the interpretation of the concepts, which differs across regions and countries. The most direct product of this work is the observational tool of "Dementia Care Mapping" that has been used in formal dementia care settings [40]. The basis for this and other types of person centred approaches is portrayed in the concept of "personhood" defined by prof. Kitwood as "A standing or status that is bestowed upon one human being by others, in the context of relationship and social being. It implies recognition, respect and trust" [38]. Person centred approach in dementia has not only had influence in different health care settings but also on regional and national guidelines exemplified by the Swedish National Board of Health and Welfare first guidelines for care of individuals with a dementia disorder [41]. The influence on this type of dementia care in Sweden was subsequently evaluated and showed significantly higher scores on person-centeredness of care at follow up 12 months later and the facilities were rated as being more hospitable [42]. For further details on person centred care for people with dementia, the reader is directed to Chapter 23 on Dementia, in the book on Person Centered Psychiatry [43].

24.7 Practical Implications for Person Centered Care

24.7.1 *Key Factors for the Implementation of Person-centered Care in Geriatric Medicine*

The eight principles of Person Centered Medicine [10] are relevant for this implementation, and among them four appear particularly important for geriatric medicine [11]: (1) Respect for the person's dignity, (2) Consideration of a biological, psychological, socio-cultural, ecologic, and spiritual framework for understanding and care, (3) Communication and empathy among health professionals, patient, and family, and (4) Educational engagement of the family and social context.

24.7.2 *To What Extent Is Geriatric Medicine Currently Centered on the Person?*

One could say that Geriatric Medicine is in practice only moderately centered on the person, despite the lofty ideals at the beginning of this clinical field. Spaces for older adults are still limited. Also limited is the development and use of relevant clinical instruments. Attention to critical events in older people such as falls and common ailments has much room for improvement.

24.7.3 *Current Obstacles in Geriatric Medicine for the Implementation of Person-centered Care*

The increasing pressure for cost containment by health authorities and individual health institutions is a major obstacle for implementation of person-centered care. This development is exemplified by the introduction of Lean production processes into health care but developed in industry [44]. In fact, by 2011, nine out of ten of Swedish hospitals had introduced lean production strategies in their service [45]. Health care service thereby becomes increasingly non-person centered and overall, in service for older people this development can be described by the following: (1) Little time in health services for the adequate evaluation and care of older patients, (2) Growing technical and laboratory complexity in medical geriatric practice, (3) Increased focus on processes rather than recipients of care, (4) Currently limited humanistic education of health professionals, (5) Limited educational efforts with carers and family members, (6) Limitations in transportation for the access of older persons to health clinics, (7) Limited familiarity of health professionals with the housing and community circumstances of their patients.

24.7.4 *Changes Necessary to Make the Practice of Geriatric Medicine More Person-centered*

In order to facilitate desirable changes for person-centered care, one should consider the following: (1) More effective person-centered medical education for medical students, residents and in continuing medical education, (2) Using more comprehensive, contextualized and person-centered evaluation instruments, (3) Ensure that health services accord more time to health professionals to care for their patients in a personalized manner, (4) Develop caring training programs for family and caregivers, (5) Attend to the mental health and personal needs of family and caregivers, and (6) Promote familiarization visits of health professionals to their patients' homes and communities.

24.8 Conclusions

Geriatric medicine evolved later than many other major medical specialties but has developed into becoming sub-specialized. From its origin, person centered approach has been the "holy grail" of the profession and this has been systemized into concepts such as "Comprehensive Geriatric Assessment" that is a truly person centered approach as it involves not only assessment as the naming suggests but also intervention and support. For this, teamwork with involvement of both medical and non-medical professions is the main tool. As geriatric medicine has been stretching its boundaries towards other medical specialties, it can be argued that the specialty has "exported" these person centered approaches to other disciplines.

Acknowledgement and Disclosure The authors do not report any conflicts of interest concerning the preparation of this paper.

References

1. Nascher IL. Geriatrics. N Y Med J. 1909;90:358.
2. Grimley Evans J. Geriatric medicine; a brief history. Br Med J. 1997;315:1075–7.
3. Warren MW. Care of the chronic aged sick. Lancet. 1946;1(6406):841–3.
4. Beck JC, Vivell S. Development of geriatric medicine in the United States (Chapter 5). In: Kassel CK, et al., editors. Geriatric medicine. New York: Springer; 1984. p. 59–81.
5. Steen B, Djurfeldt H. The gerontological and geriatric population studies in Gothenburg, Sweden. Z Gerontol. 1993;26(3):163–9.
6. Morley JE. The new geriatric giants. Clin Geriatr Med. 2017;33(3):xi–xii.
7. Mezzich JE. Psychiatry for the person: articulating medicine's science and humanism. World Psychiatry. 2007;6:65–7.

8. Snaedal J. Person centred medicine for the old patients, with specific reference to the person with dementia. Int J Pers Cent Med. 2011;1:53–5.
9. Kogan AC, Wilber K, Mosqueda L. Person-centered care for older adults with chronic conditions and functional impairment: a systematic literature review. J Am Geriatr Soc. 2016;24:e1–7.
10. Mezzich JE, Kirisci L, Salloum IM, Trivedi JK, Kar SK, Adams N, Wallcraft J. Systematic conceptualization of person centered medicine and development and validation of a person-centered care index. Int J Pers Cent Med. 2016;6:219–47.
11. Uzcategui-Martinez M. Conceptual profile of elderly centered medicine within the general framework of Person Centered Medicine. Paper presented at the International Seminar on Person Centered Medicine, Lima, Peru on June 6–7, 2019.
12. Epstein AM, Hall JA, Bestine R, et al. The emergence of geriatric assessment units: the “new technology of geriatrics”. Ann Intern Med. 1987;106:299–303.
13. Stuck AE, Siu AL, Wieland GD, Adams J, Rubinstein LZ. Comprehensive geriatric assessment; a meta-analysis of controlled trials. Lancet. 1993;342:1032–6.
14. Ellis G, Gardner M, Tsiachristas A, Langhorne P, Burke O, Harwood RH, Conroy SP, Kircher T, Somme D, Saltvedt I, Wald H, O’Neill D, Robinson D, Shepperd S. Comprehensive geriatric assessment for older adults admitted to hospital. Cochrane Database Syst Rev. 2017;9(9):CD006211.
15. Turner G, Clegg A. Best practice guidelines for the management of frailty: a British Geriatrics Society, Age UK and Royal College of General Practitioners report. Age Ageing. 2014;43(6):744–7.
16. Bassem E, Higgins KE. The geriatric assessment. Am Fam Physician. 2011;83:48–56.
17. Hill KD, Moore KJ, Dorevitch, and M.I., et al. Effectiveness of falls clinics: an evaluation of outcomes and client adherence to recommended interventions. J Am Geriatr Soc. 2008;56:600–8.
18. Gomez F, Lucia-Curcio CL, Brennan-Olsen SL, Boersma D, Phu S, Vogrin S, Suriyaarachchi P, Duque G. Effects of the falls and fractures clinic as an integrated multidisciplinary model of care in Australia: a pre–post study. BMJ Open. 2019;9:e027013. https://doi.org/10.1136/bmjopen-2018-027013.
19. Sabharwal S, Wilson H. Orthogeriatrics in the management of frail older patients with a fragility fracture. Osteoporos Int. 2015;10:2387–99.
20. British Orthopaedic Association. The care of patients with fragility fractures. London: British Orthopaedic Association; 2007.
21. Prestmo A, Hagen G, Helbostad JL, Thingstad P, Taraldsen K, et al. Comprehensive geriatric care for patients with hip fractures: a prospective, randomized controlled trial. Lancet. 2015;385:1623–33.
22. Santilli V, Bernetti A, Mangone M, Paoloni M. Clinical definition of sarcopenia. Clin Cases Miner Bone Metab. 2014;11(3):177–80.
23. Rosenberg I. Summary comments: epidemiological and methodological problems in determining nutritional status of older persons. Am J Clin Nutr. 1989;50:1231–3.
24. WHO. Ageing and life course. Geneva: World Health Organization; 2009. [cited 2009 April 30]; Available from: http://www.who.int/ageing/en/
25. Cruz-Jentoft AJ, Baeyens JP, Bauer JM, Boirie Y, Cederholm T, Landi F, Martin FC, Michel J-P, Rolland Y, Schneider SM, et al. Sarcopenia: European consensus on definition and diagnosis: Report of the European Working Group on Sarcopenia in Older People. Age Ageing. 2010;39(4):412–23.
26. Malafarinaa V, Úriz-Otanoa F, Iniesta R, Gil-Guerreroc L. Review of sarcopenia in the elderly: diagnosis, physiopathology and treatment. Maturitas. 2012;71:109–14.
27. Morley JE. Sarcopenia: diagnosis and treatment. J Nutr Health Aging. 2008;12:452–6.
28. Xue Q-L. The frailty syndrome: definition and natural history. Clin Geriatr Med. 2011;27(1):1–15.

29. Rockwood K, Stolee P, Robertson D, Beattie BL. Frailty in elderly people: an evolving concept. Can Med Assoc J. 1994;150(4):489–95.
30. Hoogendijk EO, Afilalo J, Ensrud KE, Kowal P, Onder G, Fried LP. Frailty: implications for clinical practice and public health. Lancet. 2019;394:1365–75.
31. Kojima G, Lliffe S, Jivraj S, Walters K. Association between frailty and quality of life among community-dwelling older people: a systematic review and meta-analysis. J Epidemiol Community Health. 2016;70(7):716–21.
32. Fong TG, Tulebaev SR, Inouye SK. Delirium in elderly adults: diagnosis, prevention and treatment. Nat Rev Neurol. 2009;5(4):210–20.
33. Prince MJ, Wimo A, Guerchet MM, Ali GC, Wu Y-T, Prina M. World Alzheimer Report 2015—The global impact of dementia: an analysis of prevalence, incidence, cost and trends. London: Alzheimer's Disease International; 2015. Available from: www.alz.co.uk/research/world-report-2015
34. GBD 2016 Dementia Collaborators. Global, regional and national burden of Alzheimer's disease and other dementias 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. Lancet Neurol. 2018;18:88–106.
35. WHO. ICD-11 Beta draft (mortality and morbidity statistics). Geneva: World Health Organization; 2017.
36. Sathyanarayana TS, Jacob KS, Shaji KS, Raju MSVK, Bhide AV, Rao GPS, G and Jagiwala, M. Dementia and the International classification of diseases-11 (beta version). Editorial. Indian J Psychiatry. 2017;59(1):1–2.
37. Kitwood T. The technical, the personal and the framing of dementia. Soc Behav. 1988;3:161–79.
38. Kitwood T. Person and process in dementia. Int J Geriatr Psychiatry. 1993;8:541–5.
39. Kitwood T. Dementia reconsidered: the person comes first. Buckingham Open University Press; 1997.
40. Brooker D. Dementia care mapping: a review of the research literature. Gerontologist. 2005;45:11–8.
41. The Swedish National Board of Health and Welfare. Nationella riktlinjer för vård och omsorg vid demenssjukdom 2010: stöd för styrning och ledning. Stockholm: Socialstyrelsen; 2010.
42. Ellis G, Gardner M, Tsiachristas A, Langhorne P, Burke O, Harwood RH, Edvardsson D, Sandman PO, Borell L. Implementing national guidelines for person-centered care of people with dementia in residential aged care: effects on perceived person-centeredness, staff strain and stress of conscience. Int Psychogeriatr. 2014;26(7):1171–9.
43. Brooker D, Snaedal J. Dementia (Chapter 23). In: Mezzich J, et al., editors. Person centered psychiatry. Cham: Springer; 2016. p. 309–24.
44. Mazzocato P, Savage C, Brommels M, Aronsson H, Thor J. Lean thinking in healthcare: a realist review of the literature. Qual Saf Health Care. 2010;19(5):376–82.
45. Weimarsson H. Nine out of ten hospitals have implemented lean. Lakartidningen. 2011;108(39):1915.

Chapter 25
Person-centered Neurology

Juerg Kesselring and Heena Narotam-Jeena

25.1 Introduction

Neurology is a medical specialty, which lends itself in particular to the application and practicing of person-centered medicine. It used to have the reputation of necessitating a complex way to lead to a diagnosis or broad differential diagnosis and that not much in terms of therapies could be offered (for a historical account in a most distinguished setting see: [3]). As an excuse for therapeutic nihilism, Cajal was often quoted: *"Once development was ended, the founts of growth and regeneration of the axons and dendrites dried up irrevocably. In adult centers the nerve paths are something fixed, ended, immutable. Everything may die, nothing may be regenerated.* [4]. But he added also: *It is for the science of the future to change, if possible, this harsh decree*" [5].

25.2 New Knowledge and Their Professional Engagement

In the mid-sixties a novel discovery faced the traditional idea on the immutability of the adult brain. In 1965, Altman and Das published their seminal article [6], although Altman had already suggested this idea years earlier [7]. This discovery was neglected up to the 80's when Fernando Nottebohm demonstrated adult neurogenesis in the avian brain [8].

J. Kesselring (✉)
Department of Neurology and Neurorehabilitation, Rehabilitation Centre, Valens, Switzerland

H. Narotam-Jeena
Division of Neurology, Department of Medicine, Tygerberg Hospital,
Cape Town, South Africa

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_25

Since these serendipitous discoveries of adult neurogenesis and the heated discussion about 'Limits of Neurogenesis in Primates', the field has come a long way and amassed a more than critical and multifaceted body of evidence supporting the existence of adult neurogenesis in human brains. Human evolution might have found very efficient ways to balance proliferation and the duration of the critical maturation period in order to provide the level of hippocampal plasticity that the individual requires [9].

It has been demonstrated that neurogenic rate and morphology of adult-born neurons can be regulated by external factors such as sensory stimuli, exercise, experience, and stress through given molecular pathways [9]. This rate can be altered during disease, particularly in stroke, epilepsy, Down syndrome and neurodegenerative disorders, and its potential therapeutic capacity is being investigated even though this neurogenic capacity still needs to be further explored in human brains [10]. A few numbers may illustrate the incredible cosmos of our brain network: there are 86 billion nerve cells [11] in the adult human brain. When most of them are formed in utero, this would amount to ca. 4300 new nerve cells formed per second; the combined length of these individual 1 mm neurones would amount to 86,000 km, which is nearly twice the radius of Earth … As for function, even more important than the mere number of nerve and glial cells is the formation of connections (synaptogenesis), which certainly occurs in utero and continues into old age: if we assume on solid grounds: 10^3–10^4 synapses per neuron, this comes to 10^{14} synapses in an adult human brain. Counting these synapses at a rate of 1/s would take 27 billion years to complete! In this neuronal network natural selection works in connectivity: connections are stabilized when used actively ("What fires together wires together").

For person-centered medicine, however, more important than these fascinating studies and discoveries on the tissue level, which are still hotly debated [12] and the new methods of finding the correct diagnosis with additional help of modern techniques, it is to consider the situation of the person with neurological condition. This needs to be holistic, considering biological, psychological and socio-cultural aspects. This in turn forms the basis for understanding and care as well as the empathetic manner of arriving to diagnosis in a collaborative manner with the patient and family. Biologic resilience (neuroplasticity) and personal resilience (the persons' resources and attitudes) will promote improved therapies for people experiencing neurologic disorders.

25.3 Neuroplasticity

Neuroplasticity is defined as the physical ability of the nervous system to adapt to changes. The recognition of recovery mechanisms in neurological tissue is not new; Constantin von Monakow proposed the idea of *diaschisis*, now known as neuroplasticity, in 1914 [13]. This affects the ability of the brain to recover during neurological disease or after injury. von Monakow believed that neurons in contact with or surrounding damaged brain areas, suddenly function abnormally or cease to function. This proposal was highly prescient and was confirmed by imaging and electrophysiological studies almost a century later [14, 15].

Neuroplasticity involves functional adaptations that occur at various levels [16–18]. At the cellular level, changes include axonal sprouting (increased arborisation of neurones), changes of synaptic stability and reorganisation of synapses. At the tissue level, there is resorption of oedema and rearrangement of Na-channels on axons beyond the nodes of Ranvier. Re-myelination also occurs, even in adult brains. On the system level, takeover of functions occurs via the contralateral homologous cortex and enlargement of representation zones. Not all the changes in brain activity occurring in neurological disorders, however are adaptive, and thus behaviourally beneficial. Neuroplasticity can also be maladaptive and contribute to or sustain disability and therefore methods of applying therapies on the basis of neuroplasticity must be guided by therapists who are experienced in the application of treatment modalities based on the mechanisms of neuroplasticity.

At the behavioural level, neuroplasticity can be induced using novel motor and cognitive strategies, which counter problems of despair and resignation common to many neurological patients. These principles were demonstrated in a study of rats given a single neurological lesion using pro-inflammatory cytokines [19]. Despite cellular damage and inflammation at the lesion site, function was restored over 28 days post-injury. At cortical sites remote from the lesion, reorganisation of neurones effectively bypassed the damage, suggesting high levels of neuroplasticity.

fMRI studies on human brains show that simple functions such as moving a hand involves more brain areas and more energy usage in neurological patients (e.g. with multiple sclerosis (MS)) than in normal control individuals. Various other MRI studies indicate recruitment of related brain regions after damage has occurred at a specific lesion. These changes in brain connectivity affect various functions, e.g. motor function, cognition and memory. In some conditions such as stroke, there is restoration towards the original physiological network over time [20]. After an initial increase, brain functional connectivity declines over the following 2 years, resulting in a decreased ability to compensate for neuronal damage. Timely intervention by appropriate professionals such as social workers, clinical psychologists and members of the allied healthcare team is important not only for better prognosis, but also for allowing the patient to become more actively engaged in the recovery process [21]. A meta-analysis of different treatment modalities for aphasia and their effect in the recovery of speech [22] concluded that when treatment is started in the acute period, the average effect size (ES) for treated individuals is 1.83 times greater than that for untreated individuals. The treatment initiated during the acute stage should be intensive for best effect and to prevent mortality (mortality is higher in patients with post-stroke aphasia than in stroke patients without aphasia) [23–26]. The 2010 South African Guidelines for Stroke Management [27], which also advises intervention by speech therapists from the onset of aphasia in patients, suggests that alternative forms of communication be explored and that education of family members, particularly about the levels of frustration experienced by these patients, takes place. Patients with sudden-onset disability and associated memory deficits place emphasis on the importance of their families as well as on their need for trust in them, in view of their loss of independence and cognitive disturbances (memory deficits and difficulty with concentration) [28].

Neuroplasticity is sustained by changes in the grey and white matter in the central nervous system, together with other tissues such as glial cells and angiogenesis. In order to develop novel interventions to promote or enhance plasticity underlying functional recovery, both experimental evidence and clinical studies are needed. The interdependence between the body and nervous system and factors that contribute to motor, sensory and cognitive functions need to be appreciated in order to provide effective rehabilitation to people with MS [29]. The WHO International Classification of Disability and Health (ICF) framework is defined as ‘a framework which conceptualizes functioning and disability as a dynamic interaction between a person’s health condition and their contextual factors’. Contextual factors involve two components, namely environmental and personal factors [30] (see Fig. 25.1). It looks beyond the idea of a purely medical or biological conceptualization of dysfunction and allows for the impact of the environment and other contextual factors on the functioning of an individual or population to be studied [32]. This creates a platform for holistic patient assessment and a deeper, more meaningful understanding of the patient experience. It resonates with the WHO’s definition of health: ‘health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’ [33].

Rehabilitation strategies in neurological disorders are “show cases” of personalized medicine. The example of multiple sclerosis (MS) [34–36] can be equally applied *mutatis mutandis* to other neurological disorders as they are described in leading textbooks on Neurology [37].

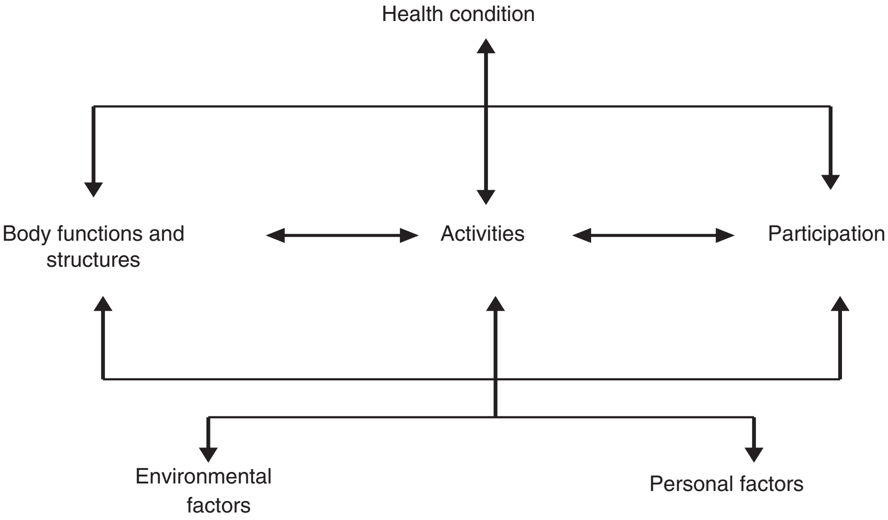


Fig. 25.1 ICF framework for interviews [31]

Approaches to managing neurological diseases such as multiple sclerosis and stroke are changing rapidly and are achieving markedly improved efficacy in inhibiting disease processes by alleviating harmful consequences. The most apparent reason for these achievements is more efficient logistics in acute affections (e.g. improvement in urgent transportation of patients, more efficient treatment algorithms in “Stroke Units”, improved neuro-surgical interventions and increasing use of new disease-modifying drugs (DMDs) that are more effective than those previously available. Despite these advances in new medications and the more rapid treatments, there remains a need for comprehensive rehabilitation interventions in order to reduce disease symptoms and sequela, and to achieve maximal independence and quality of life, particularly in patients with progressive disease. When initiating a neurorehabilitation programme, it is important to appreciate the value of maintaining resilience and neuroplasticity in patients and to understand the approaches that can encourage these factors and promote neurorehabilitation. It is therefore critical that in settings beyond a standard stroke unit, clinicians treating patients with neurological disorders are aware of the therapeutic potential of physical and cognitive strategies, and the benefits which neurorehabilitation can provide [38].

25.4 Resilience

The concept of resilience comprises physical, mental and emotional components including good nutrition, rest and self-belief (see Fig. 25.2). Without such activity and participation, there is insufficient neuronal stimulation, diminishing or eliminating the prospect of recovery. Patients must be encouraged to develop resilience and to develop more self-confidence in order to maximise their potential for regaining some degree of their lost physical abilities.

Patient experience is centred on the acknowledgement of their individuality, the facilitation of communication, psychological impact and feelings of trust and vulnerability, as well as introspection and thoughts about their future. An appreciation of these experiences can lead to critical evaluation of current management practices, with the intent of optimising holistic acute care to facilitate positive progression of the course of the illness and improvement of patients’ well-being [21].

A study performed on patients at a large district hospital in South Africa explored the patterns of patient experiences in relation to expressive aphasia following brain injury, in order to identify helpful recommendations for alternative communication and for promoting mental health and well-being. Expressive aphasic patients’ ability to react appropriately to the environment contributes to their hospital experience, and ultimately their mental health and recovery. The challenge of communication for these patients makes it important to anticipate their experiences. The study findings stressed the importance of holistic management as well as the value of family input, with the aim of improving the mental wellbeing of these patients, in an attempt to improve both functional and emotional outcome [21]. The rehabilitation

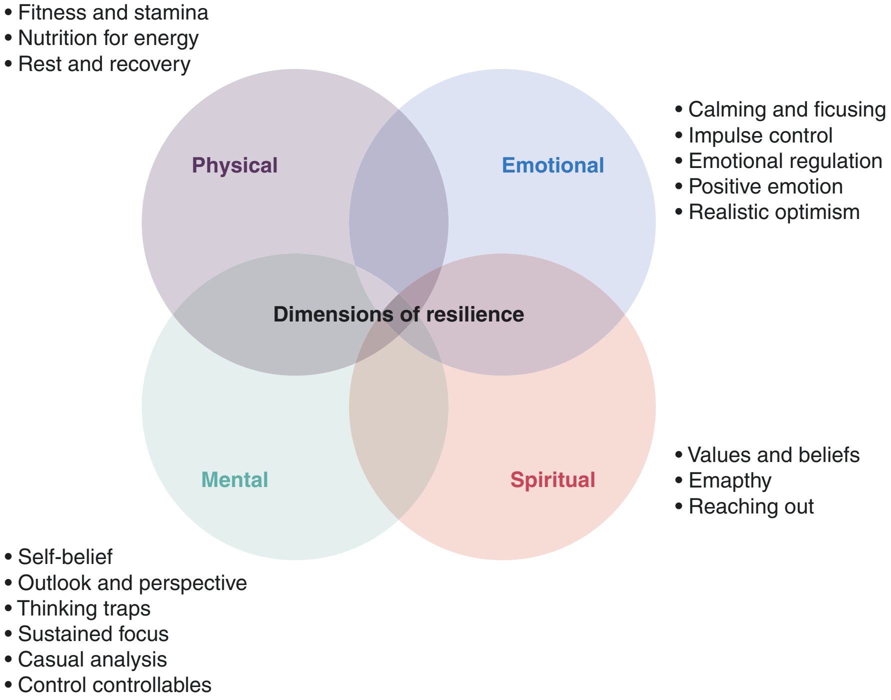


Fig. 25.2 Dimensions of resilience in response to disease and treatment

process should begin on the day of admission, and focus not only on functional recovery but also on emotional support, motivational strategies, and reintegration back into society. This notion rests on the idea that for the patient to be active in his/her management, he/she should be motivated and mentally capable to engage in the various components of a rehabilitation programme.

Communication is an important facilitator in the person-centered medicine approach. It is a means of providing information to patients and their families as well a mechanism of generating constant feedback and enabling the patient to think, assess, re-assess and act accordingly. It also allows family members to understand and plan the way forward, including reintegration back into society. “*They thought I was dead*” is a powerful quote from a participant in the South African-based study, which describes the participant’s thoughts after her interpretation of her family’s behaviour at her bedside. It is important that families are able to communicate effectively with their loved ones, particularly when conventional means of communication are challenged. Furthermore, more elaborate communication regarding the disease increases awareness of the condition, and is a means of actively overcoming any obstacles which may ensue. Patients may experience vulnerability and loss of independence associated with their neurological condition and this may manifest as a fear that their role within their households and communities could be jeopardised. Current literature provides evidence that there exists a direct relationship between chronic physical impairment (such as stroke) and depression [39]. Losing the ability to be receptive to the environment and respond accordingly to stimuli can have a major impact on the mental health and well-being of a person [40].

Each person with a neurological disorder requires a coordinated planning process that includes problem assessment, goal setting and identification of appropriate treatment regimens. Critically, there must be an education-training programme designed to enable or empower each patient with impairments to maintain (and regain) life activities [34–36].

Strategies for neurorehabilitation in neurological disorders involve various different approaches. In addition to using appropriate and effective medications, it is critical to initiate therapeutic modalities aimed at addressing impairments in sensorimotor function (e.g. sensory and electro stimulation), gait (e.g. treadmill training), cognition (e.g. memory and attention training), language (speech therapy) and bulbar function (dietician and speech therapy input). One can appreciate from the above described treatment modalities that the patient's cooperation and determination to regain lost functioning is an integral component of therapy, without which holistic therapy cannot take place. In cases where lack of motivation exists, patient participation can be encouraged through several approaches, namely education and confidence-building, emphasizing the importance of quality of life (QoL), and most importantly, through identifying and addressing patient concerns. The therapeutic need for placing the patient at the center of his/her care, is once again emphasized, as failure in doing so may pose a barrier to achieving treatment success. Rieckmann and colleagues [41] demonstrated that patient-reported outcomes (PROs) are important not only in identifying possible barriers to participation in treatment modalities, but also in identifying and addressing specific-specific goals.

Patient engagement has been described as "the blockbuster drug of the century" due to its positive effects in treating various chronic diseases.

This factor can also be promoted by providing credible sources of accurate information, encouraging treatment adherence and empowering through a sense of responsibility. When patients are engaged, they are more likely to consume fewer healthcare resources, and to report issues and adverse events with treatment. As a result, such patients have an important role in improving the quality, safety and cost of interventions and in improving clinical outcomes [42]. One cross-sectional survey of MS patients (n = 199) found that MS-related Quality of life (QoL) and MS-related self-efficacy correlated significantly with patient activation. Conversely, depression had an inverse correlation [43].

25.5 Activity: Physical and Cognitive

Physical activity is an important component of neurorehabilitation and has been shown to confer numerous advantages: it helps preserve good functional reserves that are needed to reduce the risk of relapsing function impairments [44]. Regular physical activity may exert its beneficial effects through changes in neuroactive proteins such as up regulation of insulin-like growth factor-I, which appears to act as a neuroprotective agent, as well as neurotrophins, brain-derived neurotrophic factor (BDNF) and nerve growth factor. Exercise has also been found to moderate brain volume changes in patients with Alzheimer's disease, and restore some of the losses in brain volume associated with normal aging. In a systematic review and meta-analysis of 12 controlled clinical trials investigating the effects of exercise intervention programmes on cognition in people with MS, stroke or Parkinson's disease, significant improvements in cognition were found in nine of the 12 studies [45]. However, the total effect size was non-significant for changes in executive functions, due to inconsistencies between measures of cognition, training sequences and intervention period. A neurorehabilitation technique termed constraint-induced movement therapy involves intensively training the affected arm by constraining the less affected arm with, for example a sling, for 90% of waking hours for 2 weeks. Data from stroke patients suggest that this therapy induces neuroplastic changes in the structure and function of the CNS [46].

In addition to simple physical exercise, gait training is an important aspect of improving walking and mobility in patients with neurological disorders. It reduces physical load during walking, provides an efficient training of leg muscles and postural stability and enhances central adaptive processes. Parameters of walking (effect sizes) may not significantly improve versus convention walking but improvements in walking velocity, walking distances and knee extensor strength can be observed and measured.

Various cognitive neurorehabilitation strategies are proposed in neuropsychology, however Cochrane reviews conclude that heterogeneity of studies limits the strength of the evidence in favour of cognitive rehabilitation.

Treating pain is an essential strategy in neurorehabilitation. Recently, the Italian Consensus Conference on Pain in Neurorehabilitation published two articles evaluating the role of pharmacological and non-pharmacological strategies in the treatment of pain in neurorehabilitation. In the first, cryotherapy, soft tissue mobilisation, graded manual traction, exercises for regaining range of motion, deep flexors stabilisation exercises and proprioceptive neuromuscular facilitation, were identified as useful in the treatment of cervical pain [47]. In the second, the investigators performed a systematic review of 400 studies evaluating the effect of psychotherapies on pain intensity in neurological disorders: psychological interventions are safe and effective treatments that can be used within an integrated approach for patients undergoing neurological rehabilitation for pain [48].

Spirituality is another important component to address when considering holistic management of a patient. Patients who have undergone traumatic or life-changing events may undergo changes in perception of self, inter-personal relationships and philosophy of life, and this may be represented in a realization of new possibilities, a deeper sense of life's purpose, and a need to give back in altruistic ways [49]. Patients have a desire to communicate about spirituality when faced with end-of-life situations or when in spiritual distress [22]. The relationship between spirituality and health has demonstrated that spirituality is a positive factor towards recovery; it has also explained how patients draw on their spirituality during ‘times of stress’ to address their ‘psychological needs’, such as feelings of vulnerability and low mood [25].

25.6 Assessment of Neurorehabilitation Strategies

Neurorehabilitation is a critical part of treatment in neurology but evaluating its effects is problematic. In neurorehabilitation there is a lack of standardisation of methods, making comparisons between studies challenging. There is also a moral reluctance to use a control group, difficulties with blinding and a lack of consensus on outcome assessments for determining parameters such as impairment, disability, quality of life, goal achievement, coping skills and self-efficacy. There is also a variable choice of goals that are clinically useful, scientifically valid and appropriate to the population studied [50, 51].

25.7 Multidisciplinary and Person-centered Approaches

In order to adopt the above strategies and rehabilitate a person with neurological disorders requires a multidisciplinary team that centres on the patient and their caregiver, and takes into account the individual’s history. This team should involve a neurologist trained in rehabilitation medicine, and multiple other therapists including speech therapists, psychologists, MS and other specialised nurses, orthopaedic technicians, physiotherapists, occupation (ergo-) therapists and social service representatives.

All these persons should interact and operate in a coordinated way and work to an integrated clinical care pathway. This should include patient-defined needs and goals, and therapists’ assessment of problems (mobility, self-care ADL, communication, daily occupations and social interactions). Setting of common goals should be performed at an interdisciplinary level and should be clear, specific, meaningful, realistic and measurable. Assessment of goal achievements should be regular and goals adapted if necessary. Cochrane reviews regularly identify trials investigating multidisciplinary rehabilitation programs in neurological disorders, e.g. MS [52]: although limited, available evidence suggests that inpatient or outpatient rehabilitation programmes may improve disability, bladder dysfunction, and participation, and the effects may last up to 12 months.

25.8 Practical Issues in the Implementation of Person-centered Care

25.8.1 Key Factors for the Implementation of Person-centered Care in Neurology

In 2016, Mezzich et al. published a set of principles and strategies for Person Centered Medicine and they can to great extent be applied to Neurology [53]. The dignity and autonomy of the patient needs to be central in planning for treatment and care. The patient's biological, psychological and cultural situation needs to be addressed and communication should be empathetic, thoughtful and effective.

25.8.2 To What Extent Is Neurology Currently Centered on the Person?

In some sections of neurology, treatment and service is truly person centered. This is exemplified by the service provided for special neurological conditions such as multiple sclerosis and MND where teams have successfully been built for comprehensive and holistic service [54]. The service for the same condition can however vary greatly in a region as exemplified in treatment and care for stroke in South Africa. Certain centers have the ability to offer cutting edge diagnostics, along with intense, twice-daily rehabilitation in specialized stroke units, while other centers may only be able to offer a very basic package of care without cranial imaging or rehabilitation. A schism exists between the well-funded private healthcare services, and the state healthcare services, which operates on approximately 20% of the healthcare budget, to treat 80% of the population. A further disparity exists between facilities depending on the presence or absence of "stroke-interested" clinicians.

25.8.3 Current Obstacles in Neurology for the Implementation of Person-centered Care

There are many such obstacles as the increasing pressure for cost containment and increased sub-specialization with primary focus on processes and technical solutions in diagnosis and treatment rather than building a firm and robust relationship with the patient. This is not unique for neurology as the same development has been occurring in many other fields of medicine exemplified by introduction of lean production strategies as developed in industry [55].

25.8.4 Changes Necessary to Make the Practice of Neurology More Person-centered

These should not least focus on medical education for medical students, residents and in continuing professional development. Evaluation instrument used in practice should be comprehensive and contextualized and more time should be accorded for health professionals to care for their patients.

Local government and managerial policies, administrative challenges, and the knowledge, attitudes and practices (KAP) of treating clinicians and allied health workers, all have an influence on person-centered care, across the globe.

In South Africa, person- centered stroke care varies massively. Certain centers have the ability to offer cutting edge diagnostics, along with intense, twice-daily rehabilitation in specialized stroke units, while other centers may only be able to offer a very basic package of care without cranial imaging or rehabilitation. A schism exists between the well-funded private healthcare services, and the state healthcare services which operates on approximately 20% of the healthcare budget, to treat 80% of the population. A further disparity exists between facilities depending on the presence or absence of "stroke-interested" clinicians. Due to a number of factors, there has however been a tangible shift in practice. This has been driven by increased awareness of the prevalence of stroke, more advocacy groups and the advances in treatment of acute strokes. The advancement in treatment is in part driven by the increased utilization of vascular and perfusion studies to enhance patient selection and guide reperfusion strategies. The shift in practice has been a welcome change, and attempts to place the patient, their specific deficits, and risk profile at the center of the care paradigm are encouraging.

Similar to stroke units elsewhere, South African stroke units aim to incorporate the knowledge of neuroplasticity and the dimensions of resilience in response to disease, in order to deliver tailored therapeutic strategies to optimise patient outcomes. This is facilitated by stroke units having dedicated allied health professional team members, skilled in the theory and practice of neurorehabilitation, who deliver intensive therapy on a regular basis to these selected patients. Furthermore, the setup of these units is such that the allied staff screen all stroke unit patients for the need of their services, in contrast to many other clinical settings where these team members would only treat patients specifically referred to them by treating clinicians. This process of broader screening can be of particular use in instances where a potential gap in the knowledge of, and recognition of impairment and disability, exists. Despite the clear benefit of these units, many hospitals in South Africa lack the physical and human resources to create dedicated stroke units. It is in these instances particularly that the key benefits relating to stroke units, namely education and upskilling of healthcare workers treating patients with strokes, are emphasized. The costs of equipment, are far in excess of the costs of training. Dedicated training programmes are a low-cost intervention that may rapidly facilitate the creation of stroke units, and ultimately improve patient outcomes.

25.9 Conclusions

This chapter brings to light a perspective on how to practice person-centered care in general neurology as well as the basis for and the importance of rehabilitation as a component of management in neurological disease and the value of the person-centered medicine approach. It explains the evidence for non-pharmacological management approaches and highlights the limitations in implementation of these strategies, as well as offers suggestions for overcoming these challenges. In addition, the chapter offers background information on the concept of neuroplasticity and its role in disease progression and possible recovery.

Significant advances have been made in treatments of neurological disorders in recent years: new medications and other treatment strategies, and in particular the mobilization of inherent resilient forces on the basis of neuroplasticity have substantially improved the prognosis for patients with neurological disorders There remains, however, a great need for personalised regimens that aim to maximise resilience and neuroplasticity by stimulating the individual to strive for improvement and actively participate in their neurorehabilitation process. It is no wonder that patient engagement has been described as the “blockbuster drug of the century” as without this most, if not all, neurorehabilitative therapies are squandered. The human brain has sophisticated mechanisms for recovery of function at sites distant from a circumscribed lesion that compensate for damage. This altered neuronal function has been clearly demonstrated in fMRI studies on patients. Stimulating such mechanisms, however, requires effort from the patient and encouragement/guidance from healthcare providers. Successful neurorehabilitation requires a multidisciplinary team that centres on the patient and their caregiver who all work toward a defined clinical care pathway with clear achievable goals for which progress is frequently monitored. Providing such intensive individual attention to all patients with neurological disorders is a challenge since access to treatments and services is highly variable in different contexts and often limited by the availability of healthcare resources.

Neurorehabilitation takes many forms depending on the various physical or mental manifestations of the disease in each patient and the problems they encounter. Some of these symptoms can be addressed using an increased range of drug therapies. Other symptoms however, require treatments that harness the neuroplasticity of the CNS, i.e. its innate ability to adapt to change. These include physical therapy such as exercise programs and gait training whereas others require cognitive or psychiatric therapy. Numerous studies have demonstrated the considerable value of such interventions and these are especially effective when used in conjunction with conventional medications. Treatment of neurological disorders should be holistic and address all of the patient’s symptoms and concerns; it is vital that a multidisciplinary approach is taken rather than relying on a single therapy pathway. It is essential, however, that standardised measures and endpoints for determining neurorehabilitation interventions are agreed in order to properly assess their value in different patient populations around the world.

There are now strong grounds for more optimism in caring for persons with neurological disorders. Increased use of newer medications coupled with defined programmes of education/training and goal setting are likely to substantially improve the prognosis in many patients, particularly during the early disease stages and promote the quality of their lives. These interventions collectively promote neuroplasticity and neurorehabilitation and have the potential to halt further neurodegeneration. As a result, neurological patients can expect substantially more active and fulfilling lives, generally better outcomes and possibly some recovery of lost function and even greater attainment of their life projects.

Acknowledgements and Disclosures The authors do not report conflicts of interest concerning the preparation of this paper

References

1. Mehta AR, Mehta PR, Anderson SP, MacKinnon BLH, Compston A. Etymology and the neuron(e). Brain. 2020;143:374–9.
2. Cassell EJ. The nature of suffering and the goals of medicine. N Engl J Med. 1982;306:639–45.
3. Compston A, Shorvon S, editors. Queen Square history. Cambridge: Cambridge University Press; 2018.
4. Cajal SR. Degeneration and regeneration of the nervous system, vol. 2. New York: Haffner; 1928. p. 750.
5. Cajal SR. Estudios Sobre la Degeneración y Regeneración del Sistema Nervioso. Madrid: Moya; 1914.
6. Altman J, Das GD. Autoradiographic and histological evidence of postnatal hippocampal neurogenesis in rats. J Comp Neurol. 1965;1965(124):319–35.
7. Altman J. Are new neurons formed in the brains of adult mammals? Science. 1962;135:1127–8.
8. Nottebohm F. A brain for all seasons: cyclical anatomical changes in song control nuclei of the canary brain. Science. 1981;214:1368–70.
9. Kempermann G, Gage FH, Aigner L, Song H, Curtis MA, Thuret S, Kuhn HG, Jessberger S, Frankland PW, Cameron HA, Gould E, Hen R, Abrous DN, Toni N, Schinder AF, Zhao X, Lucassen PJ, Frisén J. Human adult neurogenesis: evidence and remaining questions. Cell Stem Cell. 2018;23(1):25–30.
10. Martinez-Marcos A, Trejo JL, López-Mascaraque L. Editorial: 50th Anniversary of adult neurogenesis: olfaction, hippocampus, and beyond. Front Neurosci. 2016;10:319.
11. Herculano-Houzel S. The human brain in numbers: a linearly scaled-up primate brain. Front Hum Neurosci. 2009;3(31):1–11. https://doi.org/10.3389/neuro.09.031.2009.
12. Petrik D, Encinas JM. Perspective: of mice and men—how widespread is adult neurogenesis? Front Neurosci. 2019;13:923. https://doi.org/10.3389/fnins.2019.00923.
13. Kesselring J. Constantin von Monakow's formative years in Pfafers. J Neurol. 2000;247:200–5.
14. Carrera E, Tononi G. Diaschisis: past, present, future. Brain. 2014;137:2408–22.
15. Fornito A, Zalesky A, Breakspear M. The connectomics of brain disorders. Nat Rev Neurosci. 2015;16:159–72.
16. Dobkin BH. Neurobiology of rehabilitation. Ann N Y Acad Sci. 2004;1038:148–70.
17. Flachenecker P. Clinical implications of neuroplasticity—the role of rehabilitation in multiple sclerosis. Front Neurol. 2015;6:36.
18. Henze T. Symptomatische Therapie der Multiplen Sklerose [Symptomatic treatment of multiple sclerosis]. Stuttgart: Georg Thieme; 2005.

19. Kerschensteiner M, Bareyre FM, Buddeberg BS, et al. Remodeling of axonal connections contributes to recovery in an animal model of multiple sclerosis. J Exp Med. 2004;200:1027–38.
20. Calautti C, Baron JC. Functional neuroimaging studies of motor recovery after stroke in adults: a review. Stroke. 2003;34:1553–66.
21. Narotam H, Sammons HE. Exploring experiences of expressive aphasia in brain injury patients: a qualitative study. Int J Pers Cent Med. 2017;7(2):125–37. [Online] Available from: http://www.ijpcm.org/index.php/IJPCM/rt/printerFriendly/622/0 (Accessed: 30 Nov 2019).
22. Robey RR. A meta-analysis of clinical outcomes in the treatment of aphasia. J Speech Lang Hear Res. 1998;41(1):172–87. [Online] Available from: http://www.pubmed.com (Accessed: 8 March 2014).
23. Godecke E, Rai T, Ciccone N, Armstrong E, Granger A, Hankey GJ. Amount of therapy matters in very early aphasia rehabilitation after stroke: a clinical prognostic model. Semin Speech Lang. 2013;34(3):129–41. [Online] Available from: http://www.pubmed.com (Accessed: 8 March 2014).
24. Laska AC, Kahan T, Hellblom A, Murray V, von Arbin M. A randomized controlled trial on very early speech and language therapy in acute stroke patients with aphasia. Cerebrovasc Dis Extra. 2011;1(1):66–74. [Online] Available from: http://www.pubmed.com (Accessed: 8 March 2014).
25. Mattioli F, Ambrosi C, Mascaro L, Scarpazza C, Pasquali P, Frugoni M, et al. Early aphasia rehabilitation is associated with functional reactivation of the left inferior frontal gyrus: a pilot study. Stroke. 2014;45(2):145–52. [Online] Available from: http://www.pubmed.com (Accessed: 10 Jan 2014).
26. Poslawsky IE, Schuurmans MJ, Lindeman E, Hafsteinsdóttir TB. A systematic review of nursing rehabilitation of stroke patients with aphasia. J Clin Nurs. 2010;1-2(19):17–32. [Online] Available from: http://www.ncbi.nlm.nih.gov/pubmed/20500241 (Accessed: 17th July 2016).
27. Bryer A, Connor MD, Haug P, Cheyip B, Staub H, Tipping B, Duim W, Pinkney-Atkinson V. South African guideline for management of ischaemic stroke and transient ischaemic attack 2010: A guideline from the South African Stroke Society (SASS) and the SASS Writing Committee. S Afr Med J. 2010;100(11):24–5. [Online] Available from: http://www.samj.org.za/index.php/samj/article/viewFile/4422/3005 (Accessed: 13 Aug 2015).
28. McColl MA, Bickenbach J, Johnston J, Nishihama S, Schumaker M, Smith K, Smith M, Yealland B. Spiritual issues associated with traumatic-onset disability. Disabil Rehabil. 2000;12(22):555–64. [Online] Available from: http://www.ncbi.nlm.nih.gov/pubmed/11005745 (Accessed: 20 July 2016).
29. Khan F, Amatya B, Galea MP, Gonzenbach R, Kesselring J. Neurorehabilitation: applied neuroplasticity. J Neurol. 2017;264(3):603–15.
30. Howea TJ. The ICF contextual factors related to speech-language pathology. Int J Speech Lang Pathol. 2008;10(1-2):27–37. [Online] Available from: http://www.tandfonline.com/doi/pdf/10.1080/14417040701774824?redirect=1 (Accessed: 18 July 2016).
31. Centre for Rehabilitation Studies. (2012) Rehabilitation an Introduction. In: Centre for Rehabilitation Studies. (ed.) Lecture notes: Rehabilitation an introduction. Stellenbosch University. pp. 5-12.
32. WHO. International classification of functioning, disability and health (ICF). Geneva: World Health Organization; 2016. Available from: http://www.who.int/classifications/icf/icf_more/en/ (Accessed: 18 July 2016).
33. WHO. About mission. Geneva: WHO; 2017. Available from: http://www.who.int/about/mission/en/ (Accessed: 3 Jan 2017).
34. Kesselring J, Beer S. Symptomatic therapy and neurorehabilitation in multiple sclerosis. Lancet Neurol. 2005;4(643–52):40.
35. Kesselring J, Comi G, Thompson AJ, editors. Multiple sclerosis: Recovery of function and neurorehabilitation. Cambridge University Press; 2010.
36. Kesselring J. Neurorehabilitation in multiple sclerosis—resilience in practice. Eur Neurol Rev. 2017;12(1):31–6.

37. Clarke C, et al., editors. Neurology: a queen square textbook. Chichester: Wiley-Blackwell; 2016.
38. Silverman AM, Verrall AM, Alschuler KN, et al. Bouncing back again, and again: a qualitative study of resilience in people with multiple sclerosis. Disabil Rehabil. 2017;39:14–22.
39. National Collaborating Centre for Mental Health (UK). Depression in adults with a chronic physical health problem. NICE clinical guidelines. Leicester: British Psychological Society; 2010. [Online] Available from: http://www.ncbi.nlm.nih.gov/books/NBK82916/ (Accessed: 15 Aug 2015).
40. Worrall L, Ryan B, Hudson K, Kneebone I, Simmons-Mackie N, Khan A, Hoffmann T, Power E, Togher L, Rose M. Reducing the psychosocial impact of aphasia on mood and quality of life in people with aphasia and the impact of caregiving in family members through the Aphasia Action Success Knowledge (Aphasia ASK) program: study protocol for a randomized controlled trial. Trials. 2016;17:153. https://doi.org/10.1186/s13063-016-1257-9.
41. Rieckmann P, Boyko A, Centonze D, et al. Achieving patient engagement in multiple sclerosis: A perspective from the multiple sclerosis in the 21st Century Steering Group. Mult Scler Relat Disord. 2015;4:202–18.
42. Coulter A. Patient engagement—what works? J Ambul Care Manage. 2012;35:80–9.
43. Goodworth MC, Stepleman L, Hibbard J, et al. Variables associated with patient activation in persons with multiple sclerosis. J Health Psychol. 2016;21:82–92.
44. Mostert S, Kesselring J. Effects of a short-term exercise training program on aerobic fitness, fatigue, health perception and activity level of subjects with multiple sclerosis. Mult Scler. 2002;8:161–8.
45. Kalron A, Zeilig G. Efficacy of exercise intervention programs on cognition in people suffering from multiple sclerosis, stroke and Parkinson's disease: A systematic review and meta-analysis of current evidence. NeuroRehabilitation. 2015;37:273–89.
46. Arya KN, Pandian S, Verma R, et al. Movement therapy induced neural reorganization and motor recovery in stroke: a review. J Bodyw Mov Ther. 2011;15:528–37.
47. Tamburin S, Lacerenza MR, Castelnuovo G, et al. Pharmacological and non-pharmacological strategies in the integrated treatment of pain in neurorehabilitation. Evidence and recommendations from the Italian Consensus Conference on Pain in Neurorehabilitation. Eur J Phys Rehabil Med. 2016;52:741–52.
48. Castelnuovo G, Giusti EM, Manzoni GM, et al. Psychological treatments and psychotherapies in the neurorehabilitation of pain: evidences and recommendations from the Italian Consensus Conference on Pain in Neurorehabilitation. Front Psychol. 2016;7(115):84.
49. Silverman ME. Community: the key to building and extending engagement for individuals with aphasia. Semin Speech Lang. 2011;32(3):260–1. [Online] Available from: http://www.ncbi.nlm.nih.gov/pubmed/21968561 (Accessed: 22 July 2015).
50. Albert SJ, Kesselring J. Neurorehabilitation of stroke. J Neurol. 2012;259(5):817–32.
51. Beer S, Khan F, Kesselring J. Textbook of neurorehabilitation. 2nd ed. Cambridge: Cambridge University Press; 2014.
52. Khan F, Turner-Stokes L, Ng L, et al. Multidisciplinary rehabilitation for adults with multiple sclerosis. Cochrane Database Syst Rev. 2007;2007(2):CD006036.
53. Mezzich JE, Kirisci L, Salloum IM, Trivedi JK, Kar SK, Adams N, Wallcraft J. Systematic conceptualization of person centered medicine and development and validation of a Person-centered Care Index. Int J Pers Cent Med. 2016;6:219–47.
54. Van Capelle AC, Visser LH, Vosman F. Developing patient-centered care for multiple sclerosis (MS). Learning from patient perspectives on the process of MS diagnosis. Eur J Pers Cent Healthc. 2016;4(4):675.
55. Mazzocato P, Savage C, Brommels M, Aronsson H, Thor J. Lean thinking in healthcare: a realist review of the literature. Qual Saf Health Care. 2010;19(5):376–82.

Chapter 26
Person-Centered Psychiatry and Psychology

Michel Botbol, Diogo Telles, Maria Ammon, and Ihsan M. Salloum

26.1 Introduction

It is well known that the current revival of Person-Centered Medicine started in Psychiatry, more precisely in the World Psychiatric Association (WPA), during the presidency of Prof Juan Mezzich (2005–2008). But it is sometimes forgotten that this emergence was preceded by an important work of the WPA Classification and Nosography Section, when, at the beginning of the APA process towards DSM5, the

---

M. Botbol (✉)
Child and Adolescent Psychiatry, University of Western Brittany, Brest, France

World Association for Dynamic Psychiatry (WADP), Berlin, Germany

International College of Person-Centered Medicine, New York, NY, USA

World Psychiatric Association, Geneva, Switzerland

D. Telles
Faculty of Medicine, Psychiatry and Psychology Department, University of Lisbon, Lisbon, Portugal

M. Ammon
German Academy for Psychoanalysis (DAP), Berlin, Germany

World Association for Dynamic Psychiatry (WADP), Berlin, Germany

I. M. Salloum
Institute of Neuroscience, Department of Neuroscience, University of Texas Rio Grande Valley School of Medicine, Harlingen, TX, USA

University of Miami Miller School of Medicine, Miami, FL, USA

Section of Classification, Diagnostic Assessment and Nomenclature, World Psychiatric Association, Geneva, Switzerland

International College of Person Centered Medicine, New York, NY, USA
e-mail: ihsan.salloum@utrgv.edu

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_26

discussions focused on the limitations of DSM IV in covering the needs of mental health research and practice. For many psychiatrists this nosographic specificity of psychiatry into medicine became the entry point into what later became Person-Centered Psychiatry and Medicine.

Psychiatry is indeed particularly exposed to the limitations of a Disorder-Centered approach and thus particularly interested in a shift to a Person-centered perspective [1]. For example, more than any other medical specialty, psychiatry fails in its quest for **the classifier's Holy Grail: that is to find a classification corresponding to natural kinds or at** least to establish between the classes it defines, connections corresponding to the real relations between the natural kinds it classifies. Indeed, psychiatric classifications do not fail only in giving us knowledge about kinds themselves, but also in giving us knowledge about the relationships between these kinds, that is to say to comply with the minimal epistemological requirement of any classification [2]. The result is that we do not know if the syndrome these classifications consider as discrete entities are "constellations or nebula" to draw on the illuminating distinction made by Hacking [3].

The choice of characters on which a classification is based is, then, essential: between the kinds and their classifications there is a theory determining the way in which we define, describe and classify them [4].

The American Psychiatric Association DSM adopted a cautious stance regarding these categorical issues: "there is no assumption that each category of mental disorder is a completely discrete entity with absolute boundaries dividing it from other mental disorders or from no mental disorders [5]. Across the DSM third edition (1980), the fourth (1994), and the fifth (2013), this American classification of mental health disorders did not change much in this regard. However, "naturalization" of the disorder's categories became widespread among most DSM users transforming a provisional descriptive construct into a "natural" thing [6]. Such use seems to ignore Spinoza's dictum, "the astral constellation *Dog* does not bark" [1].

26.2 Person Centered Diagnosis Models

Before being extended to medicine in general, Person-centered Integrative Diagnostic Model (PID) [7, 8] was, logically, first elaborated in psychiatry to deal with this nosographic issue and bring back psychiatry to what it should have always been: A Person-centered discipline, at if not out of humanism at least out of necessity. This elaboration begun with a preliminary work of the WPA Classification Section: the WPA International Guidelines for Diagnostic Assessment (IGDA) project which was successfully published in well-recognized psychiatric international journal [9].

Fully developed during the WPA International Institutional Program for Person-Centered Psychiatry (IPPP), PID is a diagnostic scheme that operationalizes the principles of Person-centered Medicine to be applicable in psychiatric clinical practices. The PID has been adopted by the Latin American Guide of Psychiatric Diagnosis, Revised Version [10]. Key features of the PID were already what it became with its application to medicine at large: the evaluation of both ill health and positive health domains along three levels: health status, contributors to health, and health experience and values. As it is still the case in PCM, it involved the use of pluralistic descriptive procedures (categories, dimensions and narratives) and the partnerships among clinicians, patients, and families in the evaluation and the decisions related to the care process. The PID integrated in the determinants it considers, risk and protective factors (intrinsic and extrinsic; biological, psychological, and social), objective and subjective aspects. i.e., Among the factors important for the prevention of chronic diseases, PID included life style and other key factors listed in the Health Improvement Card [11]. These include diet, exercise, avoidance of alcohol and other hazardous drugs, stress-control, adequate rest and sleep, and participation in social and creative activities.

"*Everything comes from the psyche, bad things and good things for the body and the whole person*" [12] said Socrates. The primary role of the psyche for well-being, and the holistic and integrated view of the person in medicine, has been recognized since antiquities. It was echoed in modernity by the WHO Director General proclamation at the 54th World Health Assembly *"There is no development without health, and no health without mental health"* [13].

Based on these same assumptions which are crucial for Person-centered medicine and care in general, Person-centered Psychiatry places the "person in context" at the center of care, as an overarching model for optimized care for all individuals. It is highly relevant and applicable for specific psychiatric conditions.

The key principles underlying person centered psychiatry are the same as those of person-centered medicine in proclaiming that the person is at the center of health. They include:

- Ethical Commitment, upholding the dignity of every person seeking care;
- Cultural Awareness and Sensitivity;
- Holistic scope, considering both ill health and positive aspect of health;
- Relational Focus with a partnership approach;
- Individualized Care;
- Common Ground for Collaborative Diagnosis and Care;
- People-centered Systems of Care;
- and Person-centered Education and Research.

It emphasizes the role of communication, shared decision making, empowerment, subjectivity and a partnership approach with patient, family or other health stakeholder and a focus on recovery [8]. It highlights the crucial role of behavioral factors, and related self-care, for the prevention of chronic ailments and for recovery and the promotion of well-being. Person-centered Psychiatry and Medicine are aimed at promoting the fulfillment of the whole person [14].

As such, it is inclusive, integrative and destigmatizing which is particularly pertinent for the treatment of highly stigmatized-health conditions such as mental illness and substance use disorders.

26.3 Person-Centered Approach for Specific Psychiatric Disorders

Compelling applications of the person-centered models to several specific mental disorders have been advanced [15]. It is the case for most major disorders, including dementia, substance use disorders, schizophrenia and related disorders, bipolar disorder, depression and anxiety disorders, eating disorders, sexual disorders, personality disorders, child and adolescent psychiatry, and psychiatric and general medical comorbidity.

For example, a person-centered approach to understanding the experience of those affected with dementia with its progressive cognitive impairment, is the maintenance of personhood, a concept coined by Kitwood in 1997 (in [16]). Personhood in dementia has since been used as a key outcome for long-term care and supportive services; it grounds the idea that care for people afflicted by dementia should be value base asserting the absolute value of all human lives, individualized approach, recognizing the uniqueness of every human being, striving to understand the world from the perspective of the person suffering of dementia, and promote a positive social psychology in which the person living with dementia can experience relative well-being.

For substance use disorder (SUD), Person-Centered Psychiatry (PCP) approach is uniquely befitting for the optimal comprehensive assessment and integrated treatment of SUDs. PCP is particularly important for conditions where stigma, discriminations and disparities are pronounced, such as the case of mental illness in general and substance use disorders in particular [17].

In schizophrenia, a bio-psycho-social approach, from biological and epigenetic mechanisms to symptoms manifestation, social functioning and recovery strategies are considered [18].

PCP as model for the management of chronic severe mental disorders such as schizophrenia and bipolar disorders, where there is a high degree of complex clinical presentations and an associated high rate of comorbidity, disability, disease burden and early mortality. The application of a Person-centered Integrative Diagnostic model to the complex problems presented by bipolar disorder contrasted traditional disease-focused approach to diagnosis highlight the suitability of a person-centered approach in addressing the treatment and recovery needs for this highly challenging clinical population [19].

PCP or PCM approaches, integrate effective medical interventions with values-based medicine when they consider the underlying mechanisms involved in the pathogenesis of depression and anxiety as well as the unique illness experiences of the patient. These considerations are indeed articulated by the person-centered integrative diagnosis model (PID). This model promotes the proposed integrative approach with a focus on both symptom presentation and the health and illness experiences of the patient, encouraging a collaborative relationship between the clinician and patient, where there is crucial role for patient perspective and consumer advocacy [20].

A person-centered approach to eating disorder (ED) puts the individual and her/his unique characteristics in the center of the diagnosis, therapy and research. The importance of this model is the focus on recovery addressing all the aspects of the ED: psychological, physical, behavioral, social and interpersonal [21].

For personality disorders, the Person-centered Psychiatry (PCP) is key to the assessment of personality because it allows the promotion of health by stimulating greater self-awareness leading to greater flexibility and resilience, thereby promoting the integration of all aspects of a person's life. Thus, therapeutic mechanisms are embedded into the framework of this model and it offers hope for a group of disorders that have been traditionally viewed as treatment resistant [22].

The Person-centered Psychiatry and Person-centered Medicine approaches are highly relevant for specific psychiatric disorders, as it is for chronic diseases in general. Its application in clinical practice is becoming increasingly important in view of the current urgent need to addressing chronic diseases, achieving recovery and enhancing prevention and public health efforts at the individual and population levels. This entails integration of care and addressing diversity, cultural awareness and health disparities.

26.4 Theoretical Consequences for the Treatments in Psychiatry

Taking a Person-centered perspective in psychiatry has of course considerable theoretical and practical consequences on the therapeutic models. At the core of these therapeutic consequences is the need of Person-centered interventions to be integrative. This integrative characteristic is important in all dimensions of PCP (from primary prevention to treatment), likewise in other fields of medicine at large. But it is even more crucial in psychiatry considering that more than other fields of medicine, psychiatry deals with long lasting conditions, with uncertain etiologies and imprecise delimitations; furthermore, psychiatry is characterized by the fact that most its pharmacotherapeutic approaches are mainly symptomatic, and Sociotherapy particularly needed. Additionally, as in other fields of medicine when dealing with chronic and/or complex illnesses, subjectivity plays a major role in psychiatry. As a consequence, treating the psychologic dimension, has an especially important role in psychiatry either as adjunct treatment or as main psychotherapeutic action which one of pillars of psychiatric cares. It is well documented that Psychotherapy in general is a highly effective form of treatment in psychiatry [23]. It is therefore not surprising that psychiatry is particularly diverse in its therapeutic modalities which include Pharmacotherapy, Psychotherapy and Sociotherapy.

26.4.1 Pharmacotherapy

Pharmacotherapy can and should include elements of PCP and PCM, in order to achieve higher treatment effectiveness. Person-centered (PC) pharmacotherapy has to actively involve the patient in the choice of drugs, trying not only to address the symptoms of the illness but also the individual characteristics of the patient, as well as making them part of the pharmacological selection process to allow them a sufficient mastery of this part of their treatment [24]. Obviously, PC pharmacotherapy does not exclude the elements of traditional pharmacotherapy (such as knowledge in pharmacokinetics and pharmacodynamics), but adds to these considerations other factors that can improve treatment outcomes not only because it can contribute to improve the relevance of the drug choice, but also because it increases the level of patients 'compliance [22].

26.4.2 Psychotherapy

Clearly, the above is also the case for Psychotherapy which needs to be person-centered to be effective. Its base is indeed the person's individual needs [25]; its aims should be in accordance with the patient's personal values and feelings concerning his view of his physical mental social and existential well-being [26]. It means that psychological thinking has to be integrated in psychiatric treatment to consider and understand these dimensions both at a cognitive and subjective level.

Moreover, the multiplicity of the factors involved in mental health, and of the methods and theories aiming at explaining psychic phenomena, require an integrated scientific approach to treatment developed on the basis of an integrative psychiatric and psychological model [27]. This integrative model demands the creation of an integrative theory for personality and psycho-pathology [28].

This methods-integration cannot be a mere theoretical eclecticism referring to various systems that do not need to match epistemologically and ontologically; it needs the creation of something new, defining a super-ordinate level, a kind of meta-theoretical framework of personality [29, 30]. This meta-theoretical framework may be grounded on various perspectives (psychodynamic, phenomenological, cognitive etc.) [31, 32].

In other words, unlike some of these perspectives, Person-centeredness does not compel to select one of these perspectives over all the others: it is an overarching principle of a Person-centered psychotherapeutic model. The criteria for the methods-integration in Person-centered psychotherapy should be the human being, together with an understanding for psychic illnesses and also for constructive, creative development opportunities and should be integrated in a personality model [33]. That is to say, that beside their specific training in the technical model on which they base their psychotherapeutic practice, Person-centered psychotherapists should also be trained to include their personality within the frame of a diversified education. To this end, Ammon [27] recommends a methods-integration within psychotherapy itself encompassing the findings of different branches of science but also aspects of diverse psychotherapeutic schools. All this is put under a central principle, the holistically formulated image of humankind. A person-centered model for methods integration should be measured by the benefit for humans, i.e. to understand better the patients and to develop better healing methods. Accordingly, the theoretical model should never be inflexible; it should be an open system with the possibility of change and constant integration processes. It should then favor a multidimensional approach.

Numerous psychotherapeutic methods (from psychodynamic to CBT approaches through family or milieu Therapies) are fully consistent with this overarching principle which, finally, are more related to the person of the therapist (and to the type of relation he has with his theoretical references) than to the characteristics of the psychotherapeutic schools to which he/she refers. What is crucial here is the place that the relationship between the patient and the health professional gives to Communication in general and more precisely to personal Engagement, Empathy and Subjectivity [34].

The problem is that these dimensions, and particularly subjectivity, are not easy to measure or assess objectively and are therefore frequently neglected or even rejected by Evidence-Based Psychiatry which, even more than most other branches of medicine, needs to resort to a medicine centered on the disorders to compensate for its fundamental uncertainty.

As this concern for subjectivity emerged in the Person-centered elaboration, one of the main endeavors of PCP was to address this issue, trying to find a "scientific" or at least "a non-metaphysic" way to assess the non-objective aspects of the patient, his carers, and the psychotherapist.

To elaborate on this stake PCP started with the detailed description of how the relational process is evolving naturally in settings in highly emotional relationships like those which develop in most relations between a Person seeking care and a Psychotherapist [35]

1. The first step is what we propose to name the "Emotional Empathy" defined as the feelings induced in the psychotherapist by his relation with the patient, through verbal and behavioral interactions. It is favored by "the affective permeability" induced by the process of constructing a common space in highly emotional situations (Botbol et al. [36], Chap. 10 in this book). We consider it as the first methodological step to go behind the screen of the visible and a holistic way to approach subjectivity of the patient as a holistic dimension.
2. The second step is what may be called a "Metaphorizing Empathy": It is the narratives which occurs "naturally" in the psychotherapist if he does not reject actively the emotions triggered by his Emotional Empathy. The psychotherapist captures these emotions through his capacity to transform them into narrative by metaphorizing them (put them into a story). These stories are of crucial importance because they are the best way for the psychotherapist to access, acknowledge, and give

meaning to his empathic subjective feelings about the patient. These narratives integrate (but are not reduced to) the patient's narratives to which the psychotherapist has to be attentive enough to include them among the data he consciously or unconsciously integrates in the construction of his narrative. In other word this second step is a transformation of an Emotional Mirror Empathy into a Narrative Metaphorizing Empathy [37]; it uses the professionals' representations and affects to approach and understand the patient subjectivity and integrate it in the assessment of his health status and shared decision making concerning his treatment.

3. Additionally, one has to be aware, however, that to develop his narratives, the psychotherapist uses his idiosyncratic sensitivity which recognize and highlight specific aspects of the patient's subjective life. It is acceptable only if the psychotherapist acknowledges that this story is a construct in which he is subjectively involved. The third step of the Narrative Empathy process in therefore the psychotherapist's deliberation on his narratives. In this internal deliberation the psychotherapist has to elaborate on the part he is taking in this subjective construct; he has particularly to keep in mind two risks he has to control because they both lead to neglecting the patient's subjectivity: (i) to be not enough inferential loosing the unique way to get access to the patient's unexpressed or unconscious feelings or representations or (ii) conversely to be too inferential and impose his idiosyncratic feelings and representations over those of the patient.

Our hypothesis is that, whatever the school to which he/she refers, a psychotherapist has to go through this basic process if he wants to access the subjectivity of the patient, which is a condition to be genuinely Person-centered. In other word this process could be seen as one of the general psychotherapeutic factors mentioned by Fonagy in its research on psychotherapies evaluation [38].

Furthermore, our hypothesis is that, with the extension of this PCP's principles to medicine in general, this process is also involved in any Patient-Health Professional relation (beyond psychotherapy) whenever the HP wants to integrate subjectivity in the relevant dimensions of his understanding of a person, that is whenever he wants to be Person-centered [36]. It is of course a step forward towards the extension to medicine at large, what psychiatry and psychotherapy have forged in their quest for a non-metaphysical way of integrating subjectivity in PCP [36].

26.5 Sociotherapy

Obviously, this has to be also the case concerning sociotherapy, which has to focus mainly on the social dimension of human experience in both its objective and subjective aspects rather than on its biological psychopathological aspects [39]. In that sense, Sociotherapy should not be seen as a competitor to other forms of treatment, but as a complement contributing to alleviate human suffering. In Psychiatry as in other part of Medicine, Person-centered Sociotherapy has to know the individual, his interpersonal relationships and his environment, in order to be able to intervene in the way this specific individual interacts with his environment or in his environment itself [40].

In this frame, **rehabilitation plays a major role in psychiatry**. In its Person-centered model, it has to integrate the notion of **Recovery,** which is "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles "[41] regarding the illness and its consequences. It is of course particularly important in Psychiatry in which stigmatization is frequently adding to the burden of the disease. In this context, Recovery "is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness" [41].

Recovery in Psychiatry intends to achieve psychosocial rehabilitation so that patients reach an optimal level of functioning in the community, with the maximum degree of autonomy. It includes improving individual skills but also introducing some changes in society in order to create opportunities for people who suffer/have suffered from mental illness, and allow them to live with a good level of quality of life.

Marianne Farkas has proposed the notion of PCPR (personal center psychiatric rehabilitation/recovery to encompass all these needs: She considers that it is a special kind of recovery based on four main values: (1) Personal Orientation (includes seeing the person holistically, taking into account the person's physical, emotional and intellectual functioning); (2) person involvement (the meaningful involvement of the patient in all the planning and the process of recovery is essential); (3) choice or self-determination (it is important to consider where and in what role the patient wants to live); (4) hope (trying to take into account the patient's personal aspirations and possible changes that can be made so that these aspirations can be achieved) [42].

26.6 Practical Implications for the Implementation of Person-Centered Care in Psychiatry

As already mentioned psychiatry and psychology are currently facing strong pressure to come closer to the biomedical paradigm of a Disease centered Evidence-Based Medicine they put at the top of their agenda. As discussed earlier, the fact that most psychiatric nosographical categories are far from reaching the same level of objectivity as most of the nosographic categories in other medical fields, does not temper this ambition but, on the contrary, reinforced it insofar as, for lack of sufficient biological criteria to define the psychiatric categories selected, nosography is responsible for defining what cannot be defined otherwise. Thus, although international classifications warn against the risk of over-naturalization of these categories, it is precisely on this potential drift, that much of the works and practices of disorder-centered psychiatry and psychology are grounded. Under these conditions, it becomes imperative that the definition of these categories be strictly objective. As a consequence, it is imperative for disorder-centered psychiatry and psychology to, at least, eradicate every subjective or relational and circumstantial aspects which are not consistent with the “physiopathological bet” [6] underlying this perspective. As we saw it earlier, it is exactly what Person-Centered-Psychiatry aims to correct by relying on several of the conceptual propositions we have evoked in this chapter, particularly the PID and the questions relating to the integration of subjective aspects in the evaluation and cares it proposes, involving the patient, his/her carers, and the professionals alike. Inevitably the practical implementation of these conceptual propositions comes up against the force of the arguments opposed to it by the disease-centered perspective it seeks to modify. These arguments are both conceptual and practical.

Born from the desire to bring medicine back to what it should never cease to be, the promotion of medicine of the person is above all the promotion of a medicine which puts the whole of the person and not just its disease at the center of its objectives and of its care. The fist difficulty for PCP is to show that it is not as commonplace and obvious as some of those who criticize the need for such a claim to defend a thesis that, supposedly no one would dispute in psychiatry, precisely because it is, mainly, a clinical discipline The denial comes in fact from practices which tend to focus on the disorder by relegating to the rank of adjuvants, remedies based on obscurantist methodologies and concepts, the attention given to subjectivity and contexts in the evaluation and the treatment of the patient. Of course, these critics do note deny that individualization of treatment is a categorical imperative of Psychiatry as much as it is for medicine at large, including its disease centered version. Admittedly, also, immense progress has been made in many places of the world concerning the respect of the rights of patients, especially in Psychiatry and Mental Health; but it is above all, the application to the suffering man of the democratic and legal rules which are valid for anyone and are mostly the affirmation of the right of patients not to be excluded from the benefit of common legal and democratic rules, on the grounds that they need care. This respect is of course the least of things, for the patient as for any consumer or user regardless of the service to which he claims to access; but it is more up to the application to each of the rules of law that apply to all than to the recognition of the subjectivity of the person of the patient, as it is the declared ambition of PCP. In short, this means that PCP cannot be reduced either to the individualization of care or to respect for rights since it aims at something more: the recognition of the individual subjectivity of the patient’s person, its totality beyond what characterizes his illness or his sick status. What becomes crucial here is the commitment of the person of the Mental Health Professional (MHP) to the person of the patient and with him, to the extent of the patient’s need for care in his irreducibly singular vital situation.

This specific requirement imposes on the PCP to introduce important modifications in at least two crucial areas: **education and training of MHP on the one hand and clinical practices on the other hand.**

Beyond the place that it must give to PCM principles and their declension in psychiatry and psychology**, education and training of MHP** should stress the particularity of the relations between most nosographical categories in psychiatry and natural facts. It means that the education and training of MHP can be person-centered if, and only if, it integrates into teaching, the idea that, beyond nosography, which is no more than a small part of the diagnosis of the patient's health status, the assessment of the care situation must also integrate:

- The other levels and aspects which are considered in the PID
- And the conditions required to access the patients' subjectivity: that is, without neglecting the objective aspects of their state of health, to acknowledge that subjectivity is not only a negative bias in the therapeutic relation but also a valuable tool to access and integrate subjectivity, and that there is no empathy without subjectivity. This implies the inclusion of a specific training on team-work and individual and/or collective deliberation to control and regulate this promotion of subjectivity of the MHP in their clinical practices

This has to translate into clinical practices which have to implement it concretely in the practices using the different available methods: case studies, supervision, practice analysis, or intervision (i.e. on the model of Balint groups) [43, 44].

Complying with these conditions should be the yardstick for assessing the reality of establishing PCP or transitioning from a disease-centered perspective to a person-centered one.

These requirements are also relevant for **Primary Prevention and Mental health in general** in psychiatry, as much as it is in medicine in general; indeed, nosocentric approaches are generally considered an obstacle for health promotion and primary prevention. Preventive psychiatry, must indeed include not only the individual but also their circumstances; it is and must be holistic and person-centered by nature. Conversely, because it deals with the totality of a person existence and needs, Person Centeredness is the ideal strategy [1, 45] in prevention at large.

26.7 Conclusions

Because of the uncertainty of the relation between its current international nosographical systems and of the role played by psychological and subjective dimensions in its contributing factors and its categorical and dimensional delimitations, Psychiatry is particularly vulnerable to a disorder centered approach. It is therefore not surprising that, in its scope and fields, it is in psychiatry that Person-centeredness emerged (or re-emerged) in health-related issues. However, it is the extension of its principles to Medicine at large that made it become the movement it is today. Strengthened by the extension and diversification of its principles and of its ambitions, PCP is now a part of PCM with which it shares the ambition of contributing to improve the health system and the service it brings to patients and to their carers, without losing sight of the need to protect the health professionals and their working conditions in order to foster their genuine personal subjective engagement.

Acknowledgements and Disclosures The authors do not report any conflicts of interest concerning the preparation of this paper.

References

1. Botbol M, Banzato C, Carulla LS. Categories, dimensions, and narratives for Person-centered diagnostic assessment. Int J Person-Centered Med. 2012;2(2):196–200.
2. Duhem P. La théorie physique, son objet, sa structure [The physics' theory, its object, its structure]. Paris: Chevalier et Rivière; 1906.
3. Hacking I. A tradition of natural kinds. Philos Stud. 1991;61(1–2):109–26.
4. Kirsch M. La connaissance des choses: définition, description, classification [The knowledge of things: definition, description, classification]. Phiopsis e-e-edition; 2008.
5. American Psychiatric Association. DSM IV TR. Arlington, VA: American Psychiatric Publishing; 2000.
6. Banzato CEM, Mezzich JE, Berganza CE. Philosophical and methodological foundations of psychiatric diagnosis. Psychopathology. 2005;38(4):159–61.
7. Mezzich JE, Salloum IM, Cloninger CR, Salvador-Carulla L, Kirmayer L, Banzato CE, Wallcraft J, Botbol M. Person-centered integrative diagnosis: conceptual bases and structural model. Can J Psychiatr. 2010;55:701–8.
8. Salloum IM, Mezzich JE. Conceptual appraisal of the person-centered integrative diagnosis model. Int J Pers Cent Med. 2011;1:39–42.
9. Mezzich JE, Berganza CE, von Cranach M, Jorge MR, Kastrup MC, Murthy RC, Okasha A, Pull C, Sartorius N, Skodol AE, Zaudig M. Essentials of the WPA International Guidelines for Diagnostic Assessment (IGDA). Br J Psychiatry. 2003;182(Suppl):45.
10. Asociación Psiquiátrica de América Latina. Sección de Diagnóstico y Clasificación. Guía Latinoamericana de Diagnóstico Psiquiátrico, Version revisada (GLADP-VR). Lima: Asociación Psiquiátrica de América Latina; 2012.
11. Seyer J. Development of the health improvement card developed by the world health professions alliance. Paper presented at the 5th Geneva conference on Person-Centered Medicine. International College of Person-Centered Medicine; 2012.
12. Dyson M. Some problems concerning knowledge in Plato's Charmides. Phronesis. 1974;19:102–11.
13. Brundtland G. Preface to mental health: a call for action by world health ministers. Ministerial rounds at the 54th world health assembly. Geneva: World Health Organization; 2001.
14. Wagner P, Perales A, Armas R, Codas O, de los Santos R, Elio-Calvo D, Mendoza-Vega J, Arce M, Calderón JL, Llosa L, Saavedra J, Ugarte O, Vildózola H, Mezzich JE. Latin American bases and perspectives on person centered medicine and health. Int J Pers Cent Med. 2014;4:220–7.
15. Mezzich JE, Botbol M, Christodoulou G, Cloninger R, Salloum IM, editors. Person centered psychiatry. Heidelberg: Springer Verlag; 2016.
16. Brooker DJ, Snaedal J. Dementia. In: Mezzich JE, Botbol M, Christodoulou G, Cloninger R, Salloum IM, editors. Person centered psychiatry. Heidelberg: Springer Verlag; 2016. p. 309–24.
17. Abou-Saleh M, Tarter R, Salloum IM. Substance abuse. In: Mezzich JE, Botbol M, Christodoulou G, Cloninger R, Salloum IM, editors. Person centered psychiatry. New-York: Springer; 2016. p. 325–43.
18. Gaebel W, Zielasek J. Schizophrenia and related disorders. In: Mezzich JE, Botbol M, Christodoulou G, Cloninger R, Salloum IM, editors. Person centered psychiatry. Heidelberg: Springer Verlag; 2016. p. 354–62.
19. Salloum IM, Christodoulou G. Bipolar disorder. In: Mezzich JE, Botbol M, Christodoulou G, Cloninger R, Salloum IM, editors. Person centered psychiatry. Heidelberg: Springer Verlag; 2016. p. 363–72.
20. Campbell MM, Stein DJ. Depression and anxiety disorders. In: Mezzich JE, Botbol M, Christodoulou G, Cloninger R, Salloum IM, editors. Person centered psychiatry. Heidelberg: Springer Verlag; 2016. p. 373–80.
21. Gonidakis F, Lancien AS. Eating disorders. In: Mezzich JE, Botbol M, Christodoulou G, Cloninger R, Salloum IM, editors. Person centered psychiatry. Heidelberg: Springer Verlag; 2016. p. 381–92.

22. Cloninger CR, Svrakic DM, Lester NC, Lecic-Tosevsky D, Koldobsky N, Botbol M. Personality disorders. In: Mezzich JE, Botbol M, Christodoulou G, Cloninger R, Salloum IM, editors. Person centered psychiatry. Heidelberg: Springer Verlag; 2016. p. 427–44.
23. Solms M. The scientific standing of psychoanalysis. BJPsych Int. 2018;15(1):5–8.
24. Jakovljevic M, Abou-Saleh M. Person centered psychopharmacotherapy. In: Mezzich JE, et al., editors. Person centered psychiatry. Cham: Springer; 2016. p. 235–46.
25. Cloninger CR, Zohar AH, Cloninger KM. Promotion of well-being in person centered mental health care. Focus. 2010;8(2):165–79.
26. Cloninger CR, Cloninger KM. Person centered psychotherapy. In: Mezzich JE, et al., editors. Person centered psychiatry. Cham: Springer; 2016. p. 247–61.
27. Ammon G. Methodenintegration aus der Sicht der Dynamischen Psychiatrie. In: Ammon G, editor. Handbuch der Dynamischen Psychiatrie 2. München: Reinhardt; 1982. p. 25–48.
28. Ammon M. Dynamische Psychiatrie, ein integratives theoretisches und praktisches multidisziplinäres Behandlungskonzept. Dyn Psychiatry 2014;47(262–263):89–107.
29. Lazarus A. The practice of multimodal therapy: systematic, comprehensive and effective psychotherapy. New York: McGraw-Hill; 1981.
30. Lazarus, Arnold (1984): Multimodal therapy, in: Raymond Corsini, Current psychotherapies. Itasca: Peacock.
31. Lazarus A. In support of technical eclecticism. Psychol Rep. 1957;21:415–6.
32. Petzold H, Orth I, Sieper J. Erkenntniskritische, entwicklungspsychologische, neurobiologische und agogische Positionen der "Integrativen Therapie" als "Entwicklungstherapie". In: Petzold H, Shay P, Scheiblich W, editors. Integrative Suchtarbeit. Innovative Modelle, Praxisstrategien und Evaluation Wiesbaden: VS Verlag für Sozialwissenschaften; 2006. p. 627–713.
33. Beitman BD, Goldfried MR, Norcross JC. The movement toward integrating the psychotherapies: an overview. Am J Psychiatry. 1989;146(2):138–47.
34. Botbol M. Conclusion générale. Du manifeste au subjectif: ce qu'est la médecine de la personne. In: Kipman SD, editor. Médicine de la personne: un manifeste collectif qui s'adresse aux médecins, soignants, malades et décideurs. Paris: Wolters Kluwer; 2012. p. 317–26.
35. Botbol M, Lecic-Tosevsky D. Subjectivity, intersubjectivity and psychological functioning. In: Mezzich JE, Botbol M, Christodolou GN, Cloninger RC, Salloum I, editors. Person-centered psychiatry. New York: Springer; 2016.
36. Botbol M, Adams N, Mezzich JE. Establishing common ground, engagement and empathy. In: Mezzich JE, Appleyard WJ, Glare P, Snaedal J, Wilson CR, editors. Person centered medicine. Cham: Springer; 2023. [Ahead to print].
37. Lebovici S. Arbre de vie: Éléments de Psychopathologie du Bébé [The tree of life: principles of infant psychopathology]. Toulouse: Eres; 1999.
38. Roth A, Fonagy P. What works with whom? A critical review of psychotherapy research. London: The Guilford Press; 2006.
39. Probst B. In: Mezzich JE, et al., editors. Person centered psychiatry. Cham: Springer; 2016. p. 263–75.
40. Williams J, Karls JM, Wandrei K. The Person-in-Environment (PIE) system for describing problems of social functioning. Hosp Commun Psychiatry. 1989;40(11):1125–7.
41. Anthony WA. Recovery from mental illness: the guiding vision of the mental health service system in the 1990s. Psychosoc Rehabil J. 1993;16(4):11–23.
42. Farkas M, Anthony W, Montenegro R, Gayvonskaya E. (2016) Person centered sociotherapy. In Mezzich JE et al. Person centered psychiatry. Springer Cham: p 262–275.
43. Nease DE, Lichtenstein A, Pinho-Costa L, Hoedebecke K. Balint 2.0: a virtual Balint group for doctors around the world. Int J Psychiatry Med. 2018;53:115–25.
44. Otten H. The theory and practice of Balint group work: analyzing professional relationship. Routledge; 2017.
45. Mezzich JE, Kallivayalil RA, Bennegadi R, Botbol M, Christodolou G, Cozman D, et al. Articulating social psychiatry and Person-centered medicine: conceptual bases and international implications for Covid-19. World Soc Psychiatry. 2020;2:58–68.

Chapter 27
Person-Centered Emergency Medicine

Al O. Giwa, Cailey Simmons, Christopher Clifford, Melissa Villars, Clifford Marks, and Demis Lipe

27.1 Introduction

Emergency Medicine's founding and practice have long been intertwined with bioethics and the principles of ethics. Principlism, which dominates the modern code of ethics within healthcare, dictates a practice of medicine that is inherently person centered [1]. Beneficence, non-maleficence, respect for autonomy, and justice are best achieved when a physician understands and treats their patients not as just a vessel for an illness, but as human beings; acknowledging and respecting their norms, beliefs and values [2]. Person-centered medicine (PCM) reorients the practice of medicine to bring physicians back to these basic ethical principles of care. In no other setting does this reorientation become more crucial than in the fast paced, critical care environment of the Emergency Department (ED).

Person-centered medicine goes a step beyond the more widely circulated term patient-centered medicine. Patient-centered medicine laudably seeks to put the patient at the center of their health care journey—incorporating their values, preferences, and expressed needs into decisions regarding their care. However, modern scholars and medical practitioners have elevated their consciousness to the concept of person-centeredness to emphasize that each person seeking medical care is more than a diagnosis or a chief complaint—they are humans whose needs and values stretch far beyond the confines of an ICD code [3].

A. O. Giwa (✉) · C. Simmons · C. Clifford · M. Villars · C. Marks
Department of Emergency Medicine, Icahn School of Medicine at Mount Sinai,
New York, NY, USA
e-mail: al@bema.nyc; cailey.simmons@mountsinai.org

D. Lipe
Department of Emergency Medicine, University of Texas—MD Anderson Cancer Center,
Houston, TX, USA

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_27

Emergency medicine poses unique challenges to those seeking to practice in such a person-centered manner. A walk through a busy ED on a typical day lays bare some of the core obstacles: too many patients, too little time, and too few resources and staff. The notion that a provider under these conditions would or should fully engage on a human level with each of their patients will strike some in the field as unrealistic. And indeed, a clear-eyed assessment of how providers practice emergency care today must acknowledge how very far we are from this ideal.

Nonetheless, a number of departments have pioneered innovative ways to adapt the principles of person-centeredness to the acute care setting. In doing so, they have shown not only that PCM has a home in the Emergency Department (ED), but also that there are aspects of acute care that make person-centeredness particularly vital to the provision of high-quality care. In this chapter, we will detail the burgeoning PCM movement in Emergency Medicine, explore the challenges facing such efforts, and discuss future opportunities for person centeredness within the ED.

27.2 Person-Centered Care in Emergency Medicine

A number of clinicians and hospitals have already demonstrated the potential of person-centeredness to improve care in the ED. Among the clearest examples is the use of shared decision-making to better align clinical decisions with an ill person's values instead of the traditional paternalistic physician determined treatment plan. Shared decision-making is defined as "an approach to care that seeks to fully inform patients about the risks and benefits of available treatments and engage them as participants in decisions about the treatments" [4]. While a handful of patients may prefer to defer entirely to the judgment of their physician, the vast majority of patients value having a say in their medical care. Indeed, a recent multi-center survey of ED patients found 98% wanted to be involved in medical decision-making for a serious health issue and that 94% agreed with the statement "If given enough information, I am capable of participating in decisions about my medical care" [5].

Well implemented shared decision-making can do more than provide patients a sense of self-efficacy—it can actually change care in a way that improves outcomes and lowers cost. A multi-center trial of care for low-risk chest pain patients found use of a shared decision-making aid reduced the number of admissions without any increase in cardiac events [6].

This model of person centeredness is not without its challenges in the ED. The framework for ED shared decision-making elaborated by Probst et al. looks at three factors to assess whether such an approach is appropriate: clinical uncertainty, patient decision-making ability, and time [7]. Clearly time is in particularly short supply in the acute care setting, both because of the acuity of conditions and due to the competing demands of other patients. Another factor in shared decision-making that has not been well explored, but is particularly relevant to ED care, is whether and how to integrate cost into shared decision-making conversations. In this era of out-of-network physician groups and balance billing, patients may be charged astronomical sums for ED care. Any attempt at informed decision-making that omits such a financial burden cannot fully capture the costs and benefits of the choice the patient is being asked to help make. However, efforts to incorporate cost run afoul of deeply held views on the separation between care decisions and cost. Beyond that, the fragmented U.S. payer landscape can make providing accurate cost estimates a near impossibility.

Some emergency departments (EDs) have also sought to adapt their physical space and workflows to better address the needs of specific patient subsets. Pediatric EDs provide an early example, particularly in their use of Child Life services—a practice that began as an inpatient offering but has become commonplace in pediatric EDs since the early 1990s. A number of studies demonstrate that Child Life interventions reduce patient anxiety and their perceived pain levels [8–10].

More recently, emergency departments have begun trialing ED divisions devoted to other patient subgroups. Some emergency departments have experimented with palliative care models to serve those with terminal illnesses—these interventions include screening questionnaires, closer integration with inpatient palliative care services, and adding dedicated ED staff for palliative care screening and coordination [11]. Currently, several institutions are embarking on a landmark study (PRIM-ER) to study and train ED staff on the necessary discussions for the type of care wanted at the end-of-life [12]. Programs such as "Education in Palliative and End-of-life Care" or EPEC, offered by Northwestern Medicine, teaches emergency physicians how to quickly perform a rapid palliative care assessment in the ED. They also provide education on hospice medicine as well as how to assess patients for psychological, spiritual, and social needs. It is programs like these that are helping ED providers transition from patient centered medicine to person centered medicine.

Just 15 years ago, there were few if any EDs with specialized care for geriatric patients. Today, the American College of Emergency Physicians is actively encouraging the development of geriatric EDs with a three-tier accreditation system based on the availability of specially trained staff and environmental features, such as non-slip floors, easily available walking aids, and soft or natural light to reduce the rate of delirium [13].

The box opposite this page presents one of the more intriguing recent examples of person-centered emergency medicine: an ED at the MD Anderson Cancer Center designed to address the particular needs of cancer patients.

An Oncologic Emergency Department

Despite the incidence of cancer continuing to rise over the last 20 years in the U.S., the 5-year survival rate of most cancers is improving. This has led to a need for specialized emergency departments that respect the totality of the person with cancer. Over half of the people with cancer presenting to the ED are admitted to the hospital. They not only have complex medical histories, but also complex social, mental, and ethical end-of-life issues. Caring for people with advanced and terminal illnesses requires the clinician to see the person as a whole; incorporating the physical, emotional, and spiritual needs of the person into their medical care. One of the goals of the oncologic ED is to relieve suffering of people with advanced illness as well as provide emergent care.

In 2010, The University of Texas, MD Anderson Cancer Center created the first cancer focused ED within a comprehensive cancer center. Shortly thereafter in 2015, The James Cancer Hospital's ED opened as part of an integrated portion of The Ohio State University's Medical Center ED. Similarly, the urgent care center (UCC) associated with Memorial Sloan Kettering Cancer Center in New York City, which has similar capabilities to an ED for people with cancer, offers a 21-bed acute care unit which is open 24 h a day, 7 days per week.

Specialized EDs have the advantage of offering a more individualized approach to the care of the person with cancer. Additionally, the patients who present to these EDs are already associated with the cancer center, making their information sharing, integrated communication, and interdisciplinary approach to care-planning much easier. This approach also offers an environment and organizational culture that is more in-line with most people's expectations. It is common for individuals with cancer to present to the ED for either complications related to their cancer treatment or due to problems caused by the cancer itself. In this case an interdisciplinary team that is familiar with these complications and treatment side effects, as well as having a good understanding of end-of-life care, can potentially provide superior, individualized, goal-oriented care for this specific population.

Given the international reputation of many specialty cancer centers in the U.S., a key demographic is the international patient and their loved ones. Cancer is already a life-changing condition and seeking care far from home adds still further stress to the patient and their family. MD Anderson has an international center to be able to help patients with their transition into the local area. International patients have an international patient representative assigned to them to guide them not only through appointment preparations and unexpected ED visits, but also offer assistance with visas, help with transportation, interpreter services, as well as other cultural and religious amenities.

All these offerings serve the same overarching purpose: treating not just the patient's disease but rather the whole patient. It is the hope of the oncologic EDs within cancer centers to focus on respecting human life and the person's autonomy, instead of succumbing to a blind desire to extend life at the expense of those aspects of life our patients hold dear.

These initiatives show the potential of person centeredness to improve the care we deliver in the ED. However, successfully expanding on these will require adapting our interventions to the unique difficulties inherent in the acute care setting.

27.3 Challenges to Person-Centered Care in the Emergency Department

The environment of the ED is arguably one of the more challenging to establish a culture focused on person-centered medicine. Emergency medicine focuses on rapid stabilization, diagnosis, and disposition. 'Sick or not sick' rather than a person's norms, beliefs, and values is classically the central question in the traditional ED setting. Consequently, the space, time, and infrastructure needed to provide thorough person-centered care is often lacking. This section will focus on each aspect of the environment divided into challenges based on time, space, and infrastructural barriers.

The challenges involving time include those based on a reversing of the medical-management timeline, leading to the prioritizing of management over preferences for the sake of saving time. One of the major pillars of person-centered medicine is the focus on collaboration between the provider, the person being treated, and their family in order to ensure their goals, values, and socioeconomic considerations are incorporated into care [14]. The standard application of this is through a timeline that starts with the initial assessment which incorporates a discussion of goals with the patient and family, followed by gathering of additional information to drive a diagnostic decision, and ultimately a dialogue with the patient on direction of medical management. However, in many emergent situations the timeline is reversed, as medical management becomes the first and foremost focus. Initial instability of many patients arriving to the ED creates an environment in which intervention takes precedence over discussion. The pressured environment can force patients to confront weighty decisions without adequate time to process their options. This time pressure creates a fundamental barrier to providing PCM and may lead to treatment decisions that do not align with a patient's values.

Take as an example the elderly or palliative care populations that present to the ED without a surrogate and lacking capacity to make healthcare decisions. In a recent study of patients presenting to an ED with Medical Orders for Scope of Treatment (MOST) forms, 69% were incomplete [15]. In another, a considerable majority had no formal prior conversations regarding end-of-life care [16]. In emergent situations this leads to physicians making decisions about a patient's care based not on their values but rather on the emergent need for treatment [15]. Put simply, there is no guarantee that EM providers will have the time needed to engage in truly person-centered medicine.

Physical space within the ED also poses a barrier to providing PCM. ED overcrowding is a concerning national issue that is associated with decreased patient safety, treatment delays, and even increased mortality rates [17]. It also poses a large barrier to the capacity to provide person-centered medicine in the ED. As department overcrowding worsens, the resources to patient ratio declines [18]. This translates to decreased space per patient, with even newer EDs designed with private rooms sometimes forced to deliver care in spaces separated by curtains or in open hallways. Less physical space means less patient privacy—not only a prerequisite for sensitive PCM conversations but required by U.S. law (HIPPA) and hospital regulatory and certifying agencies such as The Joint Commission [19]. Family members may also have trouble fitting into the provided space to be engaged in the decisions made about a loved one's care.

As the number of patients in a department swells, so do the noise and patient levels of post-traumatic stress disorder related to ED visits [20, 21]. Certain patient populations may be more susceptible to adverse effects of these chaotic environments than others. The creation of dedicated EDs, such as those for pediatrics, psychiatric emergencies, or geriatrics, reflects a burgeoning effort to address such challenges to delivering PCM in the ED setting.

Overcrowding also has deleterious effects on providers' ability to dedicate the time and mental energy needed to engage in PCM, as interruptions multiply and the time for each individual patient declines [22]. With this comes a decrease in physician capacity for empathy and dedicated time to explore a patient's values, goals, and beliefs. Since lack of time is one of the key barriers physicians perceive as preventing them from having the conversations necessary for PCM, overcrowding directly impairs providers' ability to deliver person-centered care. In a world of limited time per patient, it becomes considerably easier to take the cognitively easier shortcut of ordering sometimes unnecessary or undesired diagnostic tests without taking into account individual patient preferences [23–25].

The final collection of challenges stems from those related to infrastructure. Many EDs recognize the importance of PCM and include full-time positions for social workers or patient advocates. While these professions play a vital role in helping to provide PCM in the ED, additional infrastructure is lacking. The reimbursement model of emergency medicine, like that for most fields, rewards procedures and high patient turnover. The metrics are focused on time to seeing a patient, time until disposition, and in some cases, time to intervention. However, in current payment models there exists little incentive to engage in or document patient conversations surrounding goals, beliefs, and values. Lastly, the lack of continuity within the ED lends itself to a need to communicate the conversations with the patient to the subsequent provider. At present, however, these transitions of care are huge sources for missed information.

Despite these challenges, the environment of the ED also provides unique opportunities for person-centered medicine. EDs are society's safety net, with access not restricted by time of day, day of the week, or ability to pay. Patients for whom the outpatient network has failed frequently reconnect to medical care through the ED. This difficult time in a patient's life provides a chance to connect and have the conversations necessary to provide care that centers on patients' goals, values, beliefs, and cultures. The next section will examine novel approaches to addressing some of these challenges.

27.4 The Future of Person-Centered Care in Emergency Medicine and Practical Implications

Perhaps the most important step forward in advancing person-centered care in the emergency department is the recognition of acute care's value in the medical care at home model. While many chronic and primary care visits perhaps would be avoided in a more person-centered system, EDs—in their accessibility and resources—play a critical role in providing both expedient and integrated care. Despite the proliferation of urgent care centers and attempts at offering extended access to primary care physicians, the growth in the rate of emergency visits continues to outpace population growth. With an aging and increasingly medically complex population the likelihood is high that the trend towards increased ED utilization will continue.

Despite the challenges facing the emergency care system, many mechanisms already exist to make emergency care more person-centered. Through at-home telemedicine consultations and paramedic health units, EDs have expanded their reach into people's homes. For instance, Memorial Sloan Kettering Cancer Center has set up a Tele-Triage program that allows patients to get care input from MSKCC providers while seeking care at regional centers closer to home. This program has resulted in expedited discharge for the patients using Tele-Triage. Those who had radiologic studies ordered via Tele-Triage and done prior to checking in at the UCC were discharged over one and a half hours earlier [26]. In the wider community, some pre-hospital systems are looking to eliminate the one-size-fits-all model that reflexively funnels 911 patients to the ED in favor of triage systems that adapt disposition decisions to the person's actual needs. Community paramedicine programs, such as the paramedicine program run through the Mount Sinai Hospital System, create a collaboration between Emergency Medical System (EMS) providers, telemedicine physicians and visiting nurse services to deliver appropriate, person centered care in a patient's home when possible avoiding unnecessary or unwanted ED visits [27]. The U.S. government will soon (currently scheduled for Fall 2020) actively encourage similar prehospital services through its Triage, Treat, and Transport model, which will begin paying prehospital providers to treat in place or transport to primary care offices when clinically appropriate—presently, transporters are only paid for delivering a patient to the hospital [28]. This shift in payment models will help increase innovation and promotion of person-centered medicine throughout the EMS and emergency systems [29]. Programs like these have the potential to better address the needs of specific populations, including the worried well, those with primary care concerns, and patients with acute-on-chronic illnesses. In so doing, they can prevent unnecessary ED visits, reduce crowding, and avoid superfluous workups.

Multi-specialty hubs have also been put forth as an alternative to Emergency Departments in the USA; a landscape where many hospitals are consolidating (or closing) and many hospital based EDs are decreasing while the number of ED visits increase [30]. Multi-specialty hubs, in contrast to free-standing EDs, focus integrated care that aligns with and utilizes a patient's existing care plan and specialty input. Healthcare systems, such as Kaiser Permanente and Mid-Atlantic States, preferentially utilize urgent care centers that focus on seeing less acute illnesses, same day specialist referrals, and direct admissions to participating hospitals when necessary [31].

At the same time EDs have been expanding the resources within their departments to better address the care needs of different subsets of patients. For patients with low health literacy or access to medical care, some EDs have added health educators, patient advocates, financial counselors, and 24-h social work coverage. EDs often find themselves at the front line of addressing the many and varied needs of socioeconomically disadvantaged and marginalized members of our society. Examples abound of the efforts that emergency providers have made towards meeting these needs. EDs provide person focused care following sexual assault through use of Sexual Assault Nursing Examiner (SANE) and Sexual Assault Forensic Examiner (SAFE) programs [32, 33]. In response to violent crime, the impacts of which are felt throughout every ED, physicians across the country have responded. There are more than 30 programs spanning over 15 states focused on preventing interpersonal violence that were either started by or work in coordination with ED staff [34]. Emergency providers have created screening tools for domestic violence [35], established programs to provide comprehensive services to U.S asylum seekers that are survivors of torture and human rights abuses [36], and provided system wide means for direct connections to recourses following narcotic overdoses [37]. From providing legal aid to refugees and asylum seekers to preventing gun violence and human trafficking, emergency providers have and will continue to recognize the specific needs of their communities and build structures and organizations to address them.

Emergency medicine has also made strides in addressing chronically ill and medically complex patients with frequent readmissions. For these patients, EDs have attempted to address the specific cause of frequent readmission, such as: difficulty obtaining medications or supplies, gaps in understanding of complex medical problems, barriers to accessing care, etc. Many EDs have begun staffing case managers and working with our colleagues in internal medicine and other specialty services to meet patients at their level of access and understanding by providing visiting nurses and at-home hospital services. In these examples the use of non-medical, nursing, and mid-level providers significantly augment a physician's and the system's ability to provide person-centered care while at the same time making acute care less episodic and more integrated into the health system.

On a provider level there has been a new emphasis in many emergency medicine residencies to better understand and respect an ill person's goals of care in the acute setting. Resident education has shifted to include topics focused on expanding the knowledge and delivery of person-centered medicine. Over 65% of residencies now have formal didactic education on cultural competency and that number is growing

[38]. Additionally, over 50% of residencies have added palliative care rotations and curriculum to address end of life care [39]. Despite these expansions a need still exists for a cultural shift with legal and reimbursement reform to promote enhanced communication, shared decision-making, and decreased “interventionalism.” Our current focus on moving people through EDs as quickly as possible, and on standardized workups and care bundles, can dampen patient autonomy. As long as our current legal and reimbursement climate favors providers who do more rather than less, many providers will inevitably shy away from efforts at shared decision-making.

Adult EDs might consider taking a cue from their pediatric counterparts in focusing more carefully on ways to decrease patient anxiety, particularly with procedures such as paracentesis, which need to be done urgently but still allow for some preparation time. Guided meditation has shown some promise in such scenarios: Ratcliff et al. performed a randomized control trial where they analyzed guided meditation for women undergoing stereotactic breast biopsy. While guided meditation did not appear to decrease pain, it did reduce anxiety during the acute medical procedure [40]. EDs might also consider acupuncture for the same purpose. Though there are certainly substantial logistical hurdles to its use in acute settings, it is worth noting that patients receiving acupuncture in an inpatient setting reported significant improvement after treatment for pain, sleep disturbances, anxiety, nausea, and fatigue [41].

27.5 Conclusions

There is broad recognition within Emergency Medicine that person-centeredness is a desirable aim. But there also exists a skepticism in some corners that unique aspects of the acute care environment should make pursuit of PCM at best a subsidiary goal. As previously noted, such concerns are not entirely without merit—the time and space constraints in the ED complicate efforts to engage ill-persons in the conversations and deliberations needed for person-centered care. However, the strategies outlined in this chapter demonstrate that such obstacles need not be insurmountable. Indeed, the ED affords an opportunity to reach those most alienated from our health care system—those for whom person-centered medicine may in fact have the most consequential impact.

Whether the specialty ultimately prioritizes PCM to the degree needed to ensure its widespread adoption remains to be seen. The understanding and the organizational structures exist to make emergency care more person-centered. The challenge lies in spreading this understanding, more broadly implementing new care formats, and in funding the additional time and personnel it takes to care for the people who seek our help.

Acknowledgements and Disclosures The authors do not report conflicts of interest concerning the preparation of this paper.

References

1. Beauchamp TL, Childress JF. Principles of biomedical ethics. New York: Oxford University Press; 1994.
2. Miles SH. The Hippocratic oath and the ethics of medicine. Oxford: Oxford University Press; 2004.
3. Mezzich JE, Snaedal J, van Weel C, Heath I. Toward person-centered medicine: from disease to patient to person. Mt Sinai J Med. 2010;77:304–6.
4. Veroff D, Marr A, Wennberg DE. Enhanced support for shared decision making reduced costs of care for patients with preference-sensitive conditions. Health Aff. 2013;32(2):285–93.
5. Schoenfeld EM, Kanzaria HK, Quigley DD, Marie PS, Nayyar N, Sabbagh SH, et al. Patient preferences regarding shared decision making in the emergency department: findings from a multisite survey. Acad Emerg Med. 2018;25(10):1118–28.
6. Hess EP, Hollander JE, Schaffer JT, Kline JA, Torres CA, Diercks DB, et al. Shared decision making in patients with low risk chest pain: prospective randomized pragmatic trial. BMJ. 2016;355:i6165.
7. Probst MA, Kanzaria HK, Schoenfeld EM, Menchine MD, Breslin M, Walsh C, et al. Shared decision making in the emergency department: a guiding framework for clinicians. Ann Emerg Med. 2017;70(5):688–95.
8. Hall JE, Patel DP, Thomas JW, Richards CA, Rogers PE, Pruitt CM. Certified child life specialists lessen emotional distress of children undergoing laceration repair in the emergency department. Pediatr Emerg Care. 2018;34(9):603–6.
9. Heilbrunn BR, Wittern RE, Lee JB, Pham PK, Hamilton AH, Nager AL. Reducing anxiety in the pediatric emergency department: a comparative trial. J Emerg Med. 2014;47(6):623–31.
10. Sanchez Cristal N, Staab J, Chatham R, Ryan S, Mcnair B, Grubenhoff JA. Child life reduces distress and pain and improves family satisfaction in the pediatric emergency department. Clin Pediatr. 2018;57(13):1567–75.
11. George N, Phillips E, Zaurova M, Song C, Lamba S, Grudzen C. Palliative care screening and assessment in the emergency department: a systematic review. J Pain Symptom Manag. 2016;51(1):108–19.
12. Grudzen CR, Brody AA, Chung FR, Cuthel AM, Mann D, McQuilkin JA, et al. Primary Palliative Care for Emergency Medicine (PRIM-ER): protocol for a pragmatic, cluster-randomised, stepped wedge design to test the effectiveness of primary palliative care education, training and technical support for emergency medicine. BMJ Open. 2019;9(7):e030099.
13. American GS, Geriatric EDGTF, American College of Emergency Physicians, & Emergency Nurses Association. Geriatric emergency department guidelines. Ann Emerg Med. 2014;63(5):e7–25.
14. NEJM Catalyst. What is patient-centered care? NEJM Catalyst. 2017; https://doi.org/10.1056/CAT.17.0559.
15. Clemency B, Cordes CC, Lindstrom HA, Basior JM, Waldrop DP. Decisions by default: incomplete and contradictory MOLST in emergency care. J Am Med Dir Assoc. 2017;18(1):35–9. https://doi.org/10.1016/j.jamda.2016.07.032.
16. Beynon T, Gomes B, Murtagh FE, Glucksman E, Parfitt A, Burman R, Edmonds P, Carey I, Keep J, Higginson IJ. How common are palliative care needs among older people who die in the emergency department? Emerg Med J. 2011 Jun;28(6):491–5. https://doi.org/10.1136/emj.2009.090019.
17. Yarmohammadian MH, Rezaei F, Haghshenas A, Tavakoli N. Overcrowding in emergency departments: a review of strategies to decrease future challenges. J Res Med Sci. 2017;22:23. https://doi.org/10.4103/1735-1995.200277.
18. Institute of Medicine Committee on the Future of Emergency Care in the U.S. Health System. The future of emergency care in the United States health system. Ann Emerg Med. 2006;48:115–20.

19. Moskop JC, Sklar DP, Geiderman JM, Schears RM, Bookman KJ. Emergency department crowding, part 1—concept, causes, and moral consequences. Ann Emerg Med. 2009;53:605–11.
20. Graneto J, Damm T. Perception of noise by emergency department nurses. West J Emerg Med. 2013;14(5):547–50. https://doi.org/10.5811/westjem.2013.5.16215.
21. Konrad B, Hiti D, Chang BP, Retuerto J, Julian J, Edmondson D. Cardiac patients' perceptions of neighboring patients' risk influence on psychological stress in ED and subsequent posttraumatic stress. BMC Emerg Med. 2017;17(1):33. https://doi.org/10.1186/s12873-017-0144-3.
22. Weigl M, Beck J, Wehler M, Schneider A. Workflow interruptions and stress at work: a mixed-methods study among physicians and nurses of a multidisciplinary emergency department. BMJ Open. 2017;7(12):e019074. https://doi.org/10.1136/bmjopen-2017-019074.
23. Barrett TW, Rising KL, Bellolio MF, Hall MK, Brody A, Dodd KW, Grieser M, Levy PD, Raja AS, Self WH, Weingarten G, Hess EP, Hollander JE. The 2016 Academic Emergency Medicine Consensus Conference, "Shared decision making in the emergency department: development of a policy-relevant patient-centered research agenda" diagnostic testing breakout session report. Acad Emerg Med. 2016;23(12):1354–61. https://doi.org/10.1111/acem.13050.
24. Kanzaria HK, Brook RH, Probst MA, Harris D, Berry SH, Hoffman JR. Emergency physician perceptions of shared decision-making. Acad Emerg Med. 2015a;22(4):399–405. https://doi.org/10.1111/acem.12627.
25. Kanzaria HK, Hoffman JR, Probst MA, Caloyeras JP, Berry SH, Brook RH. Emergency physician perceptions of medically unnecessary advanced diagnostic imaging. Acad Emerg Med. 2015b;22(4):390–8. https://doi.org/10.1111/acem.12625.
26. Stutman RE, Reidy D, Napoli J, et al. TeleTriage at a high volume cancer center urgent care: aligning patient volume and need with available resource. Poster presented at Oncologic Emergency Medicine Conference, Jan 2019.
27. New York Mobile Integrated Healthcare Association. 2019. http://nymiha.org
28. Centers for Medicare & Medicaid Services. Emergency triage, treat, and transport (ET3) model. https://innovation.cms.gov/initiatives/et3/. Accessed 15 June 2019.
29. Munjal KG, Margolis GS, Kellermann AL. Realignment of ems reimbursement policy: new hope for patient-centered out-of-hospital care. JAMA. 2019;322:303–4.
30. Hsia RY, Kellermann AL, Shen YC. Factors associated with closures of emergency departments in the United States. JAMA. 2011;305(19):1978–85.
31. Pearl RM, Loftus B. How multi-specialty hubs fill a major gap in the care continuum. NEJM Catalyst. 2017. https://catalyst.nejm.org/how-multi-specialty-hubs-fill-a-major-gap-in-the-care-continuum
32. International Association of Forensic Nurses. https://www.forensicnurses.org
33. New York State Department of Health. Sexual assault forensic examiner (SAFE) program. https://www.health.ny.gov/professionals/safe
34. Public Health and Injury Prevention Committee. Resources for emergency physicians: reducing firearm violence and improving firearm injury prevention: an information paper. American College of Emergency Physicians. 2018, April. https://www.acep.org/globalassets/uploads/uploaded-files/acep/clinical-and-practice-management/resources/publichealth/violence/resources-for-emergency-physicians%2D%2D-reducing-firearm-violence-and-improving-firearm-injury-prevention.pdf
35. Choo EK, Houry D. Managing intimate partner violence in the emergency department. Ann Emerg Med. 2015;65(4):447–451.e1.
36. The Mount Sinai Human Rights Program. https://mountsinaihumanrights.org/
37. Ahmed OM, Mao JA, Holt SR, Hawk K, D'Onofrio G, Martel S, Melnick ER. A scalable, automated warm handoff from the emergency department to community sites offering continued medication for opioid use disorder: lessons learned from the EMBED trial stakeholders. J Subst Abus Treat. 2019;102:47–52.
38. Mechanic OJ, Dubosh NM, Rosen CL, Landry AM. Cultural competency training in emergency medicine. J Emerg Med. 2017;53(3):391–6.

39. Kraus CK, Greenberg MR, Ray DE, Dy SM. Palliative care education in emergency medicine residency training: a survey of program directors, associate program directors, and assistant program directors. J Pain Symptom Manag. 2016;51(5):898–906.
40. Ratcliff CG, Prinsloo S, Chaoul A, et al. A randomized controlled trial of brief mindfulness meditation for women undergoing stereotactic breast biopsy. J Am Coll Radiol. 2019;16(5):691–9.
41. Garcia MK, Cohen L, Spano M, et al. Inpatient acupuncture at a major cancer center. Integr Cancer Ther. 2018;17(1):148–52.

Chapter 28
Person-Centered Infectious Diseases and Pandemics

Eduardo Ticona, George Fu Gao, Lei Zhou, and Marcos Burgos

28.1 Person Centered Medicine Perspectives on Infectious Diseases and Pandemics

Eduardo Ticona and Marcos Burgos

Authorship Focus: This complex chapter about Person-centered Care for Infectious Diseases and Pandemics was written by a group of experts from various countries. The authorship focus for each one of its four sections is noted at the beginning of each section.

E. Ticona (✉)
"Dos de Mayo" National Hospital, San Marcos University (UNMSM), Lima, Peru

Infectious and Tropical Diseases, San Marcos National University, Lima, Peru
e-mail: eticonac@unmsm.edu.pe

G. F. Gao
China Center for Disease Control and Prevention, Beijing, China
e-mail: gaofu@chinacdc.cn

L. Zhou
Branch for Emerging Infectious Disease, Public Health Emergency Center, China Center for Disease Control and Prevention, Beijing, China
e-mail: zhoulei@chinacdc.cn

M. Burgos
Infectious Diseases, School of Medicine, University of New Mexico, Albuquerque, NM, USA

Infectious Diseases, New Mexico VA Health Care System, Albuquerque, NM, USA

New Mexico Department of Health, Santa Fe, NM, USA
e-mail: Mburgos@salud.unm.edu

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_28

28.1.1 A Person as a Living Being in Nature

A person is a living being, who needs the existence of other living organisms in order to thrive. Not only we interact, feed, shelter or use the various products that animals and plants provide, but we also develop an interdependence with them. That codependence we develop through time and space with other organism and the impact we have in other species or through intermediate species is the driving force of evolution and the essence of understanding our own well-being and existence.

The history of life on earth is closely linked to microbes that play a transcendent role in evolution and goes back in time before the appearance of the first eukaryotic cells, and multicellular organisms. For instance, all living organisms today evolved first from microorganisms and most of the biodiversity on our planet is microbial in nature and its evolution had been underway for billions of years [1]. All plants and animals evolved in environments populated by trillion of interdependent microorganisms co-evolving in metabolic processes in codependence or favoring or preventing various diseases through the effect of the microbiota of higher living organisms. For example, microorganisms that allow the decomposition processes of organic matter such as termites that digest wood, to those that facilitate fermentation, putrefaction or to those that produce essential vitamins in the human intestines. In this regard, an example of the importance of the relationship between microbial evolution and human health is the spread of antibiotic resistance mechanisms in the microbial world because of the indiscriminate use of antibiotics [2]. Thus, it is important to understand the interconnection of human beings with the microbial environment and nature, which must be one of coexistence and respect in order to avoid a potential undesirable impact on human health.

28.1.2 The Nature of Infectious Diseases: Relationships Among Human Being, Infectious Agent, and Environment for the Disease to Occur

Most microorganisms do not impair normal tissue function or cause disease. In fact, most microorganisms are not pathogenic, able to produce disease, because they effectively compete with potentially dangerous organisms for resources, preventing the emergence of a likely infectious agent. An infection may result when a microorganism capable of causing disease enters and begins multiplying within a given host.

The phenomenon of infectious disease is amazing, and the following are some of the factors that are at play for infection to occur:

1. Pathogenicity of the agent: Not all microbes are equally pathogenic, some are opportunistic, that is, they will only cause disease when the host is immunosuppressed. That is pathogens that will not cause disease in a normal host may cause disease in the immunocompromised. Examples of immunocompromised indi-

viduals are those persons living with HIV or who have AIDS, or cancer patients receiving chemotherapy.

2. Immune response of the individual: The same infectious agent can pass from an asymptomatic person to produce mild or severe disease in another individual or vice versa. A timely illustration is the emergence of COVID-19 and the variety of immune responses from individuals to this infectious agent which may range from asymptomatic disease, mild disease to severe disease [3], requiring hospitalization and even causing death. Thus, the complexity of the immune system can make us vulnerable to certain types of infectious diseases but immune to others. Furthermore, the immune status of a person is variable over time, due in part to aging because of immunosenescence and inflammation. These last two concepts may play a role in the high mortality associated with COVID-19 infection among the elderly in addition to other comorbidities associated with aging [4].
3. Some diseases are seasonal and others are restricted to certain environments (climate, humidity, altitude, type of flora or fauna, etc.) where the ecological characteristics allow greater reproduction of the agent or vectors and/or transmission to humans. In this category some examples of infectious agents are endemic mycosis, dengue and malaria.
4. Modes of transmission of infectious agents can be through insects (dengue, malaria), water contamination or food preparation (rotavirus infection, cryptosporidiosis, giardiasis, salmonella, and cholera), the respiratory tract by aerosols or droplets (measles, tuberculosis, influenza, COVID-19), direct contact with the patient (chickenpox, scabies), sexual intercourse (HIV, gonorrhea, syphilis), blood transfusion (HIV, viral hepatitis). These modes of transmission are all examples of horizontal transmission because the infectious agent is generally passed from person to person in a group. Vertical transmission from mother to child occur during the processes of reproduction, fetal development or birth and occurs with infectious agents such as HIV, syphilis, toxoplasmosis and herpes virus [5].
5. Social determinates of health are mostly conditions in which people are born or live, and therefore are shape by the environment. These include factors like socioeconomic status, where we live, a city a neighborhood, work activity, type of housing, quality of access to care, social support systems and cultural preferences. In turn these social determinants may facilitate or mitigate the risk of contracting a particular infectious agent, such as for example tuberculosis, HIV and COVID-19. These insights in the relationship of social determinants and infectious diseases are key aspects in developing public health strategies to effectively combat endemic infectious diseases [6].

Therefore, for an infectious disease to occur, a series of factors need to coincide in a given environment and person(s), to become infected or ill. In turn, infectious diseases can be averted by exploiting vulnerabilities in the infectious cycle when the pathogen is most susceptible. For instance, vector-borne infectious diseases could be averted by control measures of the vector or prevention methods to minimize exposure to humans. In the case of direct person-to-person transmission strategies such as improving sanitary conditions as well as education and/or barrier protection methods, could help reduce infection. In other cases, infection may be prevented with vaccination strategies. In some occasions, drugs (chemoprophylaxis) may help suppress an infectious agent or abrogate the continuation of the disease process. Nevertheless, there are many infectious diseases for which we do not have adequate control methods, or the methods are undeveloped, or absent. Therefore, the importance of understanding and addressing the biological aspects of transmission and the social determinants of health associated to a given infectious agent.

28.1.3 The Person's Environment and Infectious Diseases

28.1.3.1 The Community and Infectious Diseases

The health of individuals is affected by the environment in which they live, and vice versa, a person's health status affects their community. As social beings, we share our activities and express our feelings through actions, which can facilitate the transmission of infectious agents. Thus, some diseases in the community are highly endemic, placing people living in that community at high risk of acquiring an infection. Also, the environment has a role in directly affecting social interactions within cities and neighborhoods. For example, in resource-poor neighborhoods in Peru, geographical space, economic and social context all influence transmission dynamics of pathogens such as tuberculosis [7] and more recently COVID-19. For these reasons understanding the dynamics of infectious diseases is constructed on the organization of human social networks, the behavior of individuals and on the context of patterns of the transmission of the infectious agent(s) within the community.

The main aim of infectious disease control strategies is to prevent disease outbreaks from occurring in the first place and if an outbreak occurs, to use effective mitigation strategies to contain the epidemic. These control measures are built around the environment of the community and characteristically involves separation of ill individuals from the rest of the population, i.e., isolation or quarantine, and/or closing public places such as schools and more generally the use of social distancing methods. For these reasons, communities need to know which infectious diseases they are at risk and to what extent they are or may be affected, so that they can establish prevention and control strategies based and implemented on the community level needs.

One of the most effective and safest strategies to prevent infectious diseases in a given community is vaccination. In fact, vaccinations are recognized to be one of the ultimate public health achievements, with an estimated 2–3 million deaths prevented each year. Over the last century, vaccinations permitted the eradication of smallpox, and the containment of polio and reducing the overall global child mortality rates and lifelong disabilities [8]. Moreover, the benefits offered by vaccines can be extended to the community, through herd immunity, to those unvaccinated individuals, including vulnerable populations, i.e., the young and the elderly, or the immunosuppressed not able to mount robust immune responses [8]. Nonetheless, even if we have a very effective vaccine(s), we need to reach optimal vaccine coverage to achieve the full benefits of vaccination.

A well-timed, important illustration is the COVID-19 pandemic and the importance of vaccinations. There are now multiple very effective COVID-19 vaccines that prevent infection, hospitalization and death [8, 9]. However, due to vaccine hesitancy and lack of access to vaccines, there are many communities in the world that are still experiencing high number of cases, hospitalizations and deaths because of low vaccination rates. Therefore, the most important public health action to end the COVID-19 pandemic remains increasing vaccination coverage to achieve the full benefits of vaccination, which saves lives, prevents illness, and reduces the spread of COVID-19 [9, 10].

28.1.3.2 The Reason for Pandemics, Endemics and Epidemics

The main characteristic of a pandemic is when a disease's growth is exponential and that the infectious agent covers a wide area, affecting several countries and populations [11]. The definition of a pandemic does not consider other features of the infectious agent, such as disease severity or the immunity of the population.

Endemic infectious diseases are present when the factors that condition these diseases cannot be controlled and may be limited to a particular region [11]. Thus, the number of cases remains stable over time, and the endemicity may be mild, moderate or severe. Malaria, for example, is considered an endemic infectious disease limited to certain regions and countries. In the case of COVID-19 experts believe it is becoming an endemic disease, but we do not have enough information to know if it is going to be contained to certain regions of the world and its endemicity will mild, moderate or severe.

Epidemic diseases occur when a new infectious agent emerges in a community, or one or more of the factors that condition diseases have been neglected and there is a reemergence [11]. For instance, yellow fever, smallpox, measles, and polio are examples of epidemics that occurred in many parts of the world.

It is important to consider that an epidemic can progress into pandemic. An example is COVID-19, it was originally identified and localized to Wuhan China, but rapidly spread and became a pandemic, out of control and covering a wide area, affecting all countries of the world and populations. But a pandemic can also, become endemic. For example, COVID-19 is so well adapted for human-to-human transmission that we will not be able to eradicate and, thus it is likely already endemic.

28.1.3.3 Stigma and Infectious Diseases

In the past, infectious diseases, being widely transmitted and not having a cure, generated an attitude of rejection towards the affected persons, in order to avoid contagion. However, the better knowledge that we have about their transmission and prevention have significantly reduced the stigma against them. However, the appearance of new "emerging" diseases and the appearance of old ones that were thought to be controlled or "reemerging" causes people to revive attitudes of rejection of those affected. In many parts of the world, lack of information/misinformation or inadequate public health education and cultural attitudes is the main driver of the stigma continue.

There are differences in infectious disease-related stigma that are associated to distinct features of the infectious agent and how a population perceives a potential treat. HIV/AIDS, a sexually transited disease, is also a pandemic and an epidemic. Experts believe that HIV/AIDS, evolved from a virus found in chimpanzees that was transferred to humans in Africa in the early1900s. By the late 20th century, the virus had made its way around the world becoming a pandemic. HIV/AIDS is probably the most prominent infectious disease associated with high levels of stigma across the world [12].

HIV/AIDS in most societies, is generally perceived as a chronic fatal disease associated with negative connotations such as homosexuality, drug abuse, sex work, incarceration and poverty. Although this perception is changing with the advent of effective anti-retroviral therapy, the stigma in some parts of the world persists [13].

If we compare infectious diseases like COVID-19 with HIV/AIDS, the stigma differs substantially because the social factors associated with COVID-19 are not considered as morally unacceptable and most persons are at risk of infection with COVID-19 independently of their social background. For instance, at the beginning of the pandemic infected individuals and health care workers, experienced substantial incidents of stigmatization [14]. In addition, stigmatization of COVID-19 is mainly driven by the fear of the disease itself. From a public health viewpoint, fear and its associated stigma is a barrier to seek help and people may not use health services to avoid the stigma or dishonor associated with finding out that they are infected. As COVID-19 is a continuing danger, the stigma associated with this pandemic would remain for the foreseeable future and it could become a longstanding concern for the world.

28.1.4 The Commitment of the Physician and the Health Authorities

28.1.4.1 Early Diagnosis and Treatment of Infectious Diseases

Proper diagnosis is the basis of treatment and recovery of the patient. For this, the physician must offer a human approach and enough time to the suffering person.

The interaction between the infectious agent and the immune response generates tissue damage. The longer the diagnosis and treatment of the infection are delayed, the greater the consequences or the risk of losing the person's life.

The consequences of infection in any organ are unfortunate, however, the delay in the diagnosis and treatment of an infection of the Central Nervous System (CNS) is inexcusable. Thus, early diagnosis of a CNS infection is a must when suspected. The consequences of delays of diagnosis, and implication for an adverse health outcome, will not only affect the patient, but also the family that will have to care for a potential disabled person.

We have better diagnostics and better antimicrobials; however, they are not always available, which is very unfortunate especially in many developing countries. In these cases, it is important to try to offer the best available treatment to these patients.

In the approach to infectious diseases, we will not always have the agent isolated prior to the start of therapy, since the person may be very seriously ill, and we must decide on empiric therapy. In such cases it is important to make every effort to obtain samples for cultures, prior to the most convenient decision on antimicrobial therapy.

Any therapeutic decision must be adjusted in consultation with the person, since in the end it is he/she who is going to follow the treatment. It is not enough to choose the best treatment option, but it must also be adapted for the circumstances surrounding a given person and with their consent. In other words, making the patient an active participant in his/her health care decisions.

28.1.4.2 Hospital/Health System and Infectious Diseases

The person who has lost his health from an infectious disease, leaves the comfort of their house to go to the hospital, usually an unfamiliar environment, where there is limited privacy and where one feels often isolated. Most of these people are in a fragile state due to their disease and they may not be able to make decisions, or they may feel not in control of their life and may feel at the mercy of strangers. In this situation it is important to take a holistic, individualized, respectful approach to care that meets the health and psychological needs of the person.

Due to the severity of the infections and/or types of germs, broad-spectrum antibiotics are used in hospitals, so people may develop adverse events related to the antibiotics or may developed colonization from multi-resistant germs from a hospital associated infection. For this reason, hospitalization should be decided only under terms in which outpatient care is not possible. Health systems must adapt to this new reality by facilitating increasingly complete care at the outpatient level.

28.1.4.3 Infection Control Measures and the Health Worker

We have mentioned about the conditions that favor the emergence of multi-resistant germs in the hospital, so it is very important that hospitals have infection control programs. In addition, every worker must be aware that he is an infection control agent, and a potential generator of infection transmission in the hospital. Therefore, the health care system must have indicators that allow them to know the situation in real time of the sentinel events of infections that occur in the different hospital environments. It is important to emphasize that nosocomial infections cannot be eliminated, but they can be limited or controlled in a reasonable manner, so that they remain at low levels. Thus, monitoring these infections should be a quality indicator of a hospital [15]. The health worker must also be cared for by the health system, because they maybe at risks of acquiring an airborne infection such as tuberculosis or from an accidental needle stick, an infection such as HIV or a viral hepatitis.

28.2 Evaluation, Treatment and Care of the Person With Covid-19

Eduardo Ticona

The pathogenesis of COVID-19 is not dissimilar to that of other infectious diseases, where many people are exposed, fewer are infected and even less individuals experience the disease [16]. However, in the case of respiratory viruses, under the circumstances of a pandemic with mostly a susceptible population, the numbers of exposed, infected and disease individuals could be enormous. Therefore, as we experienced with this pandemic, in a very short time the health services of a community became overwhelmed, huge numbers of people seeking care, and the health care infrastructure buckled in many places under the pressure of COVID-19 cases [17].

We conceive of a person as healthy, when he/she does not present clinical discomfort, is emotionally stable, participates in his/her social environment and also achieves well-being in his environment. However, this condition can be temporarily or permanently lost due to external or internal (genetic) factors.

During a pandemic, the external factors not only gradually affect many people, but the transmission dynamics of exposure, infection and disease of the virus, generates social, mental and spiritual suffering [18, 19]. The magnitude of the waves of infection can compound the social and economic dislocation from locality to locality, intensifying the suffering and feeling of hopelessness and isolation. Obviously, these internal and external factors of the pandemic generate a significant negative impact on people's daily lives [20].

Therefore, an individual in quarantine, a person in contact with a person with COVID-19, a person with a suspected or confirmed diagnosis, an asymptomatic person with a positive test, a patient after a hospital discharge, and grieving family member(s), all are affected from the actual chain of transmission of the virus and from a physical, environmental, social and psychological response to the virus. In each and every one of these cases, COVID-19 impacts the person, the family and their community from the disease perspective and in a psychological, social and spiritual manner.

(a) *Person in quarantine, in isolation, inside a reduced space without meaningful social interaction*

People in quarantine are significantly affected mentally, generating feelings of loneliness, sadness, anguish and despair. They fear leaving their homes, but at the same time they cannot stay inside them, because they have to get their daily income, keep their jobs, or buy basic necessities; thus they expose themselves to the risk of contracting the disease. On the other hand, the alarmist news through the media, emphasizing the negative side of the control measures on the part of the government or citizens, or the knowledge that a neighbor, family member or friend has been affected or has died, further generates a sense of helplessness and hopelessness.

It is considered that, in the month of March 2020, a third of the world population was under quarantine.

(b) *Contact person of a person with COVID-19, at risk of becoming ill*

People's fear of getting sick, especially in people who have been in close contact with a sick person, have led them to take medications or non-medical products from doubtful sources.

The situation has been more severe, when people took care of their relatives, offering care to their patients at home with poorly ventilated environments, with limitations of disinfection and protection supplies, which resulted in further transmission and caused more illness and death.

(c) *Person with suspected or confirmed case of COVID-19*

During the active community transmission phase of the pandemic, people with upper respiratory symptoms, fever, or general malaise were considered suspect for COVID-19, and if the cases were corroborated through a confirmatory test, they were isolated. This generated additional anxiety in the person at the possibility of becoming severely ill and/or transmitting it to loved ones at home [21]. In this same group can be included the asymptomatic person who for various reasons was tested and found to be positive.

(d) *Person who is discharged from hospital after COVID-19*

A person suffering from severe COVID-19 often resulting in hospitalization, experiences a stressful environment, in isolation, gasping for air, feeling of hopelessness, seeing people die and confronting their own mortality. Their illness, definitely does not stop upon discharge, in some circumstances it is accompanied by a long period of post-COVID-19 sequelae or discomfort, which the person thinks could disable his or her respiratory system for life [22].

(e) *Person grieving for COVID-19*

So many have been affected by this pandemic that most people have had a loved one or known some who had severe disease or died of COVID-19. Although death saddens us knowing that we will not be able to share physically with the person in the future, the suffering is compounded from special situations occurring during the pandemic, since family members died alone, not in company of their love ones during their agony, not able to accompany them to their burial, and in some instances several members of the same family also died around the same time and in similar circumstances [23]. Even with the pandemic in its third year, there is a feeling this cycle could be repeated and thus the struggle continues and there is an overall feeling of impotence.

(f) *Absence of oxygen for the sick person*

After a year of pandemic, even medical science does not have an antiviral treatment that allows to eliminate this virus from the affected person. However, supportive management has been significantly improved, especially in moderate and severe cases, both due to the better knowledge of the pathogenesis of the virus, as well as the greater skill of medical teams. However, in some scenarios, there was an inconceivable lack of oxygen in hospital establishments, oxygen being a vital element to sustain life, not only caused preventable death, but also generated panic in families, communities and in society at large [24].

28.2.1 The Community Response in the Prevention and Control of COVID-19

Undoubtedly, in the face of a pandemic that generates a sudden and unexpected number of cases, the health system and resources for an adequate health response will always be insufficient. This will be more evident in environments of poverty, where resources were previously limited and the social factors that favor transmission and its consequences are prominent.

In this context, a community response is the best way to face a pandemic, which must start at the local neighborhood level, and advance to engage progressively a whole nation, including governmental and non-governmental organizations. At the larger levels, political support is fundamental [25, 26].

Thus, "during the pandemic, community participation can help identify and respond to priority problems and their social and health aspects" [27]. This participation allows solidarity efforts to be successful towards one person or many people, even strengthening the health system at all levels.

Death, which is a natural process that concludes the life of every human being, and that due to the development of science and technology has been delayed considerably towards older age, now the pandemic has brought it closer to us at any age. By not being prepared for it, a lot of fear has been generated, and we once again recognize that we are passengers in this life and have to learn to confront our own death.

Society in its desperation has lost control of its reactions, generating political upheaval, questioning its leaders, pointing fingers, and wanting to find someone responsible. On the other hand, some politicians took advantage of these circumstances by insisting discontent towards the government generating distrust and discouragement in the population with the aim of augmenting their own power.

Thus, during the COVID-19 pandemic, people not only require adequate medical care when they are sick, but also require person-centered human care, since their entire being is suffering. On the other hand, this panorama is broader, since all people suffer and require the same humane treatment. It is in this moment that, in the face of the threat of death, our spirituality expressed in love for our neighbor and vocation of service should lead us to understand that we cannot face this situation in isolation. We need the response of the community as a whole, where there is no time to look for the guilty. It is to be expected under these circumstances that difficulties are always accentuated, and therefore, they could not stop affecting us. The faster we realize that the answer lies with us, the less damage the pandemic may cause.

Likewise, as a human response, we must understand that the pandemic has a general cause expressed in the deterioration of the environment. If this is not stopped, similar threats to humanity will appear in few years. Infection control measures will remain in our daily practice, both in health services and in our homes, generating a new lifestyle.

Finally, the care of the person with COVID-19 includes the care of all the people in society affected by the pandemic, which in its beginning and end depends on the people themselves organized in community.

28.3 Practical Implications for the Implementation of Person Centered Care in Pandemics

Eduardo Ticona

(a) *Key factors for the implementation of person-centered care for infectious disease*

The person with an infectious disease, realizing that an infectious agent is in their body, fears for health damage, as well as putting people around you at risk, which generates stress due to fear of to the outcome of your illness or if it will transmit to a loved one. On the other hand, the people around him adopt protective attitudes. Thus, the patient is deeply affected physically, mentally, and socially. In the case of an acute infectious disease, this process lasts a few days or weeks, but in chronic ones, the person is affected for months or years.

Person-centered medicine offers affected people a comprehensive and holistic management [28], and also allows us to better recognize and treat the social determinants of health that were involved in exposure to the infectious agent or difficulties experienced by the patient in obtaining health care [29]. If we do not act on them, or do not consider them in the treatment, is likely to happen a poor evolution of the disease, reinfection, or a relapse are likely. The eight principles of Person-Centered Medicine [28] specify the basics of complete and essential human care. The greatest crisis of care occurs during epidemics or pandemics, for which we must prepare, since great population growth, new lifestyles, and the affectation of biodiversity, among other factors, increase the likelihood of pandemics.

(b) *To what extent is the care given to the person with infectious disease focused on the person?*

The care focused on the person affected with infectious disease depends on (i) the type of infectious disease, (ii) if the management is hospitalized or outpatient, (iii) if the care is in an urban or rural environment, or (iv) if it is produced under an endemic, epidemic o pandemic situation. For some of these diseases, despite the good attitude and preparation of health personnel, person-centered care is limited by the infection control measures that are implemented in health services, which indirectly creates a barrier for proper and person-centered care. Therefore, health personnel should show a humane and warm treatment that allows them to overcome the barrier of clothing or procedures that they have to perform.

In other circumstances, it is the stigma ascribed by the community to these diseases, in which health personnel may also participate, that discriminatory behaviors towards affected persons occurs. Stigma is considered a key social determinant of health, which leads to disease, death, and health disparity [30].

(c) *Current obstacles to the implementation of person-centered care for those suffering from an infectious disease.*

The main obstacle occurs in scenarios with limited resources, where there are: (1) lack of infrastructure, materials and equipment for the implementation of infection control measures, so that health personnel do not feel protected and their activity at bedside is limited to minimal care, (2) the lack of education and training programs for health personnel, which is why they are unable to free themselves from the stigma towards certain infectious diseases and generate an attitude of rejection, low quality and coldness in care, and (3) the lack of commitment of health service managers, who, given the limitation of resources and the previously mentioned attitudes neglect person-centered care.

(d) *Changes necessary to promote person-centered care for infectious disease*

Regardless of the available resources for proper health care, which could be rationalized for your best use, the most important factor to maximize person-centered care is the attitude of health personnel and health service managers, who must free themselves from prejudices and stigmas. It is necessary that the principles of person-centered medicine be incorporated fully in the educational programs of physicians, health personnel and managers of health services. Then, in the work environment itself, a continuous process of evaluation and feedback for person-centered care is needed, which could require periodic workshops to improve day-to-day experience for all involved.

28.4 China's Management of the COVID-19 Pandemic and Its People-Centered Strategies

George F. Gao and Lei Zhou

At the end of December in 2019, a novel virus, later named SARS-CoV-2 coronavirus [31] was detected and reported through the China's surveillance system [32, 33] when attacking Wuhan City in the Hubei Province of China and causing an outbreak in urban Wuhan [34]. Several weeks later, the virus gradually spread to the whole city of Wuhan, and then the overall Hubei Province, and finally the whole nation, reaching epidemic peak in early February 2020 [34]. The number of new cases per day increased to 3700 and a large number of cases needed hospitalization. Due to the ensuing medical service crisis, a considerable number of patients died [34]. The epidemic situation was extremely severe at that time: as of February 1, 2020, a total of 86,601 cases had been confirmed in China, with 4753 deaths and a crude fatality rate of 5.5%. With the gradual effectiveness of prevention and control strategies and measures, the epidemic situation began to decline significantly since February of 2020 and on March 18, the domestic cases in Mainland China were completely zeroed out [35, 36].

Meanwhile, the number of imported cases gradually increased and became the principal risk to China [37], and imported cases continued to exist since then. The later mode of epidemic of COVID-19 in Mainland China was following closely an epidemic peak of imported cases, subsequently occurring a small-scale domestic outbreak [38].

So far, this kind of imported-ahead of-domestic events with local transmission have been repeated for about 40 times. Almost all the small-scale domestic outbreaks could be effectively controlled within the 1–2 longest incubation period of COVID-19, and the number of cases ranged from a few to more than 1000. All cases have been actively treated, and there was no medical system crisis and no death of patients anymore.

COVID-19 has been present for more than one and a half years. Looking back to previous epidemic control in China, the unique strategy and tactics implemented in China have been summarized. As the first country to detect and report the COVID-19, China has been insisting on a proactive strategy to control the epidemic [35, 39].

As of December 5, there were 86,619 confirmed cases and 4634 deaths, resulting a CFR (case fatality rate) of 5.3%. As the first anniversary of COVID-19 is coming, in retrospect, China has kept adhering to patient-centered and life-first principles while fighting COVID-19.

Based on the fully multidisciplinary alliance of virology, epidemiology, clinical medicine, social medicine, psychology and other sciences and technologies, China identified and isolated the COVID-19 virus seven days after outbreak detection and developed a diagnostic test kit after the various genomes were revealed on Jan 3, shared the whole gene sequence quickly [31–33, 40, 41], decisively closed the market and even locked down the whole city, relied on core NPI (non-pharmaceutical intervention) measures such as 4 lines, 4 levels and 4 earlies, and timely updated technical guidelines and protocols [35].

On due course, the first wave of COVID-19 in China was successfully controlled in March. During the subsequent COVID-19 outbreak control and response, China has persevered on science-based and precision principles, timely updated the national COVID-19 control strategy from containment to the combination of preventing importation and domestic transmission [35, 36].

The first wave of epidemic response has left us valuable experiences. In comparison with previous infectious disease outbreaks response, when fighting the COVID-19 outbreak, China sticked to the principles of social mobilization and whole-society response all the time. At the very beginning of the COVID-19 outbreak, President Xi and the State Council demanded the implementation of the "people-oriented" concept, which has been highly emphasized all through the whole response. The four centralized principles of treatment, doctors, drugs and medical resources are adopted in clinical case treatment to provide early diagnosis, early treatment and early medication in order to reduce severity and death as much as possible. All medical expenses during the response are paid by the government. During the period of "shut down", community staff and volunteers were mobilized to deliver all kind of necessities for people isolated at home. Free psychological consultation and support were provided to people working and living in the epidemic area, including medical staff and the general public. It was due to the close cooperation of the government and the general public that the epidemic could be controlled so quickly. Based on the experience of the first wave response, when China was entering the second stage of COVID-19 response and facing the threat of imported-ahead of-domestic cases from time to time, it was easier for China to find a balance between social-economic development and epidemic control. On the one hand, non-pharmaceutical interventions (NPI) which had been proved to be effective in the first wave response, including four earlies, large-scale nucleic acid screening, and close tracking and management, were continuously adhered to. On the other hand, social mobilization and whole-society engagement was continuously strengthened and the "people's war" was adhered to all the time. The government encouraged Chinese people to follow personal protection even during the period of no case reports. During the second to the seventh waves of COVID-19 outbreaks responses, China has successfully interrupted the chain of virus transmission and prevented its possible wider spread into the community [35], which provided valuable time for vaccine research and development to come about.

With the success of vaccine research and development [42], and rapid promotion of vaccination in the Chinese population [43], the interval of imported-ahead of-domestic events has been gradually extended, the scale and duration of each outbreak has been gradually reduced and shortened, respectively. As a result, the social and economic impact of each outbreak has been clearly attenuated. Although the fighting against COVID-19 has not stopped, the Chinese government has growing confidence on epidemic control and response, and the strategies and measures are becoming increasingly mature. The Chinese people have higher acceptance of and better compliance with the current situation and response [44]. The COVID-19 control and response in China are more scientific, accurate, calm and efficient. At the end of the day, China has a stronger community-level public health service [26].

28.5 Conclusions

A rapid spreading pandemic of an infectious disease over a wide geographic area, crossing international boundaries, with high number of infected individuals and high morbidity and mortality can have enormous economic, social, psychological and political consequences for the whole world as we are currently experiencing with the COVID-19. As a strategy for preparedness for pandemics and epidemics, individuals and communities need to know which infectious diseases they are at risk for and to what extent they are or may be affected, so that they can establish prevention and control strategies based and implemented on the community level needs. In this context, the relationship of social determinants and infectious diseases are key aspects in developing public health strategies to effectively combat epidemics. In addition, treatment and vaccines based on scientific evidence need to be make available as soon as possible to mitigate the potential high morbidity and mortality associated with the pandemic. As an integral part of these strategies, person- and people-centered care for infectious diseases and pandemics and strengthening public health structures informed by science and world-wide solidarity should be priorities.

Acknowledgements and Disclosures The authors do not re report conflicts of interest in the preparation of this manuscript.

References

1. American Academy of Microbiology Colloquia Reports. Microbial evolution: this report is based on a colloquium convened by the American Academy of Microbiology on August 28–30, 2009, in San Cristobal, Ecuador. American Society for Microbiology; 2011.
2. Iwu CD, Korsten L, Okoh AI. The incidence of antibiotic resistance within and beyond the agricultural ecosystem: a concern for public health. Microbiol Open. 2020;9(9):e1035. https://doi.org/10.1002/mbo3.1035.
3. Waqar W, et al. SARS-CoV-2 associated pathogenesis, immune dysfunction and involvement of host factors: a comprehensive review. Eur Rev Med Pharmacol Sci. 2021;25(3):7526–42. https://doi.org/10.26355/eurrev_202112_27453.
4. Cavaillon JM, Levin J. Revisiting Metchnikoff's work in light of the COVID-19 pandemic. Innate Immunity [Preprint]. 2022; SAGE Publications Ltd. https://doi.org/10.1177/17534259211070663.
5. Anderson RM, May RM. Infectious diseases of humans dynamics and control. Oxford: Oxford University Press; 1992.

6. Beltran RM et al. Social determinants of disease: HIV and COVID-19 experiences. Current HIV/AIDS Reports [Preprint]. 2022. https://doi.org/10.1007/s11904-021-00595-6.
7. Ticona E, et al. Tuberculosis screening using ability to provide sputum in an endemic emergency department: TABLE 1. Eur Res J. 2016;47(1):330–3. https://doi.org/10.1183/13993003.00877-2015.
8. Pascale C-CE, et al. Communicating benefits from vaccines beyond preventing infectious diseases. Infect Dis Ther. 2020;9:467–80. https://doi.org/10.6084/m9.figshare.12482654.
9. Alagoz O, et al. The impact of vaccination to control COVID-19 burden in the United States: a simulation modeling approach. PLOS One. 2021;16(7):e0254456. https://doi.org/10.1371/journal.pone.0254456.
10. Hadj Hassine I. Covid-19 vaccines and variants of concern: a review. Reviews in Medical Virology [Preprint]. John Wiley and Sons Ltd.; 2021. https://doi.org/10.1002/rmv.2313.
11. Columbia University Website. Epidemic, endemic, pandemic: what are the differences? 2021. https://www.publichealth.columbia.edu/public-health-now/news/epidemic-endemic-pandemic-what-are-differences. Accessed 22 Feb 2022.
12. Smith EA, et al. Measuring HIV/AIDS-related stigma across South Africa: a versatile and multidimensional scale. Health Educ Behav. 2014;41(4):387–91. https://doi.org/10.1177/1090198113515245.
13. Seeley J, Blanc AK. Reducing stigma and discrimination: new evidence and its implications. AIDS (London, England). 2020;34 https://doi.org/10.1097/QAD.0000000000002647.
14. Bagcchi S. Stigma during the COVID-19 pandemic. Lancet Infect Dis. 2020;20(7):782. https://doi.org/10.1016/S1473-3099(20)30498-9.
15. Centers for Disease Control and Prevention (CDC). Monitoring hospital-acquired infections to promote patient safety—United States, 1990–1999. Morbid Mortal Weekly Rep. 2000;49(8):149–53.
16. Jin Y, et al. Virology, epidemiology, pathogenesis, and control of covid-19. Viruses: MDPI AG; 2020. https://doi.org/10.3390/v12040372.
17. Armocida B et al. The Italian health system and the COVID-19 challenge. Lancet Public Health. 2020;5:e253. https://doi.org/10.1016/S2468-2667(20)30074-8.
18. Cénat JM, et al. Prevalence of symptoms of depression, anxiety, insomnia, posttraumatic stress disorder, and psychological distress among populations affected by the COVID-19 pandemic: a systematic review and meta-analysis. Psychiatry Res. 2021;295:113599. https://doi.org/10.1016/j.psychres.2020.113599.
19. Ferrante G, et al. Did social isolation during the SARS-CoV-2 epidemic have an impact on the lifestyles of citizens? Epidemiol Prev. 2020;44(5–6):353–62. https://doi.org/10.19191/EP20.5-6.S2.137.
20. Vindegaard N, Benros ME. COVID-19 pandemic and mental health consequences: systematic review of the current evidence. Brain Behav Immunity. 2020;89:531–42. https://doi.org/10.1016/j.bbi.2020.05.048.
21. Cori L, et al. Fear of covid-19 for individuals and family members: indications from the national cross-sectional study of the epicovid19 web-based survey. Int J Environ Res Public Health. 2021;18(6):1–20. https://doi.org/10.3390/ijerph18063248.
22. Demeco A, et al. Rehabilitation of patients post-COVID-19 infection: a literature review. J Int Med Res. 2020;48(8):300060520948382. https://doi.org/10.1177/0300060520948382.
23. Goveas JS, Shear MK. Grief and the COVID-19 pandemic in older adults. Am J Geriatr Psychiatry. 2020;28(10):1119–25. https://doi.org/10.1016/j.jagp.2020.06.021.
24. Verhoosel H, Charlotte B, WHO Media Inquiries. "123," World Health Organization [Preprint]. 2021. https://www.who.int/news/item/25-02-2021-covid-19-oxygen-emergency-impacting-more-than-half-a-million-people-in-low%2D%2Dand-middle-income-countries-every-day-as-demand-surges. Accessed 15 Feb 2022.
25. Clara S, et al. La participación comunitaria como eje de la atención primaria de la salud Community participation as the core of primary health care. EDUMECENTRO. 2019;11(1):218–33. http://www.revedumecentro.sld.cu218

26. Li Z, Gao GF. Strengthening public health at the community-level in China. The Lancet Public Health. 2020;5(12):e629–30. https://doi.org/10.1016/S2468-2667(20)30266-8.
27. Ticona Chávez E. Social determinants and community participation in the current of COVID-19 pandemic. An Fac Med. 2020;81(2):145–52. https://doi.org/10.15381/anal.
28. Mezzich JE, Perales A. Person centered clinical care: principles and strategies. Rev Peru Med Exp Salud Publ. 2016;33(4):794–800. https://doi.org/10.17843/rpmesp.2016.334.2567.
29. Braveman P, Gottlieb L. The social determinants of health: it's time to consider the causes of the causes. Public Health Rep. 2014;129(Suppl 2):19–31.
30. Hatzenbuehler ML, Phelan JC, Link BG. Stigma as a fundamental cause of population health inequalities. Public Health. 2013;103:813–21. https://doi.org/10.2105/AJPH.
31. Zhu N, Zhang D, Wang W, Li X, Yang B, Song J, Zhao X, Huang B, Shi W, Lu R, Niu P, Zhan F, Ma X, Wang D, Xu W, Wu G, Gao GF, et al. A novel coronavirus from patients with pneumonia in China, 2019. N Engl J Med. 2020;382(8):727–33. https://doi.org/10.1056/nejmoa2001017.
32. Tan W, et al. A novel coronavirus genome identified in a cluster of pneumonia cases—Wuhan, China 2019−2020. China CDC Weekly. 2020;2(4):61–2. https://doi.org/10.46234/ccdcw2020.017.
33. Tan W et al. A novel coronavirus genome identified in a cluster of pneumonia cases—Wuhan, China 2019–2020, China CDC Weekly Chinese Center for Disease Control and Prevention CCDC Weekly/Vol. 2/No. 461. 2020. https://doi.org/10.1093/molbev/mst010
34. Epidemiology Working Group for NCIP Epidemic Response, C.C. for D.C. and P. The epidemiological characteristics of an outbreak of 2019 novel coronavirus diseases (COVID-19) in China Zhonghua liuxingbingxue zazhi 2020;41(2):145–151. https://doi.org/10.3760/cma.j.issn.0254-6450.2020.02.003.
35. Li Q, et al. Early transmission dynamics in Wuhan, China, of novel coronavirus–infected pneumonia. N Engl J Med. 2020;382(13):1199–207. https://doi.org/10.1056/nejmoa2001316.
36. Zhou L, et al. One hundred days of coronavirus disease 2019 prevention and control in China. Clin Infect Dis. 2021;72(2):332–9. https://doi.org/10.1093/cid/ciaa725.
37. Pang M, et al. Weekly assessment of the COVID-19 pandemic and risk of importation—China, March 25, 2020. China CDC Weekly. 2020;2(14):230–6. https://doi.org/10.46234/ccdcw2020.059.
38. Zhang Y, et al. Epidemiological characteristics of COVID-19 cases in outbreak in Xinfadi market in Beijing. Zhonghua liuxingbingxue zazhi. 2021;42(8):1336–40. https://doi.org/10.3760/cma.j.cn112338-20201222-01428.
39. Kraemer MUG, et al. The effect of human mobility and control measures on the COVID-19 epidemic in China. Science. 2020;368(6490):493–7. https://www.science.org.
40. Wei Q, et al. Description of the First Strain of 2019-nCoV, C-Tan-nCoV Wuhan Strain—National Pathogen Resource Center, China, 2020. China CDC Weekly. 2020;2(6):81–2. https://doi.org/10.46234/ccdcw2020.023.
41. Zheng C, et al. Interpretation of the protocol for prevention and control of COVID-19 in China (Edition 7). China CDC Weekly. 2020;2(47):902–5. https://doi.org/10.46234/ccdcw2020.245.
42. Zhao J, et al. COVID-19: coronavirus vaccine development updates. Front Immunol. 2020;11:602256. https://doi.org/10.3389/fimmu.2020.602256.
43. Wang J, et al. Acceptance of covid-19 vaccination during the covid-19 pandemic in china. Vaccines. 2020;8(3):1–14. https://doi.org/10.3390/vaccines8030482.
44. Yoo JY, et al. Comparative analysis of COVID-19 guidelines from six countries: a qualitative study on the US, China, South Korea, the UK, Brazil, and Haiti. BMC Public Health. 2020;20(1):1853. https://doi.org/10.1186/s12889-020-09924-7.

Chapter 29
Person-Centered Genetic Counselling

Vigdis Stefansdottir, Jon J. Jonsson, and Christine Patch

29.1 Introduction

Genetic counselling is a relatively new clinical field and profession, but it is developing internationally, and the number of genetic counsellors is increasing worldwide. Advances in genome-based health care are in part, the reason for this increase [1]. Genetic counsellors as health professionals have a specialized education and training in medical genetics and counselling. Their many roles include, but are not limited to, counselling clients, facilitating accurate diagnosis, discussing appropriate options for testing and surveillance, offering psychosocial support, designing and conducting research, supervising trainees, taking part in generating health care policies, teaching, developing and implementing educational tools [2]. Implementation of genomic medicine has led to questioning of the original basis of

---

V. Stefansdottir (✉)
Department of Genetics and Molecular Medicine, Landspitali, National University Hospital, Reykjavík, Iceland

Faculty of Medicine, University of Iceland, Reykjavík, Iceland
e-mail: vigdisst@landspitali.is

J. J. Jonsson
Department of Genetics and Molecular Medicine, Landspitali, National University Hospital, Reykjavík, Iceland

Faculty of Medicine, Department of Biochemistry and Molecular Biology, University of Iceland, Reykjavík, Iceland
e-mail: jonjj@hi.is

C. Patch
Queen Mary University of London, London, UK

Wellcome Connecting Science, Wellcome Genome Campus, Hinxton, Cambridge, UK
e-mail: Christine.Patch@genomicsengland.co.uk

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_29

genetic counselling practice and a push to critically evaluate traditional approaches in order to improve care for individual persons and their families.

It is, however, important to make a clear distinction between precision medicine, sometimes called personalized medicine and person-centered medicine. In precision medicine, the emphasis is on treatment and prevention of diseases based on individual variability in genes, environment and lifestyle. This does not affect precise role of the patient and the health care worker but rather what information is used to ensure the most effective treatment or prevention often based on reductionism. In contrast, person-centered medicine is shifting the focus on the patient as a whole person integrating biomedical, psychological, ethical, person's experience and humanistic values.

Also, DCT or direct to consumer testing, is available in many countries and in part can be considered patient empowerment as it allows the patient to choose whether and what is tested. However, genetic testing is complex and readily subject to misunderstanding sometimes with dire consequences. DCT, therefore needs to be assessed through websites with quality information and preferably decision aids, where a person's understanding is assessed at each step, in the absence of pre-test genetic counselling. The process has to be assessed and an option to continue or not, must be readily available. In addition, the person should have ready access to professional genetic counselling at any time to explain the process and outcome.

29.2 Non-directiveness as Key Approach

In the early phase of the development of genetic medicine, there was recognition that genetic diseases affected not only the patients but also their families in numerous ways. The need was identified for a term describing how patients with genetic problems and their families had been helped to cope, without the eugenic overtones common at the time. It was Dr. Sheldon Reed who in 1947, first named the profession genetic counselling [3]. However, Professor Melissa Richter was the first one to establish genetic counselling as a formal profession. She initiated the first training program in Sarah Lawrence College in New York in the 1960s [4]. As for increase in numbers, in a recent article, the authors concluded that the number of genetic counsellors was close to 7000 in 28 countries [2]. From its inception, non-directiveness was a key principal that became accepted in genetic counselling. Donald W. Hadley, on the NIH website says that: "Non-directiveness is an approach used in providing genetic information in counseling in as balanced a fashion as possible without exerting pressure or coercion as to what the clients' decision should be or what their actions should be following counseling sessions".

It may partly have been a response to the history of genetics and a desire to place the client at the centre of what were, at that time, mostly decisions related to reproductive choice. Professional statements still emphasize non-directiveness in genetic counselling practice. For example, the following statements can be found on the website of Code of Ethics for the National Society of Genetic Counsellors, in the USA, in Sect. II, Article 4:

> *Genetic Counsellors strive to enable their clients to make informed decisions, free of coercion, by providing or illuminating the necessary facts and clarifying the alternatives and anticipated consequences.* [5]

Likewise, the Association of Genetic Nurses and Counsellors in the UK have a similar text in their Code of Ethics:

> *Enable clients to make informed and independent decisions, free from coercion, through the use of a range of counselling theories and styles. Respect the client's personal beliefs and their right to make their own decisions.* [6]

Seymour Kessler, who was a major influence in the development of genetic counselling practice, highlighted in a series of articles in 1997 that non-directiveness is not incompatible with many developments in genomic science which will lead to improved prevention and treatment. In that setting, the counsellor might recommend that course of action. However, counselling skills based on non-directiveness are still relevant to promote autonomy and self-direction in clients [7]. In promoting autonomy, the final decisions are always in the client’s hands.

29.3 Developing Models of Care

There is general consensus internationally that genetic counselling is based on a client-centred communication process. Most definitions state that the aim is to help patients and clients understand the facts of a genetic diagnosis and includes helping counselees incorporate the genetic information into their lives by thinking about how they can rationalize and adjust to this new reality and how to explain it to relatives [8]. Genetic counsellors are keenly aware that each patient is unique in relation to personality, values, education, circumstances, genetic make-up and family history. There is no “one size, fit all” model and it is still as important as ever to provide impartial and non-directive counselling. However, there is also a need to consider additional approaches as genetic test results become more important in stratifying care and contributing to personalized medicine.

Models of care are developing and changing and are also unique to particular contexts and health care systems. The roles of genetic counsellor are also developing and changing. As technologies have developed, some genetic counsellors have moved from patient facing roles to working in laboratories providing result interpretation and reporting, customer liaison and case co-ordination. This so far has not developed in Europe where genetic services are predominantly associated with specialist laboratories and include multidisciplinary teams [9].

In systems of healthcare that have developed in Europe, the referral to genetic counselling can be either self-referral or from a health care professional. The family and medical history are gathered, either by clerical staff or a genetic counsellor, often before the first appointment and then updated in the clinic. When there is a known pathogenic variant in the family, this step can be largely omitted or at least shortened. Traditionally, genetic counselling has included pre-and post-test counselling in person [10]. However, a limited number of genetic counsellors has been a major limitation in genetic services in recent years [11]. In conjunction with increased use of technology, this has led to adaptation in the delivery mode to increase efficiency. These include increased use of telephone and video sessions, telegenetics/telemedicine and group counselling.

The term telegenetics/telemedicine refers to live videoconferencing with both visual and audio access. It has typically been mostly used in rural healthcare, but telegenetics is rapidly making its way into other types of genetic counselling. The COVID-19 pandemic has hastened this development. As an example, in Iceland, for the first 9 months of 2020, due to COVID-19, the clinical genetics service mostly turned to telegenetics/telemedicine for all kinds of genetic counselling. This has worked well in most cases, although the staff agrees on that meeting in-person is generally better due to personal contact. Obviously when the counselee must be physically examined this is much better done in the clinic. From informal communications conversations with genetic counsellors across Europe via the ENGNC forum (European Network of Genetic Nurses and Counsellors) there was agreement that there has been an increase in the use of both telephones and video sessions, with both parties in their own homes or at least the counselee (personal communication). Due to the short time period, there are few studies yet published on how much the use of telegenetics has increased due to COVID-19. However, Pagliazzi et al. [12] recently described how COVID-19 has forced a change in genetic consultation and reduced significantly the number of face-to-face visits [12]. Similarly, Bergstrom et al. [13] surveyed genetic counsellors in New York about changes in their practices before January 2020 and after March 22nd. Their results showed decrease in in-person consultation and an increase in video and telephone consults. They also showed general decrease in seeking genetic counselling [13]. Research has shown that both pre-test and post-test telephone cancer genetic counselling is acceptable to counselees and often more convenient than in-person appointments [14, 15]. Telegenetics has the benefit of allowing people to talk from their own home, which for some can be easier than face-to-face meeting and saves travel and office visits.

29.4 What Is Covered in Genetic Counselling?

The content of the clinic appointment commonly includes some of the following components:

- *Family history:*

  Taking a family history has been a traditional feature of genetic counselling and medical genetics. Family history is paramount in genetic counselling. This serves not only to establish the inheritance mode of the condition and identifying others that may need testing. It is also a communication process between the counsellor and the counselee in order to get to know each other better. Family history includes information on the proband, siblings, parents and their siblings, aunts and uncles and the generation above the parents. For each person listed, information needed includes date of birth, date of death, as well as relevant medical history, reproductive history, number of stillbirths, miscarriages and sudden unexplained deaths. Within the family history taking session, important facts may come to light, affecting the process. In many countries large genealogy databases exist, either private or public. These can be used to hasten and get more accurate family information[16]. Cancer registries often have their own genealogy databases, and, in some cases, genetic services have ascertained databases. Even accessing available material on the Internet can give vast information [17]. To establish Mendelian inheritance, a 3-generation pedigree is needed, but a 3-degree (can be up to 5 generations) pedigree proved to give the most accurate risk assessment in cancer genetic counselling [16]. Pedigree of that size is often difficult to obtain, using conventional methods in part because the counselee's knowledge of the medical history of more distant relatives is often limited. The family history can support genetic findings or prompt search for a different diagnosis. Electronic health records, if available can help in collecting the medical history, which can hasten the progress.

- *Explaining the process*:

  Before genetic testing, it is important to explain the process, what kind of genetic testing is planned, possible outcome from genetic testing, the availability of surveillance and/or preventive measures, effect on other relatives and who others in family should be tested in case of positive outcome. Further, there is a need to explain that genetic testing does not always deliver an answer and sometimes tests have to be repeated at a later date, as knowledge advances.
- *Consent for genetic testing*:

  An informed consent should subsequently be obtained. When using exome or whole-genome sequencing or similar, secondary findings have to be addressed and a clear permission or denial for giving optional secondary findings is vital. The storage and further use of the sample also need to be addressed as well as all collection of information.
- *Risk assessment*:

  The inheritance model, if known, needs to be clarified in order to explain the risk assessment for the counselee and other family members.

29.5 Precision Medicine

Tailoring medical treatment to a characteristic of a patient or subgroups of patients has been termed "precision medicine". Using precision medicine allows for specific therapeutic interventions and prevention strategies for those who will benefit out of the population of patients with similar diseases. By obtaining both genotypic and phenotypic information, it is becoming possible in increasing number of cases to inform effective and accurate treatment [18].

29.6 Practical Implications for Implementing Person Centered Care

Advances in genomic medicine, partly driven by developments in genome sequencing technologies, will move genetic counselling out of the specialist clinical and into mainstream settings. Exactly how that will affect models of service delivery and the training and expertise of genetic counsellors is unclear [19]. However, as argued by Jon Weil in 2002, as we move towards personalised medicine it becomes more important to help individuals understand genetic tests and how to use that information to make complex decisions about their health [20]. It is equally important to ensure that those ordering the tests understand their usefulness and shortfalls and are able to explain the outcomes to the persons involved. As outlined earlier in the chapter, genetic counselling is part of health care services. It has both an emotional component and a scientific component and it is the nature of genetic counselling to provide personalised care based on the unique characteristics and circumstances of the persons and families involved.

29.7 Conclusions

The practice of genetic counselling was and is informed by the practice of other health professions and will continue to respond to developments in science and technology. As advances in genomics impact the field, the core of genetic counselling practice must remain person-centred. As care evolves toward using more information to decide surveillance and treatment options, the decisions facing patients and families become more complex. Persons will increasingly need to assimilate substantial and diverse medical facts and recommendations and place them the context of personal situations and values. Traditional and evidence-based methods from genetic counselling will need to be marshalled for addressing collaboratively and thoughtfully diagnostic and therapeutic decisions with which patients and families may feel comfortable and satisfied as being full participants.

Acknowledgements and Disclosures No conflicts of interest are reported. For transparency-sake, Christine Patch reports being employed by Genomics England, a company wholly owned by the UK Department of Health and Social Care, www.genomicsengland.co.uk.

References

1. Ormond KE, Laurino MY, Barlow-Stewart K, Wessels TM, Macaulay S, Austin J, Middleton A. Genetic counseling globally: where are we now? Am J Med Genet C Semin Medl Genet. 2018;178:98–107.
2. Abacan M, Alsubaie L, Barlow-Stewart K, Caanen B, Cordier C, Courtney E, Davoine E, Edwards J, Elackatt NJ, Gardiner K, Guan Y, Huang LH, Malmgren CI, Kejriwal S, Kim HJ, Lambert D, Lantigua-Cruz PA, Lee JMH, Lodahl M, Lunde A, Macaulay S, Macciocca I, Margarit S, Middleton A, Moldovan R, Ngeow J, Obregon-Tito AJ, Ormond KE, Paneque M, Powell K, Sanghavi K, Scotcher D, Scott J, Juhe CS, Shkedi-Rafid S, Wessels TM, Yoon SY, Wicklund C. The global state of the genetic counseling profession. Eur J Hum Genet. 2019;27:183–97.
3. Resta RG. The historical perspective: Sheldon reed and 50 years of genetic counseling. J Genet Couns. 1997;6:375–7.
4. Stern AM. A quiet revolution: the birth of the genetic counselor at Sarah Lawrence College, 1969. J Genet Couns. 2009;18:1–11.
5. National Society of Genetic Counselors. NSGC code of ethics, [Online]. National Society of Genetic Counselors. 2017. https://www.nsgc.org/p/cm/ld/fid=12. Accessed 11 Aug 2017.
6. Association of Genetic Nurses and Counsellors (AGNC). Code of ethics [Online]. United Kingdom: Association of Genetic Nurses and Counsellors (AGNC). 2018. http://www.agnc.org.uk/about-us/agnc-documents/code-of-ethics/ Accessed 31 Mar 2018.
7. Kessler S. Psychological aspects of genetic counseling. 11. Nondirectiveness revisited. Am J Med Genet. 1997;72:164–71.
8. Middleton A, Hall G, Patch C. Genetic counselors and genomic counseling in the United Kingdom. Mol Genet Genomic Med. 2015;3:79–83.
9. Patch C, Middleton A. Genetic counselling in the era of genomic medicine. Br Med Bull. 2018;126:27–36.
10. Wham D, Vu T, Chan-Smutko G, Kobelka C, Urbauer D, Heald B. Assessment of clinical practices among cancer genetic counselors. Familial Cancer. 2010;9:459–68.
11. Cohen SA, Bradbury A, Henderson V, Hoskins K, Bednar E, Arun BK. Genetic counseling and testing in a community setting: quality, access, and efficiency. Am Soc Clin Oncol Educ Book. 2019;39:e34–44.
12. Pagliazzi A, Mancano G, Forzano G, Di Giovanni F, Gori G, Traficante G, Iolascon A, Giglio S. Genetic counseling during COVID-19 pandemic: tuscany experience. Mol Genet Genomic Med. 2020;8(10):e1433.
13. Bergstrom KL, Brander TE, Breen KE, Naik H. Experiences from the epicenter: professional impact of the COVID-19 pandemic on genetic counselors in New York. Am J Med Genet C Semin Med Genet. 2020;187:28–36.
14. Jenkins J, Calzone KA, Dimond E, Liewehr DJ, Steinberg SM, Jourkiv O, Klein P, Soballe PW, Prindiville SA, Kirsch IR. Randomized comparison of phone versus in-person BRCA1/2 predisposition genetic test result disclosure counseling. Genet Med. 2007;9:487–95.
15. Tutty E, Petelin I, Mckinley J, Young MA, Meiser B, Rasmussen VM, Forbes Shepherd R, James PA, Forrest IE. Evaluation of telephone genetic counselling to facilitate germline BRCA1/2 testing in women with high-grade serous ovarian cancer. Eur J Hum Genet. 2019;27:1186–96.
16. Stefansdottir V, Skirton H, Johannsson OT, Olafsdottir H, Olafsdottir GH, Tryggvadottir I, Jonsson JJ. Electronically ascertained extended pedigrees in breast cancer genetic counseling. Familial Cancer. 2019;18:153–60.
17. Kaplanis J, Gordon A, Shor T, Weissbrod O, Geiger D, Wahl M, Gershovits M, Markus B, Sheikh M, Gymrek M, Bhatia G, Macarthur DG, Price AL, Erlich Y. Quantitative analysis of population-scale family trees with millions of relatives. Science. 2018;360:171–5.
18. Jonsson JJ, Stefansdottir V. Ethical issues in precision medicine. Ann Clin Biochem. 2019;56:628–9.

19. Patch C, Middleton A. Point of view: an evolution from genetic counselling to genomic counselling. Eur J Med Genet. 2019;62:288–9.
20. WEIL, J. Genetic counselling in the era of genomic medicine. As we move towards personalized medicine, it becomes more important to help patients understand genetic tests and make complex decisions about their health. EMBO Rep. 2002;3:590–3.

Chapter 30
Person-Centered Endocrinology (Including Diabetes and Obesity)

Sanjay Kalra and Guy Rutten

30.1 Introduction

Endocrinology is the study of the endocrine system (https://www.hormone.org/what-is-endocrinology). The discipline encompasses the study of hormones and hormonal disease, including diabetes and obesity. More often than not, endocrine dysfunction is chronic in nature. The person with such a chronic condition has to cope with the disease and its lifelong therapy. Obviously, the success of the coping strategy will depend, at least partially, on the type and burden of the chosen therapy. Endocrine disease is characterized by a wide spectrum of clinical presentation and natural history, and an even broader choice of therapeutic options. This calls for individualization of management strategies.

Many endocrine syndromes require a significant amount of lifestyle modification and self-management. Health care providers support patients in this respect, as they enter into a continuous and interactive dialogue, facilitating and supporting the individual to achieve and/or apply knowledge, skills and self-efficacy to be able to manage his/her disease to achieve the best outcomes and quality of life. Tailoring self-management support to patient's self-defined needs may improve the health care provider's support, and achieve better outcomes. The health care provider should realize, that the success of self-management of chronic disease depends on Illness perceptions, a person's ideas about the consequences of the disease, it's curability, the perceived benefits and side effects of medications; personal preferences, wishes and values; self-efficacy, social factors and everyday events [1, 2]. This makes it essential to practice informed and shared decision making in endocrine

---

S. Kalra (✉)
Department of Endocrinology, Bharti Hospital, Karnal, India

G. Rutten
Diabetology in Primary Care, Julius Center for Health Sciences and Primary Care, University Medical Center, Utrecht University, Utrecht, The Netherlands
e-mail: g.e.h.m.rutten@umcutrecht.nl

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_30

practice. Person-centred medicine (PCM), therefore, is the fulcrum upon which endocrine management should be built.

An increase in the complexity of endocrine disorders, coupled with better understanding of their etiology and complications, as well as many randomized controlled trials, led to the concept of evidence-based medicine (EBM). EBM has permeated modern endocrine practice extensively and helps physicians to inform their patients about screening, monitoring and therapeutic decisions. The concept of EBM has also allowed endocrinologists to aim for long term 'hard' cardiometabolic outcomes like less complications, as opposed to provision of mere symptomatic or short-term relief or just improving laboratory or other biomedical outcomes.

This evolution is reflected in the TRIDENT (TRIpod of DiabEtes Needs and Therapy) model, based upon Maslow's theory of hierarchy of needs. The TRIDENT model, created to understand needs of persons with diabetes, states that only after the basic need of correction of symptoms is achieved, persons begin to expect glucometabolic relief, or control of glycemic parameters. The highest need, which is cardiometabolic relief, or expectations of better macrovascular and microvascular outcomes, manifests afterwards. The evolution of modern endocrine and diabetes care tends to follow this framework (https://www.touchendocrinology.com/insight/the-hierarchy-of-needs-maslows-theory-applied-to-the-science-of-diabetes/).

30.2 Limitations of Evidence-Based Medicine in Endocrinology

The practice of EBM is based upon results from randomized controlled trials (RCTs). The generalisability of RCTs is limited by their exclusion and inclusion criteria, which can be quite restrictive. This simple truth raises a question mark upon the applicability of EBM to community-based clinical endocrine practice. Another noteworthy issue is that RCTs are powered to answer specific research questions, which are reflected in their primary and secondary endpoints. It is not necessary for every person with endocrine dysfunction to aspire for the same endpoint. For example, a person with diabetes may prefer flexibility in lifestyle with less intensive therapy, while another may welcome an intrusive treatment regimen which demands strict adherence to a socially nonconforming way of life (Table 30.1).

Table 30.1 Secured model for person-centred obesity care

S	Severity of obesity	Body mass index, waist circumference
E	Expected prognosis	Expected life span
C	Comorbid conditions	Metabolic, mechanical and mood disturbances
U	Urgency of control	Biomedical or psychosocial issues which need early weight control
R	Risk of complications	Risk of malnutrition, gall stones, other complications due to rapid weight loss
E	Environmental factors	Socioeconomic factors that influence life with obesity
D	Dysfunction & disability	Biopsychosocial dysfunction & disability due to obesity

Limitations in current evidence-based practice are painfully obvious. Patient satisfaction with endocrine therapy is woefully suboptimal [3], with large proportions reporting unhappiness. In spite of tremendous advances in medical science, we are unable to contain the epidemics of diabetes, obesity, polycystic ovary syndrome, thyroid disease and subfertility [4–8]. As we grapple with existing problems, newer challenges such as endocrine disruptor chemicals raise their head [9]. The heterogeneity of endocrine syndromes, too, is increasing being recognized, as in diabetes, hypothyroidism and polycystic ovary syndrome. Most trials are underpowered to answer the question whether a specific therapy is beneficial or not for a subgroup of patients. The relevance of such a question for clinical practice is clearly demonstrated by two post-hoc analyses from the Look AHEAD trial. They demonstrate that an intensive lifestyle intervention aimed at weight loss may reduce cardiovascular events in selected patients with type 2 diabetes but may have a detrimental effect in others [10, 11]. The unique preferences and needs of special populations such as adolescents, persons of reproductive age groups, and the elderly, as well as minority or marginalised groups, have to be addressed as well.

30.3 Towards Person-Centred Endocrinology

All these factors create a ripe field for growth of PCM in endocrinology. PCM does not imply that all decisions be taken by the person living with endocrinopathy. Neither does the concept suggest that endocrinologists abdicate their responsibility to achieve optimal outcomes through rational, evidence-based interventions. PCM requires a balanced patient-provider relationship in a fair manner. Shared decision making is not a panacea for person-centred care, but provides a way for clinicians to support patients in their pursuit of good health [12–14].

A review of literature reveals that the words ‘person centred’ or ‘patient centred’ are used frequently in conjunction with diabetes, but rarely with other endocrine syndromes. We discuss the relevance of PCM to various field of endocrinology, including diabetes and obesity, in this chapter.

30.3.1 Pituitary Disorders

Most pituitary diseases are worked up in a biomedical, rather than a biopsychosocial framework. Some aspects of pituitary dysfunction, however, lend themselves to PCM. Short stature is one example. Should the definition of short stature be standardized? It is apparent that defining this syndrome is hampered by cultural and personal factors as well. Whereas one person may “suffer” from his or her short stature, another will not, may be because he or she does not feel the stature to be short. As a result, there is a lot of variability in terms of health care-seeking behavior for this syndrome. A wide range of etiologic and contributory factors, including nutritional and psychosocial deprivation, contribute to the pathogenesis of short stature. On the other hand, if a person would like his or her height increased, the cost of some therapies, such as growth hormone, may be unaffordable for families that do not have access to insurance or government funds. These factors call for PCM in short stature [15, 16].

In panhypopituitarism, conventional wisdom suggests sequential hormone replacement therapy. While some hormones are essential to prevent life-threatening complications, others may not be so important [17]. A person-centred discussion, therefore, is needed, to analyze the advantages, limitations and caveats of androgen or estrogen replacement therapy, prior to prescription [18]. Some causes of hypopituitarism, such as post-partum hemorrhage [19], snake bite and road traffic accidents, have their genesis in the socio-physical environment. Prevention of these avoidable mishaps needs a public health approach which is both sensitive to, and responsive to, the person's environment.

Pituitary hyperfunction, including acromegaly, Cushing's disease and hyperprolactinemia, is characterized by equipoise in therapy. Surgical, medical and radiotherapeutic interventions all have their advantages and disadvantages [20]. The patient should be informed regarding these, and involved in all planning. PCM helps reaching an informed decision on choice of management and monitoring tools.

Quality of life is an important aspect of pituitary disease which is often ignored in management [21]. PCM reinforces the importance of addressing health related quality of life, along with hormonal defects, while treating pituitary disease.

30.3.2 Bone and Mineral Disease

Bone and mineral metabolism include a vast array of diseases, ranging from nutritional rickets and osteomalacia to primary hyperparathyroidism and renal tubular acidosis. Calcium, vitamin D and magnesium deficiency may be linked to lifestyle and dietary choices [22], which are person-centric in character. PCM is required in order to motivate the person to adopt a healthier lifestyle and better dietary habits, to accept and adhere to optimal therapy, and to maintain these behaviors. One must also ensure that optimization of the physical environment, so as to prevent falls and fractures, is achievable. The same relates to providing safe opportunities for enjoyable exercise, to build up muscle mass. To do so, an open patient-doctor conversation is necessary. If such an optimization seems not achievable, a next best solution should be sought. Simple treatment measures such as exposure to sunlight and outdoor exercise may not be accessible to some: unique person-centred interventions have to be devised for them.

Availability of multiple therapeutic regimens and preparations, especially for osteomalacia and osteoporosis, have increased the responsibility of endocrinologists. Keeping in mind the equipoise related to definition, significance and treatment of osteocrine diseases [23, 24] there is a need to involve the patient in therapeutic planning. Osteoporosis management requires a person centred approach at every step. Ordering and interpretation of investigations, diagnostic and therapeutic thresholds, and pharmacological and supportive treatment, must be individualised [25].

30.3.3 Adrenal Disease

Similar to pituitary disease, adrenal disease etiopathology and clinical presentation are marked by heterogeneity, investigations by lack of sensitivity/specificity, and treatment options by caveats and challenges. Quality of life remains a major concern for patients with adrenal disease [26]. Person specific impact of disease, such as the need for fertility, also has to be taken into account [27]. The multiple options available have to be utilized in a person centred manner to ensure effective treatment. This, in turn, requires an in-depth understanding of both the biomedical phenotype, and the psychosocial impact, of adrenal disease. Some causes of adrenal disease, like tuberculosis and fungal disease, cannot be addressed without a person-centric understanding of the environment.

30.3.4 Gonadal Disorders

Gonadal health is a major part of endocrinology. Gonadal dysfunction, which may be due to a multitude of causes, can cause a variety of symptoms. The significance and impact of these symptoms can vary from person to person. In hypogonadism, for example, sexuality may be a major concern for one individual, and reproductive ability for another [28]. Yet others may have significant concerns related to body image, self-esteem, metabolic health or musculoskeletal competence. A similar situation is noted in polycystic ovary syndrome (PCOS), where myriad symptoms and dysfunctions interplay with each other to create multiple phenotypes [29].

PCM guides the endocrinologist in investigations and treatment options, according to preferred aims and goals of therapy. Practice of PCM is likely to improve patient satisfaction levels by ensuring realistic patient expectations and helping prioritisation of therapeutic targets. In a setting of PCOS, one may have to decide whether to prioritize menstrual regularity, or fertility, or cosmetic dermatological health as a management objective. This can be decided only after in depth informed and shared decision-making process. The same is true in menopause/andropause [30] and hypogonadism, where each individual will have unique needs, preferences and values that need to be addressed. The term ‘couple pause’ highlights and validates the concept of person centred care, by viewing mid-life partners as a single entity, and creating a unique treatment paradigm for them [31].

30.3.5 Disorders of Sexual Differentiation

Disorders of sexual differentiation (DSD) are a group of congenital diseases characterised by atypical development of internal &/or external genitalia. While most affected individuals are diagnosed at birth, by ambiguous external genitalia, others may be identified later. Excessive or inadequate virilization, delayed or absent puberty, and subfertility are some presenting features in adolescents and adults [32].

The management of DSD requires a sensitive, person-centred and family-centred approach. It must be understood that karyotypic sex, gonadal sex external phenotypic sex, sex of rearing, and gender identity may not always be concordant. The endocrinologist should lead a multi-disciplinary team while evaluating and managing DSD. Whole exome sequencing (WES) and whole genome sequencing (WGS) are increasingly being used to pinpoint the genetic etiology of DSD. However, one must be aware of ethical issues (the possibility of detecting unrelated findings), the cost, and limitations (inability to describe the functional or causal significance of detected variants).

While evaluation of DSD is ongoing, the choice of gender of rearing should be facilitated, by the endocrinologist. The sociocultural environment of the child must be kept in mind. If therapeutic measures such as gonadectomy or other genital surgery are required, these should be preceded and accompanied by adequate counseling and information sharing [33]. Newer advances in assisted reproductive technology may allow parenthood in a significant number of hitherto infertile individuals.

30.3.6 Gender Identity Disorders

Gender identity disorders are another group of conditions which require sensitive, person centred handling. While most societies assume a binary gender distribution (male and female), many countries now accept a third gender category [34]. Even within this category, there are various person-specific ‘labels’. This includes transgender, non-binary and genderqueer categories. Agender, genderfluid and other-gendered are other identifications [35]. Children, adolescents and adults with gender identity disorder need a person-centred, individualized therapy, based on their needs and preferences. Gender-affirming medical and surgical treatments should be offered only after a thorough psychological, endocrine and medical assessment.

30.3.7 Obesity

Obesity is a major endocrine public health problem which seems to have no effective solution. Traditionally, the pathogenesis of obesity has been studied as a biomedical construct, based on genetic, perinatal, environmental and consumption- expenditure energy imbalance. Most physicians assume that weight loss in overweight and obese patients is always favorable. However, as stated above, this is not true. The field of obesity is characterized by significant equipoise. It is possible that the lack of focus on person-centred factors, may be the cause of our inability to contain the obesity epidemic.

Obesity management needs a holistic approach, which addresses emotional, psychological and social aspects of weight gain. This can be done using psychobiological, attribution and social support theories. A better understanding of people's perceptions of obesity might allow more effective interventions to challenge these perceptions through lifestyle intervention programs. Individuals with persistent central obesity, irrespective of additional cardiometabolic risk factors, seem to underestimate the seriousness of their condition and experience relatively low levels of personal control. Discussing the seriousness of obesity as well as 'personal control' might be a good option in PCM of obesity [36]. The delivery of person-centred obesity care is best done through team-based, motivational interviewing [37]. Emotional and social wellbeing is as important as physical wellbeing. Individuals who are overweight or obese may expect care that is tailored to them as individuals, not to their body mass index. This implies that the person should be able to choose (in an informed manner) the criteria for diagnosis of obesity, monitoring therapy, therapeutic tools, and preferred outcomes. A detailed discussion, keeping in mind the biomedical and psychosocial needs of the person can help decide appropriate plan of care [38].

The SECURED rubric [39] is a useful framework to plan person-centred care for obesity. This has been adapted from the SECURE model used in critical care management of hyperglycemia. The necessity and intensity of interventions for weight modulation should be based upon seven factors (Table 30.1). SECURED builds upon the Edmonton obesity staging system (EOSS) [40], which attempts to provide a holistic approach to obesity care.

30.3.8 Thyroid Disorders

Thyroid disorders are a rapidly increasing group of endocrinopathies with varied etiology, clinical presentation and management. Poor levels of satisfaction suggest the need to rethink a purely biomedical approach to thyroid management. Patient centred management of hypothyroidism [13] calls for an individualized history taking, target setting, and therapy initiation, titration and timing of administration. A PCM approach helps to increase adherence to therapy [41]. There is potential for PCM to increase treatment satisfaction levels and reduce thyroid distress [42, 43].

30.3.9 Diabetes

The phrase 'PCM' has been used most frequently, within endocrine circles, in the context of diabetes. The first step towards a holistic diabetes care came about with the publication of the position statement of the European Association for the Study of Diabetes and the American Diabetes Association in 2012. It recommended the adoption of a patient-centred approach, defined as 'providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuring that patients values guide all clinical decisions' [44]. Evidence at that time underpinned the statement that HbA1c goals above 53 mmol/mol (7%) were appropriate for several categories of patients. Importantly, the statement also stipulated that any HbA1c target should reflect mutual agreement between patient and physician. Such shared decision making encourages patients to have a direct say in the control and progress of their health. Physicians are expected to coach their patients on how to become an effective participant of their own disease management [45].

To be in a position to effectively participate, individuals with Type 2 DM need adequate knowledge, motivation, skills and confidence These needs for managing a health condition are captured by the concept 'patient activation'. First, the individual believes an active role is important for disease management. He or she gets the knowledge and the confidence to take action; in the third stage the patient actually takes action. Finally, the individual is able to maintain adequate behavior, even when under stress. Cross-sectional studies on patient activation in Type 2 DM demonstrated that a patient's educational level, disease knowledge, trust in the treating physician, social support from friends and glycemic control were all positively associated with patient activation, while a negative association was found for hospitalization, emergency department visits, depression, body mass index (BMI) and macrovascular complications. In longitudinal studies age was negatively associated with patient activation, while physical health status, participatory decision making, blood pressure control and cholesterol level control were all positively associated with patient activation. Patient activation does not differ between individuals with type 2 diabetes on insulin and those on other therapies [46].

In person-centred diabetes care not only individual characteristics, but also the environment in which behaviours are enacted has great influence, from family eating patterns to the work setting. Besides contextual factors diabetes care providers are also recommended to consider an assessment of diabetes distress, depression, anxiety and disordered eating and of cognitive capacities. They should also monitor a patient's self-management behaviours as well as psychosocial factors impacting the person's self-management [47]. More importantly, all health care team members should realize that diabetes self-care behaviour is depending on patient's health beliefs or illness perceptions, self-efficacy, wishes and preferences, pro-active coping, family support, financial resources and everyday events [48]. Taking all these aspects into account goes far beyond protocolled disease management.

A comprehensive consultation model for general practitioners, internal medicine specialists, practice nurses and diabetes specialist nurses, that includes

Table 30.2 Factors influencing planned diabetes care

Demographic
- Age
- Education: If high, then associated with more intensive care for the next year

Biomedical
- HbA1c
- More comorbidities associated with more intensive care
- Use of oral blood glucose lowering medication: Associated with lower chance of more intensive care for the next year

Psychosocial
- Perception of poor control associated with more intensive care for the next year
- Concern about disease: More concern associated with more intensive care
- Emotional impact of disease
- Diabetes distress: If lower, then associated with less intensive care for the next year
- Quality of life

Consultation process
- Formulation of goals with physician/nurse: Strongly related to more intensive care

systematically discussing not only disease related but also personal factors and should result in PCM with shared decisions about diabetes treatment and care seems well applicable. The model consists of four steps. In the first step, the diabetes care provider discusses not only health related factors such as diabetes related complications, current glycemic control and medication use, but also personal factors such as quality of life, diabetes knowledge, self-management skills, illness perceptions, the social context etc. with the patient. The topics to be addressed depend on the patient's actual situation and are not based on protocol. After discussing pros and cons, in step 2–4 shared decisions will be made on personalized health related goals, treatment options, and the type and amount of professional diabetes care for the upcoming year. Such an approach resulted in more patient involvement and shared decision making and was appreciated by a substantial number of patients [49, 50]. Following the consultation, 23% of people chose more intensive care, 71% no/minimal change and 7% less intensive care. The intended intensity of care was associated with both disease- and person-related factors (see Table 30.2) [51, 52]. In their 2018 consensus report on the management of hyperglycaemia EASD and ADA once again advocate a patient-centred approach to enhance patient engagement in self-care activities. The annual circle that describes the process or care is almost identical to the conversation model described above [53].

30.4 Practical Implications for Person Centered Care

Endocrine status has a unique, and important, bidirectional link with PCM. On one hand, endocrine disease requires PCM for optimal resolution. The multifactorial pathogenesis and multifaceted clinical presentations, along with multipronged therapeutic options, undoubtedly create a need for PCM. Though endocrinology is an

Table 30.3 Examples of person-centred medicine in endocrinology

Domain of endocrinology	Examples
Screening threshold	Diseases with public health impact, e.g., congenital hypothyroidism
Diagnostic threshold	Diseases with ethnicity-specific cut offs, e.g., obesity, osteoporosis
Interventional threshold	Diseases with equivocal impact of treatment, e.g., menopause, andropause
Choice of investigations	Challenging diseases with multiple methods of diagnosis, e.g., Cushing's syndrome, hyperparathyroidism
Choice of treatment approach	Diseases with multiple methods of treatment, e.g., endocrine tumours, diabetes, Graves' disease
Intensity of treatment	Diseases with person centred targets, e.g., obesity, diabetes
Route of administration	Diseases with multiple pharmacologic therapies e.g., osteoporosis, vitamin D deficiency, hypogonadism
Monitoring threshold	Diseases with variable natural history, e.g., diabetes, disorders of sexual differentiation
Choice of outcomes	Multifaceted diseases, e.g., obesity, diabetes

evidence-based science, the equipoise that characterizes it, and the important role of the individual patient's self-care, also call for a person-centred style of management. The relevance of such PCM has been discussed in this chapter. Yet surveys indicate that management of patients with endocrine disorders such as diabetes often lacks aspects of person-centered care [54].

Table 30.3 takes a different approach, and lists examples of PCM in a hierarchal fashion, beginning with screening and diagnosis, and extending up to choice of therapeutic outcomes. At the same time, presence of endocrine disease, such as obesity in men, may negatively influence the person-centredness of treating physicians [55]. Certain endocrine syndromes such as transgender and short stature may be associated with social stigma, and may create unwanted bias in the treating physician. As endocrinologists, we should strive to integrate person centred care in every aspect of clinical practice. Clinicians must realize that the implementation of person-centred endocrinology is influenced not only by availability of time and by the patient's participation, but perhaps even more by their personal attitude. Once this is achieved, person-centred endocrinology will certainly be implemented as the 'state of the art'.

The practice of PCM requires a sensitive and empathic approach to patient care. These characteristics need to be developed and polished during training and practice. The CARES model [56] encapsulates these, and other desirable traits that a PCM practitioner should possess (Table 30.4). Confident Communication implies that the endocrinologist should be well versed with his or her craft, and be able to communicate effectively with the person seeking care. Authentic Accessibility indicates that the endocrinologist should be available and accessible for any information, as and when required. This does not necessarily mean that a single health care provider should be on 24 × 7 duty. It does demand, however, that the person seeking endocrine care should be informed of whom to contact in case of emergency.

Table 30.4 Attributes of a person centred endocrinologist—the cares model

C	**C**onfident competence
A	Accessible authenticity
R	**R**eciprocal respect
E	**E**xpressive empathy
S	Straightforward simplicity

Reciprocal Respect is a construct which asks the endocrinologist to be sensitive towards, and to respect, the person's values and preferences. This facilitates reciprocal respect from the person, and creates an environment conductive to informed and shared decision making. Expressive Empathy expects the endocrinologist to be able to express empathy towards the person. This encourages person-physician communication, and reinforces bonding between them. The last attribute, Straightforward Simplicity, reminds PCM providers to explain health-related concepts in a simple manner to their patients and community. These seemingly simple, yet practically complex, features, help in ensuring effective provision of PCM.

30.5 Conclusions

Nowadays, in endocrinology PCM with shared decision making is the 'state-of-the-art'. This implies that most health care providers (not only endocrinologists, but also primary care physicians who treat people with diabetes) need to modify their consultation behaviour to reflect a person-centric approach.

Acknowledgements and Disclosures The authors do not report conflicts of interest concerning this manuscript.

References

1. Bos-Touwen I, Schuurmans M, Monninkhof E, et al. Patient and disease characteristics associated with activation for self-management in patients with diabetes, chronic obstructive pulmonary disease, chronic heart failure and chronic renal disease: a cross-sectional survey study. PLoS One. 2015;10(5):e0126400.
2. Van Houtum L, Rijken M, Groenewegen P. Do every day problems of people with chronic illness interfere with their disease management? BMC Health Serv Res. 2015;145(1):1000.
3. Kalra S, Khandelwal SK. Why are our hypothyroid patients unhappy? Is tissue hypothyroidism the answer? Indian J Endocrinol Metab. 2011;15(Suppl2):S95.
4. Chooi YC, Ding C, Magkos F. The epidemiology of obesity. Metabolism. 2019;92:6–10.
5. Glovaci D, Fan W, Wong ND. Epidemiology of diabetes mellitus and cardiovascular disease. Curr Cardiol Rep. 2019;21(4):21.
6. Inhorn MC, Patrizio P. Infertility around the globe: new thinking on gender, reproductive technologies and global movements in the 21st century. Hum Reprod Update. 2015;21(4):411–26.
7. Lortet-Tieulent J, Franceschi S, Dal Maso L, Vaccarella S. Thyroid cancer "epidemic" also occurs in low-and middle-income countries. Int J Cancer. 2019;144(9):2082–7.

8. Mohd M, Maqbool M, Dar MA, Mushtaq I. Polycystic ovary syndrome, a modern epidemic: an overview. J Drug Deliv Ther. 2019;9(3):641–4.
9. Zoeller RT, Doan L, Demeneix B, Gore AC, Nadal A, Tan S. Update on activities in endocrine disruptor research and policy. Endocrinology. 2019;160(7):1681–3.
10. Baum A, Scarpa J, Bruzelius E, Tamler R, Basu S, Faghmous J. Targeting weight loss interventions to reduce cardiovascular complications of type 2 diabetes: a machine learning-based post-hoc analysis of heterogeneous treatment effects in the look AHEAD trial. Lancet Diabetes Endocrinol. 2017;5(10):808–15.
11. de Vries TI, Dorresteijn JA, van der Graaf Y, Visseren FL, Westerink J. Heterogeneity of treatment effects from an intensive lifestyle weight loss intervention on cardiovascular events in patients with type 2 diabetes: data from the look AHEAD trial. Diabetes Care. 2019;42(10):1988–94.
12. Kalra S, Agarwal N, Aggarwal R, Agarwal S, Bajaj S, Bantwal G, et al. Patient-centered management of hypothyroidism. Indian J Endocrinol Metab. 2017a;21(3):475–7.
13. Kalra S, Baruah MP, Unnikrishnan AG. Responsible patient-centered care. Indian J Endocrinol Metab. 2017b May;21(3):365–6.
14. Rodriguez-Gutierrez R, Gionfriddo MR, Ospina NS, et al. Shared decision making in endocrinology: present and future directions. Lancet Diab Endocrinol. 2016;4:706–16.
15. Argente J. Challenges in the management of short stature. Horm Res Paediatr. 2016;85(1):2–10.
16. Morrison M. Growth hormone, enhancement and the pharmaceuticalisation of short stature. Soc Sci Med. 2015 Apr;1(131):305–12.
17. Amayiri N, Swaidan M, Yousef Y, Halalsheh H, Abu-Hijlih R, Kalaldeh S, et al. Review of management and morbidity of pediatric craniopharyngioma patients in a low-middle-income country: a 12-year experience. Childs Nerv Syst. 2017;33(6):941–50.
18. Mitchell-Brown F, Stephens-DiLeo R. Managing panhypopituitarism in adults. Nursing 2019. 2017;47(12):26–31.
19. Mokta J, Ranjan A, Thakur S, Bhawani R, Mokta KK, Sharma JB, et al. Sheehan's syndrome-the most common cause of panhypopituitarism at moderate altitude: a sub-Himalayan study. J Assoc Physicians India. 2017;65(12):20–3.
20. Raverot G, Burman P, McCormack A, Heaney A, Petersenn S, Popovic V, et al. European Society of Endocrinology Clinical Practice Guidelines for the management of aggressive pituitary tumours and carcinomas. Eur J Endocrinol. 2018;178(1):G1–24.
21. Yano S, Kudo M, Hide T, Shinojima N, Makino K, Nakamura H, et al. Quality of life and clinical features of long-term survivors surgically treated for pediatric craniopharyngioma. World Neurosurg. 2016;85:153–62.
22. Holick MF. The vitamin D deficiency pandemic: approaches for diagnosis, treatment and prevention. Rev Endocr Metab Disord. 2017;18(2):153–65.
23. Black DM, Rosen CJ. Postmenopausal osteoporosis. N Engl J Med. 2016;374(3):254–62.
24. Manson JE, Brannon PM, Rosen CJ, Taylor CL. Vitamin D deficiency-is there really a pandemic? N Engl J Med. 2016;375(19):1817–20.
25. Kanis JA, Cooper C, Rizzoli R, Reginster JY. European guidance for the diagnosis and management of osteoporosis in postmenopausal women. Osteoporos Int. 2019;30(1):3–44.
26. Ho W, Druce M. Quality of life in patients with adrenal disease: a systematic review. Clin Endocrinol. 2018;89(2):119–28.
27. Anand G, Beuschlein F. Management of endocrine disease: fertility, pregnancy and lactation in women with adrenal insufficiency. Eur J Endocrinol. 2018;178(2):R45–53.
28. Antoniou-Tsigkos A, Macut D, Mastorakos G. Physiopathology, diagnosis, and treatment of secondary female hypogonadism. Hypothalamic-Pituitary Dis. 2018;2018:247–87.
29. Teede HJ, Misso ML, Costello MF, Dokras A, Laven J, Moran L, et al. Recommendations from the international evidence-based guideline for the assessment and management of polycystic ovary syndrome. Hum Reprod. 2018;33(9):1602–18.
30. Rees M, Lambrinoudaki I, Bitzer J, Mahmood T. Joint opinion paper—'Ageing and sexual health' by the European Board & College of Obstetrics and Gynaecology (EBCOG) and the

European Menopause and Andropause Society (EMAS). Eur J Obstet Gynecol Reprod Biol. 2018;220:132–4.

31. Jannini EA, Nappi RE. Couplepause: a new paradigm in treating sexual dysfunction during menopause and andropause. Sexual Med Rev. 2018;6(3):384–95.
32. Rodriguez-Buritica D. Overview of genetics of disorders of sexual development. Curr Opin Pediatr. 2015;27(6):675–84.
33. Anderson S. Disorders of sexual differentiation: ethical considerations surrounding early cosmetic genital surgery. Pediatr Nurs. 2015;41(4):176–86.
34. Kalra S, Kalra B. Improving compliance in hypothyroidism: what can we do? Thyroid Res Pract. 2012;9(3):78.
35. Shumer DE, Spack NP. Current management of gender identity disorder in childhood and adolescence: guidelines, barriers and areas of controversy. Curr Opin Endocrinol Diabetes Obes. 2013;20(1):69–73.
36. Den Engelsen C, Vos RC, Rijken M, et al. Comparison of perceptions of obesity among adults with central obesity with and without additional cardiovascular risk factors and among those who were formally obese, 3 years after screening for central obesity. BMC Public Health. 2015;15:1214.
37. Vallabhan MK, Jimenez EY, Kong AS. Motivational interviewing for treating overweight and obese youth: a systematic review. J Adolesc Health. 2018;62(2):S119–20.
38. Barnes RD, Ivezaj V. A systematic review of motivational interviewing for weight loss among adults in primary care. Obes Rev. 2015 Apr;16(4):304–18.
39. Kalra S, Kapoor N, Kota S, Das S. Person-centred obesity care–techniques, thresholds, tools and targets. Eur Endocrinol. 2020 Apr;16(1):11–3.
40. Sharma AM, Kushner RF. A proposed clinical staging system for obesity. Int J Obes. 2009;33(3):289–95.
41. Kalra S. The eunuchs of India: an endocrine eye opener. Indian J Endocrinol Metab. 2012;16(3):377–80.
42. Buchmann L, Ashby S, Cannon RB, Hunt JP. Psychosocial distress in patients with thyroid cancer. Otolaryngol Head Neck Surg. 2015 Apr;152(4):644–9.
43. Kalra S, Das AK, Bajaj S, Saboo B, Khandelwal D, Tiwaskar M, et al. Diagnosis and management of hypothyroidism: addressing the knowledge—action gaps. Adv Ther. 2018;35(10):1519–34.
44. Inzucchi SE, Bergenstahl RM, Buse JB, et al. Management of Hyperglycemia in type 2 diabetes: a patient-centered approach. Position Statement of the American Diabetes Association and the European Association for the Study of Diabetes. Diabetes Care. 2012;35(1–16):1364–79. https://doi.org/10.2337/dc12-0413.
45. Hendriks M, Rademakers J. Relationships between patient activation, disease-specific knowledge and health outcomes among people with diabetes; a survey study. BMC Health Serv Res. 2014;14(1):393.
46. Boels AM, Van Vugt HA, de Weerdt I, et al. Patient activation in individuals with type 2 diabetes mellitus: associated factors and the role of insulin. Patient Prefer Adherence. 2019;Volume 13:1373–81.
47. Weinger K, de Groot M, Cefalu WT. Psychosocial research and care in diabetes; altering lives by understanding attitudes. Diabetes Care. 2016;39:2121–4.
48. Powers MA, Bardsley J, Cypress M, et al. Diabetes self-management education and support in type 2 diabetes. A Joint Position Statement of the American Diabetes Association, the American Association of Diabetes Educators, and the Academy of Nutrition and Dietetics. Diabetes Educ. 2017;43:40–53.
49. Rutten GEHM, Van Vugt HA, de Weerdt I, de Koning E. Implementation of a structured diabetes consultation model to facilitate a person-centred approach: results from a nationwide Dutch study. Diabetes Care. 2018;41(4):688–95.

50. Rutten GEHM, Van Vugt H, De Koning E. Person-centered diabetes care and patient activation in people with type 2 diabetes. BMJ Open Diab Res Care. 2020;8:e001926. https://doi.org/10.1136/bmjdrc-2020-001926.
51. Van Vugt HA, de Koning EJP, Rutten GEHM. Association between person and disease related factors and the planned diabetes care in people who receive person-centered type 2 diabetes care; an implementation study. PLos One. 2019a;14(7):e0219702.
52. Van Vugt HA, Heijmans MJWM, de Koning EJP, et al. Factors that influence the intended intensity of diabetes care in a person-centred setting. Diabet Med. 2019b;37:1167–75. https://doi.org/10.1111/dme.14072.
53. Davies MJ, D'Alessio DA, Fradkin J, et al. Management of hyperglycaemia in type 2 diabetes. A consensus report by the American Diabetes Association (ADA) and the European Association for the Study of Diabetes (EASD). Diabetologia. 2018;2018:2461–98. https://doi.org/10.1007/s00125-018-4729-5.
54. Funnell MM, Bootle S, Stuckey HL. The diabetes attitudes, wishes and needs second study. Clin Diabetes. 2015;33(1):32–6. PMID: 25653471
55. Rubin R. Addressing medicine's bias against patients who are overweight. JAMA. 2019;321(10):925–7.
56. Kalra S, Kalra B. A good diabetes counselor 'cares': soft skills in diabetes counseling. Internet J Health. 2010;11:1–3.
57. The Hierarchy of Needs—Maslow's Theory Applied to The Science of Diabetes. https://www.touchendocrinology.com/insight/the-hierarchy-of-needs-maslows-theory-applied-to-the-science-of-diabetes/. Last accessed 12 Dec 2019.
58. What is Endocrinology?. https://www.hormone.org/what-is-endocrinology. Last accessed on 22 Dec 2019.

Chapter 31
Person-Centered Cardiology

Dante E. Manyari, Israel Belenkie, and Oscar Guillermo Quiroz

31.1 Introduction

Since the turn of the century [1], increasing emphasis has been placed on the importance of patient/person/family centered care in healthcare. After much debate, in 2001, the Institute of Medicine Committee on Quality of Health Care in the United States issued the report, *Crossing the Quality Chasm* on the status of health care in this country [2]. In that report, 6 characteristics of an effective healthcare system were identified: The system should be safe, effective, patient-centered, timely, efficient, and equitable. The report emphasized that "the patient is the source of control" which defined patient-centered care [3]. In 2008, a truly international institution was formed, The International College of Person-Centered Medicine [4], as a non-for-profit educational, research, and advocacy organization emerging from the Geneva Conferences on Person-centered Medicine, dedicated to the promotion of health as a state of physical, mental, socio-cultural and spiritual well being as well as to the reduction of disease, based on mutual respect for the dignity and responsibility of each individual person [5]. Since then, several groups have suggested various terminologies. The concept of including the patient as the primary focus of care, including making or sharing decisions, has evolved from patient-centered care to person-centered care (PCC). PCC refers to the care that is "respectful of and

---

D. E. Manyari (✉)
Department of Cardiology, University of British Columbia, Vancouver, BC, Canada

Cardiology Department, Surrey Memorial Hospital, Surrey, BC, Canada
e-mail: dmanyari@shaw.ca

I. Belenkie
Cumming School of Medicine, University of Calgary, Calgary, AB, Canada
e-mail: belenkie@ucalgary.ca

O. G. Quiroz
Universidad Nacional Mayor de San Marcos, Clinica Monterrico, Lima, Peru

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_31

responsive to individual patient preferences, needs, and values and ensures that patient values guide clinical decisions" [2]. It was the beginning of an approach to care that empowers patients to be active participants in their own health care [6], a message to which the cardiology community responded positively. In 2009 the American College of Cardiology Foundation (ACCF) entrusted its Clinical Quality Committee to develop a policy on PCC that was published in 2012 [7]. Other medical and nursing associations, and patient advocate organizations have also been active participants in developing the landscape of person-centered cardiology care (PCCC) which this chapter will summarize.

Current guidelines in clinical cardiology illustrate how much the science in cardiology has advanced over the last half-century and how to best translate science into clinical practice. Most guidelines acknowledge and recognize the importance of patients participating in their own care, emphasizing the need to respect the patient as a person with his/her own values, stating "the final decisions concerning an individual patient must be made by the responsible health professional(s) in consultation with the patient and caregiver(s) as appropriate". On close scrutiny however, although current cardiology guidelines are excellent sources of up-to-date scientific knowledge on which they base their specific recommendations on diagnosis and management, they fall short of adequately describing specific instruments to best translate the science into practice using a PCC approach.

This chapter will review publications dealing with the topic of PCCC in frequent and prevalent clinical settings, grouped by specific cardiac diseases, and will describe their strengths, as well as remaining gaps in need for future person-centered research. Each clinical setting will have a short section with up-to-date knowledge that will serve as a basis for the second section which will deal with its PCCC recommendation. The third section will describe challenges and barriers to adequately practice PCCC, knowledge gaps, and potential solutions. Less common conditions will be discussed as a separate group.

31.2 Evidence-Based in Cardiology

Evidence-based knowledge in clinical cardiology has advanced more than in any other specialty in medicine. Randomized clinical trials (RCT) have shaped those advances over more than 40 years and they have been successfully incorporated into clinical practice through specific guidelines for most cardiology conditions. Included are diagnostic criteria and management recommendations that are highly effective and often with only one best therapeutic choice.

Other conditions may have more than one equally effective investigate or treatment option, each with advantages and disadvantages. A third group of cardiac conditions have no evidence-based diagnostic/treatment guidelines and the recommendations for management are effectively based on expert opinions and experience. The health care team therefore may benefit from using different tools and instruments to achieve satisfactory PCCC depending on which group the

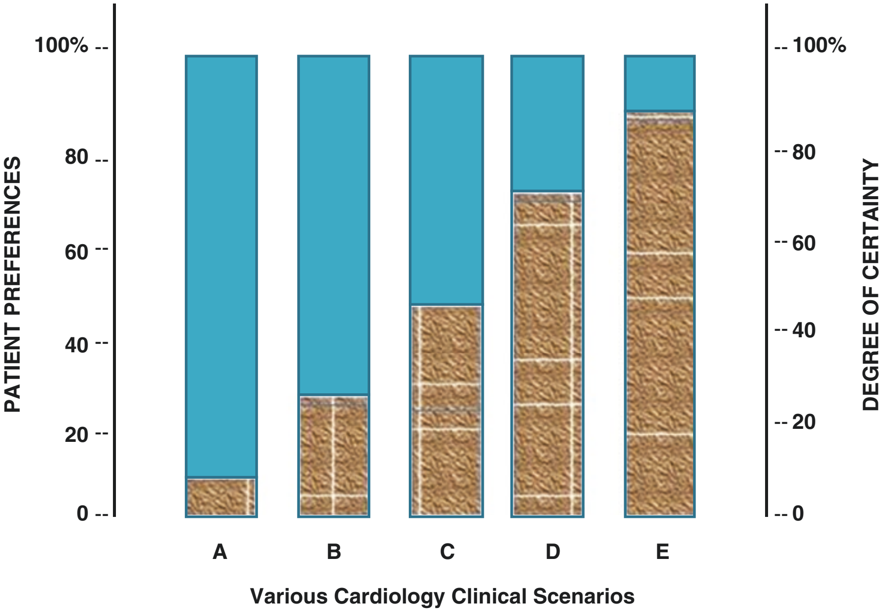


Fig. 31.1 Quantitative representation of the components of Shared-decisions in terms of Patient Preferences [blue] and Guideline and/or/Physician Recommendation are dependent on the degree of certainty [brown] of the topic under discussion (Example E = STEMI; A = HFpEF). PCCC is important across all clinical scenarios, but the opportunities of practicing it are inversely related to the degree of certainty

condition to be investigated or treated falls into, as illustrated in Fig. 31.1. The degree of certainty (strength of recommendations in the guidelines) will be a major determinant how much patient education is optimal as illustrated in Fig. 31.2.

Another factor that shapes shared-decisions in cardiology is the time available to make those decisions. Some conditions need to be investigated and treated expeditiously since even short delays in treatment diminishes efficacy, such as fibrinolysis or primary percutaneous coronary intervention (PCI) for ST-segment elevation acute myocardial infarction (STEMI). Other conditions may allow for slightly more time for adequate share-decisions to be made, such as decompensated heart failure (HF). The spectrum or urgency may vary substantially to the other extreme such as the management of primary prevention, as illustrated in Fig. 31.3. Thus, when discussing with patients and family, it is most important for the health care team to convey as clearly and simply as possible, these differences to empower patients with the tools to make the best decision.

The future landscape of cardiology will pay more attention to PCCC because there is evidence supporting its benefits beyond patient satisfaction. Studies have found that PCC is cost-effective compared with usual care when provided to patients with chronic CHF [8], and in patients with acute coronary syndrome [9]. Furthermore,

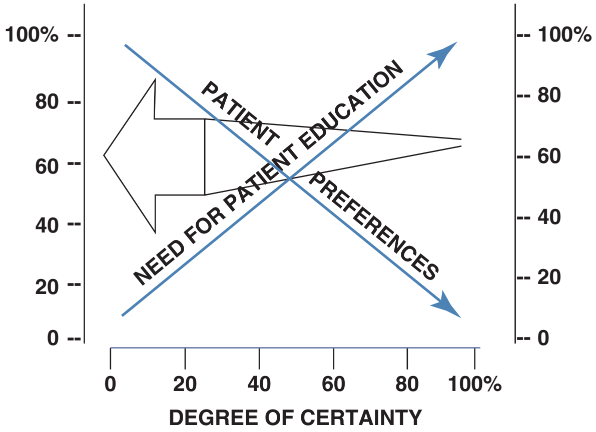


Fig. 31.2 Relationship between patient preferences, guideline recommendations, and degree of certainty during discussions leading to a shared-decision. The need for patient education is important in all clinical scenarios but quantitatively it runs in parallel to the degree of certainty of the topic under discussion. The patient preferences and believes is important in all clinical scenarios but it is quantitatively inversely related to the degree of certainty of the topic under discussion. The large open arrow represents the quantitative opportunities for using various PCCC methods

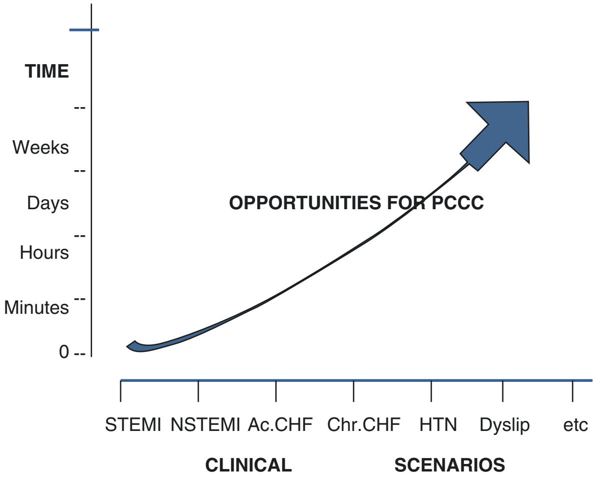


Fig. 31.3 Relationship between various clinical scenarios and the opportunities to practice PCCC in the discussions leading to a shared-decision. The time required to have an answer is critical in many cardiology clinical settings, and time is another variable, unique for each individual patient, to be considered in the discussions. Unless the patient is unconscious, such in cardiac arrest, and there are no family members, even in urgent situations, such as in STEMI, the patient opinion and consent is always required

other studies have shown that PCC is not only cost-effective but it is also associated with improved clinical outcomes [10, 11].

31.3 The Person with Coronary Artery Disease (CAD)

31.3.1 The Person with ST-Segment Elevation Myocardial Infarction (STEMI)

The pathophysiology of acute coronary syndromes (ACS) and its subsets of STEMI and Non ST-segment myocardial infarction (NSTEMI), has been well established over the past 50 years. Within the spectrum of ACS, STEMI is defined by the presence of ST-segment elevation in contiguous leads of an electrocardiogram (ECG) reflecting ischemia/damage in a myocardial region, in the appropriate clinical context of ischemic chest pain. It is associated with a substantial risk of disability or death. Along with the improved understanding of the pathophysiology, newer effective treatments have also been developed and are widely applied [12–16]. The cornerstone of modern treatment of STEMI is coronary artery reperfusion as early as possible [17, 18]. Primary PCI is the preferred method when it can be performed expeditiously in experienced centers [13, 14, 16, 19, 20]. Where primary PCI can't be timely performed chemical reperfusion (fibrinolysis) should generally be used. The efficacy of both strategies in achieving improved mortality and morbidity is dependent on timing: the earlier after symptom onset the better, as repeatedly shown in RCTs and summarized in the guidelines of the American Heart Association, the American College of Cardiology, the Canadian Cardiovascular Society, and the European Society of Cardiology [13, 14, 16, 19], among others [21]. These guidelines facilitate decision making processes to the point that a measure of good practice is one that follows guideline recommendations. Many centers have developed coordinated care systems that include rapid access to primary PCI, involving several levels of care that bring a unique opportunity for collaboration in the delivery of care and use of PCC strategies. If implemented correctly, such coordinated care systems improve outcomes substantially in patients with STEMI, which is one of the leading cause of morbidity and mortality worldwide.

Person-Centered Care in subjects presenting with STEMI may be challenging because decisions need to be made within minutes of diagnosis using the first ECG. Specialized teams of medical and paramedical professionals should be available 24/7 to respond for patients with chest pain. After a brief, focused history and physical exam, they perform an ECG which is interpreted immediately either on site or remotely. If an STEMI is diagnosed, an immediate decision needs to be made to either transport the patient to the closest cardiac catheterization laboratory for primary PCI or to administer a fibrinolytic agent. A member of the STEMI team must thus explain the diagnosis and the treatment strategy to the patient and family, as clearly and quickly as possible; convey the message that an early decision to accept treatment (if appropriate) is critical; and obtain a signed informed consent document. This is a challenging time to practice quality PCC because of time constraints. Fortunately, more people in the twenty-first century are aware of the need to treat STEMI quickly. In most cases, shared decisions are made in a timely manner, as the patient is being transported to the PCI center where he or she is informed in more detail of the benefits and risks of the procedures to be performed. Superior communication skills are therefore important to keep the patient informed in all aspects of his or her care, and answer every question with empathy and understanding, to give them the tools necessary for an informed decision. An informed patient would immediately agree to receive primary PCI unless there are special circumstances. For instance a person with advanced metastatic cancer and poor prognosis may not wish to receive a potentially life-saving therapy for STEMI and so that the primary goal may be simpler symptom-control. Thus, even in situations where the science is clear, with reperfusion as the only good focused option, the final decisions on treatment is in the hands of the patient considering his or her own personal circumstances. The health care team is obliged to abide by the individual's wishes and be supportive. Only then is a truly shared-decision made at each step from diagnosis to treatment.

In examining how the six elements of PCC [2] are involved in the process of diagnosing and treating a person with STEMI, we find that: (a) the relative *safety* of diagnostic and therapeutic measures has been confirmed in exemplary randomized controlled clinical trials. This of course does not mean that recommended therapies are risk-free. The potential morbidity (strokes and bleeding, amongst others) and mortality risks of thrombolysis and PCI are well established. These risks are much lower than the morbidity and mortality otherwise associated with untreated STEMI. As noted earlier, reperfusion therapy has a proven record of being very (b) *effective,* another element of PCC. Are the diagnostic and therapeutic procedures of persons with STEMI (c) *patient-centered*? Unfortunately, no specific and detailed guidelines or protocols are in place to practice PCC in patients with STEMI that are accepted worldwide. Each institution has or must have their own detailed protocols that involve the patient as a partner, in accordance with local socioeconomic realities, cultural and religious differences. Everyone in the medical team should be able to practice PCC if general principles of respect for the patient's preferences, values, and/or needs [22] are followed. When using methods that emphasize that the patient is the center of care, patient satisfaction is usually excellent. Moreover, PCC may not only be a source of better patient satisfaction, but also better outcomes as illustrated by a study using the CRUSADE Registry. In this study, Press-Ganey scores of patient satisfaction were positively correlated with health performance measures for acute myocardial infarction and better outcomes [23]. Endpoints of RCTs in STEMI have rarely, if ever, included patient satisfaction measures however, early benefits do extend to 5–10 years and longer, which is what the patient probably really wants. Future RCTs will hopefully include these and other patient-centered outcomes. (d) The STEMI guidelines recommend *timely* diagnosis and treatment, with an emphasis on shorter door-to-treatment times to lower morbidity and mortality due to STEMI [24, 25]. Communities or cities have specialized staff in the ambulances that responds to 911 calls for chest pain. Once the diagnosis of STEMI has been made, the team at the closest hospital with primary PCI resources is alerted by radio or telephone. By the time the ambulance arrives to the PCI center the PCI team is ready to proceed when the patient arrives. The efficiency in coordinating the efforts of nurses, paramedics, ambulance, and medical teams to respond in the shortest possible time has been one of the greatest achievements in cardiac care in the last century. (e) The next element of PCC is that care should be *efficient*. As discussed in previous lines, achieving reperfusion in a timely manner is critical to optimize outcomes with this strategy in STEMI. Finally (f), recommendations for the diagnosis and treatment of persons with STEMI promote *equitable* measures for person with STEMI regardless of gender, or socio economic status.

In reviewing work of the cardiology team when diagnosing and managing persons with acute STEMI, whatever measure we used, either the six elements of PCC as suggested by the Institute of Medicine [2] or the Picker Institute's eight principles of PCC [26], the health care team uses an exemplary PCC approach. Using effective standards and techniques, the patient remains the center of care, patient and family input are important, they are treated with respect and dignity, in a coordinated manner. Paramedics, nurses, laboratory technologists, emergency room staff, and physicians, offer not only the best care but also truly PCC. To achieve this degree of efficiency was not easy. It took years of hard work by everybody involved directing care, as well as the understanding from health care funding sources, hospital administrators, and politicians to support these projects. Each institution or department uses sets of specific protocols and guidelines in accordance with their own specialty and patient populations they serve [27, 28].

Since rapid and efficient communication between health care workers and patients and families is most important, several countries, such as Canada that is a multicultural society, hospitals obtain the service of local translators when patients do not speak either of the two official languages. Communication in the patient's preferred language is another step in the direction of good PCC.

The opportunities for expanding the patient and family involvement as partners in the health care team are greater after the initial diagnosis and treatment during the acute event. Too much happens during the acute phase for the patient to absorb more than simple important bits of information. When everything settles down is the best time to educate the patient and family on the pathophysiology of STEMI, how stents work emphasizing the role and importance of continuing therapy, the principles of secondary prevention, and the potential need for life-style modification. A multidisciplinary team composed of physicians, nurses, dietitians, and pharmacists meet with patients and families. During these sessions of *discharge planning,* the cardiology team uses the PCCC approach to teach the rationale of drug therapies, discuss their benefits and potential side effects, listen and address their concerns. There is shared decision regarding dual antiplatelet therapy for the length prescribed (usually a year), and to continue ASA and drugs to decrease serum cholesterol for life. Thus, it is not just a prescription handed to patients at the time of discharge with instructions to take them as prescribed. They are joint decisions which the patient can take ownership and responsibility. A shared decision has been shown to improve adherence and long term clinical outcomes [29–31]. An important part of the process is a discussion on how to deal with the real possibility of side effects. Measures should be in place for early detection of side effects and for timely counseling and management of these problems (first confirm the diagnosis, then change of doses or substitution of drugs, as needed). These shared decisions on long term treatments are more likely to be effective. Moreover, this process is also not static. The lines of communication with the health care team should remain open to review decisions made, make new decisions, and review progress and address further concerns that arise. This process may be facilitated by local cardiac rehabilitation programs where referral should be made at the time of discharge from hospital.

31.3.2 Potential Barriers for PCCC in the Person with STEMI

Because delay in the diagnosis and treatment of persons with STEMI is associated with net decrease on the benefits in terms of morbidity and mortality, decisions need to be taken as quickly as possible. PCC methods therefore need to be short out of necessity and could suffer with poor communication skills. As noted in Fig. 31.3, the opportunities for systematic PCC during acute STEMI is limited amongst the lowest of all cardiac conditions and physicians need to adapt methods to still deliver appropriate PCC without sacrificing time needed for prompt administration of life-saving therapies. The time constraint to deliver urgent therapy is validated by the high degree of confidence in the guideline-suggested therapies.

Other potential barriers include the lack of availability of a prepared STEMI health care team, if the acute event takes place in remote or under-serviced areas. A third potential problem may arise in timely communication between health care teams since a coordinated effort is necessary to take the patient from the field to the appropriate cardiac catheterization laboratory to the admitting hospital ward and finally to home.

31.3.3 Persons with Unstable Angina (UA) and Those with Non-ST Elevation Myocardial Infarction (NSTEMI)

Unstable angina/NSTEMI are clinical syndromes, subsets of ACS, that are usually but not always caused by atherosclerotic CAD and is associated with all the risks of acute myocardial infarction. In the spectrum of ACS, UA may or may not have objective signs of myocardial damage or ECG changes (transient ST-segment depression or prominent T-wave inversion) but just a history of increasing frequency and/or severity of ischemic chest pain. NSTEMI may have ECG changes suggestive of myocardial ischemia (excluding ST-segment elevation) or serum biomarker changes indicative of myocardial necrosis. The goals of treatment of UA/NSTEMI are to immediately relieve myocardial ischemia and prevent the occurrence of severe adverse outcomes such as myocardial (re)infarction or death [32, 33]. Treatment initially includes the administration of anti-ischemic and antithrombotic agents. Then there is consideration of the most appropriate investigation strategy, either non-invasive or invasive procedures (i.e. angiography) potentially followed by PCI or coronary artery by-pass surgery. These options are tailored to the individual patient's clinical circumstances aided by the presence/absence of high-risk markers. As soon as diagnosis is made, management of UA/NSTEMI is usually best in an impatient setting preferably in the coronary care unit.

Comparisons between a selective versus routine invasive strategy in UA/NSTE ACS have shown that the former improves clinical outcomes and reduces recurrent ACS episodes, length of hospital stay, subsequent rehospitalization and revascularization [34–36]. The optimal timing of coronary angiography and revascularization should be guided by individual risk stratification [37, 38]. Patients at very high risk should undergo an immediate invasive strategy (<2 h). In patients at high risk an early invasive strategy (<24 h) is recommended. In patients at intermediate-risk the invasive strategy may be delayed, but a maximum of 72 h window from admission to coronary angiography is recommended [39, 40]. In patients at low-risk a non-invasive stress test (preferably with imaging) looking for inducible ischemia is recommended before deciding on an invasive strategy vs. a conservative approach. Patients doing clinically well, with low risk score and without inducible myocardial ischemia may be treated conservatively.

While invasive evaluation and, if appropriate, revascularization is generally indicated in patients at high ischemic risk, in a proportion of patients this strategy may not be preferred because of the perception of insufficient benefit due to associated conditions that place the subject at increased risks related to the invasive strategy or a quality of life that may not change with the therapy. An invasive strategy may not be the best choice in the very elderly or frail with comorbidities such as dementia, severe chronic renal insufficiency or cancer, or conditions associated with high risk of bleeding complications. Usually such patients have been excluded from RCTs. Therefore, while guidelines clearly summarize the benefits of a strategy of investigation/treatment, other considerations such as those noted above in additions to the inherent risks of angioplasty or coronary artery by-pass surgery, should be included in the discussion with patients and family. Considering their own goals and preferences, patient/family and health care team together should share decisions on what is best for the individual patient. These options are clearly included in most guidelines [40, 41].

When one examines how much of the six elements of PCC can be seen in the process of caring for a person with UA/NSTEMI according to guidelines we find that: the relative (a) *safety* and (b) *efficacy* of the established diagnostic and therapeutic measures recommended have been confirmed in randomized controlled clinical trials, having also considered associated risks, which are small relative to the risks associated with less invasive treatment. *Patient-centered care* (c) is more difficult to assess. Most guidelines have a few lines that emphasize the importance of patient-centered care including statements such as: "…guidelines do not override in any way whatsoever the responsibility of health professionals to make appropriate decisions in consideration of each patient's health condition and in consultation with that patient or the patient's caregiver where appropriate and/or necessary" [13, 42, 43]. Statement like this are almost always present in most professional associations' guidelines worldwide. What is not clear in the guidelines is how should patients and families participate in the decisions to be made. They generally fall short of empowering the patient as a person to be a more active participant in decisions concerning his or her own cardiac care. For instance, an expert consensus of the Scientific Committee of the Cardiovascular Nursing and Allied Professions (ACNAP) reviewed nine ESC guidelines and found that inclusion of PCC was uncommon, an indication that patient perspectives and needs were less likely to be taken into account when developing, endorsing, or formulating recommendations [44]. In our opinion, despite laudatory promises about PCCC [45–47], guidelines from the ACC/AHA are not very different from those of the ESC in relation to the absence of practical and specific recommendations on how to translate into practice the desired objectives of PCCC. All guidelines should not only advocate patient and family involvement in the decisions regarding medical care but they should provide instruments on how to implement their recommendations using a PCC approach [7].

Are the processes of caring for a person with unstable angina/NSTEMI *timely (d)*? In developed countries, once the diagnosis is made patients are often admitted to the coronary or intensive care unit for evaluation and management, and they usually proceed in a timely fashion. Patients may experience delays before the syndrome of UA/NSTEMI is recognized. Delays may also happen in centers without the capability of invasive studies, but they usually have organized systems for *timely* inter-hospital transfers with minimal delay. The situation may be different in developing countries that lack adequate resources.

Are the recommendations to manage persons with unstable angina/NSTEMI *efficient (e)*? Yes, the guidelines are based on the results of well designed and performed, controlled, RCT's that have demonstrated significant beneficial effects on morbidity and mortality as well as in quality of life. (f) Are these recommendations *equitable*? In the last 20 years, efforts have been made to include minority groups in large cardiology RCTs [48]. In spite of those efforts it is clear that various groups, especially the frail, elderly, and those persons with co-morbidities are not routinely included in these trials [49]. The guidelines recognize these and other gaps in knowledge and have special recommendations for women, the elderly, and those with co-morbidities [40]. These gaps notwithstanding, most guidelines to diagnose and treat persons with UA/NSTEMI are equitable for all persons regardless of gender, age, socioeconomic status or geographic locations.

The opportunities to include the patient and family as full partners in the health care team are present from the initial hospitalization due to UA/NSTEMI. Education should start early and patients and families must be educated as much as they are willing to learn, about the pathophysiology of unstable coronary artery disease, the roles of invasive measures, pharmacologic therapies, the principles of secondary prevention, and the need for life-style modifications. A multidisciplinary team, as noted in the previous section, should educate and listen the concerns of patients and family to make shared decisions on the long term recommended therapies starting with the *discharge planning,* to be followed in the local cardiac rehabilitation program where the patient with unstable angina/NSTEMI should be referred after discharge.

31.3.4 Potential Barriers for PCCC in Persons with UA/NSTEMI

The degree of certainty in the diagnosis and management of patients with UA and NSTEMI according to up-to-date guidelines is high. These patients are at risk of worsening clinical condition if recommended therapies are not administered in a timely fashion. The urgency for immediate treatments is not as critical as for patients with STEMI, but nevertheless patients with UA/NSTEMI should be treated in an urgent not elective fashion. One cannot predict with confidence whether an individual unstable patient will stabilize over the near term or suddenly deteriorate. These two factors, the degree of certainty of guideline management and the relative high risk for morbidity and mortality, as noted in Figs. 31.1 and 31.2, do not give ample of opportunities to consider the patient wishes and preferences. The duty of the health care team is predominantly one of information for the patient to understand the reasons behind the suggested managements. Their consent is always needed thus, the information provided should be simple, brief, but sufficiently complete for the patient to make an informed decision.

31.3.5 Persons with Chronic Stable Coronary Artery Disease (SCAD)

The spectrum of chronic SCAD is broad and includes persons with obstructive or non-obstructive coronary artery atherosclerosis. They may be asymptomatic, have chronic stable angina, have symptomatic ischemia, prior myocardial infarction, or prior coronary artery revascularization. Initial symptoms may include chest pain, heart failure, cardiac arrhythmia, or they may be asymptomatic. The initial contact with the cardiology health care team occurs when persons seek medical attention with symptoms suspected of being cardiac in origin or when asymptomatic persons seek advice because of the presence of significant risk factors. Some are referred because of incidental abnormal cardiac tests. How to utilize the different tools for the diagnosis of SCAD, from a good history and physical exam to the most sophisticated imaging techniques, is well outlined in standard cardiology textbooks and guidelines [50, 51]. A person centered approach should be the norm prior to the performance of diagnostic cardiac tests regardless of the clinical setting. Although not all cardiac tests require a signed informed consent before the procedure, patients need to be informed on the purpose and medical indications of every cardiac test prior to their performance. The ideal process for obtaining informed consent should include: (1) A significant educational component to help empower the patient with sufficient clinical information relevant to the decision at hand. (2) A description of the test, the desired objectives, and the potential risks associated with the procedure. (3) Outline and discuss alternatives. (4) Address all the questions that patient and family may have. Only then can shared decisions between patient and health care provider be achieved. Once the patient has made a decision the obligation of the care giver is to support that decision with empathy and understanding each patient's special circumstances. How well are these tasks achieved in clinical practice? It probably varies from center to center and from physician to physician, but studies have shown they may not be done as well as desired and they appears heavily biased by physician's time and preference [52]. Too often the task of obtaining a consent is relegated to junior staff or delegates. Thus, this is an area for potential future improvement in the quest for PCCC.

Once the diagnosis of SCAD is made, it is understood that the disease can be stable for extended periods but can become unstable at any time, typically due to an acute atherothrombotic event caused by plaque rupture or progressive atherosclerotic narrowing of one or more coronary arteries. Therapy is thus designed to achieve plaque stabilization (i.e., lack of progression) or regression, by lifestyle adjustments, pharmacological therapies, and invasive interventions. How and when to utilize the different tools for the therapy of SCAD, from life-style changes to a variety of pharmacologic agents, and invasive procedures, is well outlined in standard cardiology textbooks and guidelines [50, 51, 53–55]. In patients at high risk, the prevalence of severe CAD is higher and coronary angiography can define the coronary anatomy and help planning further therapy beyond standard medical therapy. If the patient is at low or intermediate risk therapeutic decisions should be directed toward improving symptoms and functional status and cardiac catheterization maybe deferred if symptoms can be controlled well with medical therapy alone. In patients in whom angiography is performed and who are determined to be at low or intermediate risk, evidence reaffirms that it is safe to defer revascularization and institute a program of evidence-based medical therapy, because neither survival nor adverse cardiac events are averted by proceeding immediately to revascularization [56–59]. If symptoms persist despite optimal medical therapy, then revascularization should be considered for symptom relief. Optimal medical therapy include management and modifications of risk factors such as dyslipidemia, control of blood pressure, optimal diabetes control, promotion of physical activity and diet, weight management, and smoking cessation. Drugs to treat dyslipidemia have been shown to be the cornerstone of pharmacotherapy of SCAD in addition to converting enzyme inhibitors, angiotensin receptor blockers, and antiplatelet agents, for stabilization and in some cases even regression of the atherosclerotic process. Beta blockers, especially if left ventricular EF is lower than normal, nitrates calcium channel blockers, and ranolazine are also useful drugs to treat ischemia and/or hypertension [53, 55]. Most recently, the use of Metformin together with an inhibitors of the sodium glucose co-transporter-2 (SGLT-2), or a glucagon-like peptide-1 receptor agonist (GLP-1 receptor agonist), have been shown to reduce mortality and morbidity in patients with SCAD [60–62]. Persons with SCAD should then be referred to a cardiac rehabilitation program for additional teaching and self-care coaching in all aspects of life-style modifications, including supervised exercise, and medication adherence.

Examining how much of the six elements of PCC can be seen in the process of caring for a person with SCAD according to guidelines we find that: (a) the *safety* and (b) *efficacy* of established diagnostic and therapeutic measures recommended have been confirmed in controlled RCTs. Those that are not evidence-based are clearly noted. In addition to the potential side effects of drugs, their management is also described in detail. Perhaps the greatest advance over the past decade has been the establishment of the heart team approach to manage patients with SCAD, especially when revascularization procedures are considered. The heart team (clinical and interventional cardiologists along with cardiovascular surgeons and nursing staff) consider together the available options, and facilitates better engagement of the patient in the informed consent and shared-decision-making processes [63]. In our opinion, a truly PCCC should take a step further, involving the patient and family earlier in the deliberation process, not just at the time of consent. In this way, the third characteristic of person-centered care *(c- patient-centeredness),* would improve significantly.

Are the processes of caring for a person with SCAD *(d) timely* and *(e) efficient*? In general, guidelines accomplish these characteristics with evidence based on the results of large RCTs. In practice however, many countries have inadequate resources to accommodate the demand and “waiting lists” for diagnostic and even therapeutic procedures are not uncommon. This fact illustrates that an optimal PPC care is not possible without the intervention of a country’s health policy makers to deal with shortage of health care providers, equipment and funds, in some countries more than others. The guidelines promote *equitable (f)* care but they also point out that data on minorities are often missing or weak, in part because minority groups have routinely been excluded from RCTs. Only recently the different presentations, responses to therapy, and prognosis in women with SCAD compared to men have been recognized. Other groups in need for further research include the elderly and minority racial groups, to obtain equally valid guideline-directed recommendations. Recommendations to avoid biases in referrals for cardiac catherizations and revascularization procedures have been made and have been translated into guidelines [53] paving the way for better PCCC in the future. Another potential source of *inequality* is the socio-economic status of patients who can’t afford the high costs of diagnostic and therapeutic cardiac procedures, even in affluent countries.

The opportunities for PCCC and inclusion of patient and family as partners in the health care team are present from the initial encounter of patients suspected of having SCAD with the cardiology health care team, or during hospitalization for an ACS. Education on the pathophysiology of SCAD, the role of invasive measures, the importance of pharmacologic therapies, the principles of secondary prevention, and the need for life-style modification, should start early and include as much as they are willing to learn. A multidisciplinary team approach, as noted in the previous sections, is best to educate patients and families, hear their concerns, and make shared decisions. Follow up at the local cardiac rehabilitation program should include the long process of periodically titrate or change medications, repeat tests, review clinical evolution, additional education and reinforcement on diet, exercise, and medications.

31.3.6 Potential Barriers for PCCC in Persons with SCAD

The barriers for PCCC in patients with SCAD are not related to time constraints (as in ACS) but to other factors. Most important in the majority of cardiac conditions in the ambulatory care setting is timely access to specialist care. The manpower shortage is more evident in some countries than in others. This problem may be manifested by long waiting lists to see a specialist. Another problem is availability of resources, so that waiting lists for some cardiac investigations may be too long. A third barrier relates to the limited data from RCTs in minority groups, as noted in the previous paragraph.

Quality PCCC requires care givers time commitment to be able to deliver appropriate information first, to educate the person with SCAD providing patient and family with the tools necessary to make informed and meaningful shared-decisions and second, to hear their concerns and answer all questions they may have. Thereafter, care givers must spend time for adequate follow-up with periodic reviews of clinical evolution, changes in therapies, and address further concerns, etc. The busy cardiologist often leaves informative tasks to junior members of the health care team. The reasons for this practice are complex and may include time commitments to see more patients, honorarium system, lack of communication skills, etc. This aspect of a common practice leaves room for improvement in the PCCC approach [7].

There is ample evidence that in some parts of the world race is often a determinant for patients with CAD to undergo cardiac procedures, such as cardiac catheterization, etc. [64, 65], even now in 2021 [66]. The culprits for racial and socioeconomic biases during cardiac care are complex and multiple. Efforts to eliminate this complex problem have started several years ago [64, 67], and will require a multifaceted approach of many entities, clinicians, researches, hospitals, academic institutions, and governments. Achieving this quest would be facilitated if the medical team, headed by the cardiologist, uses the basic principles of PCC when taking care of patients with heart disease, with respect, understanding, and empathy, considering not just the disease process but also responsive to individual patient preferences, needs, and values.

31.4 The Person with Congestive Heart Failure (HF)

31.4.1 Chronic HF with Reduced Ejection Fraction (HFrEF)

Congestive heart failure (CHF) is a complex clinical syndrome in which impaired heart function results in clinical symptoms and signs of reduced cardiac output and/or pulmonary or systemic congestion and is associated with increased morbidity and mortality. Although the molecular biology and integrated physiology are complex and incompletely understood, several fundamental concepts and principles have evolved, especially in persons with HFrEF. Those pathophysiologic concepts, largely based on animal models, have been validated in large RCTs which demonstrated effective pharmacologic treatments [68–70].

Guidelines and standard textbooks note the best strategies to diagnose HF, from a good history, physical examination, biochemical markers, measurement of cardiac function with non-invasive imaging, and invasive techniques when appropriate. Similarly, the principles of guideline-based treatment of persons with HFrEF are well established, being based on strong evidence. Thus, for purposes of achieving optimal PCCC, the main objective of the cardiology team is teaching the many aspects of management of HF from diet and exercise to adherence to medications [68–71].

The prevalence of CHF is estimated to be 1–2% of the adult population rising to 10% or more in those above the age of 70 years [72, 73]). The readmission rate after discharge from hospital is high, up to 50% being readmitted within 6 months [74, 75]. Despite remarkable improvements in therapy, the prognosis remains disappointedly poor with a 5-year mortality of 40–50% [76, 77], with the greatest risk of death early after discharge from hospital [78]. Thus, systematic surveillance early post-discharge is important. Treatment of CHF is complex and involves drugs, diet, life-style, and exercise. Industrialized countries spend 2–4% of their annual healthcare budget in persons with HF [79] with approximately two thirds of the economic burden due to in-hospital treatment [80]. It is estimated that up to two-thirds of CHF hospital readmissions are triggered by potentially preventable factors, including suboptimal discharge planning, poor adherence to HF medications, inadequate follow-up, insufficient social support, and delays in seeking medical attention [81, 82]. Therefore, management of persons with chronic CHF by specialized multidisciplinary teams in heart failure clinics (HFC) has been proven effective in reducing morbidity and mortality [83–85]. Typically, HFCs include HF specialized physicians, nurses, dietitians, pharmacists, social worker, and exercise physiologists. These teams engage patients and families in all aspects of care including teaching basic aspects of HF, description of their illness, prescribing diets, exercise and medications, and also listening to patients' questions and concerns, and addressing relevant socioeconomic and psychological conditions. In addition, the pharmacist makes sure patients and families understand not only how to take the prescribed medications but also their mode of action, desired effects as well as potential side effects. More importantly, the team arranges adequate follow-up with a frequency that depends on the patients' symptoms and treatment plans (weekly for up-titrating medications, monthly or possible longer when they are stable). Ideally, a member of the team is available for telephone consultations 24 h a day, 7 days a week, as the most effective approach for early detection of HF decompensation. In addition, patients have an option for a clinic visit on short notice to deal with unexpected problems or concerns. In the HFC, a great deal of time is usually spent not only providing counseling and care of the patient's physical ailments but paying attention at all other familiar, social, and psychological aspects, making their care truly person-centered. All decisions for ongoing therapies, new investigations, adherence to diet, exercise and medications, possible side effects to medications, and new concern are usually addressed in consultation by the health care team with patients and their families.

Perhaps because of the culture of systematic care of patients in HFCs, the HFC team generally adhere to all the principles of effective PCC. They follow guideline-directed treatments in a manner that is effective, safe, timely, efficient, equitable, using person-centered methods. In RCTs, patients followed at a HFC have been shown to have lower hospital readmission rates, have fewer symptoms, better quality of life, more satisfaction, and a trend towards lower morbidity and mortality, compared with usual care [83–85]. Similarly, improved outcomes have been found in a meta-analysis of patients with chronic CHF treated and followed by PCC teams [86].

In summary we suggest that HFCs may be the best example of how PCC may be translated into routine practice to successfully deliver care, with resulting patient satisfaction and better clinical outcomes that are the real bottom line for health care providers. The ESC has given the highest level of recommendations in their guidelines for the management of CHF through HFCs [71]. Because of their recognized value, HFCs have proliferated but many do not have adequate human and/or technical support to provide optimal care. More detailed standards for the management of HFCs have been recently published by the ESC Heart Failure Association [87], and there are suggestions how to maintain these HFCs functioning with high standards [83].

31.4.2 Chronic HF with Preserved Ejection Fraction (HFpEF)

Our understanding on the pathophysiology of HFpEF is not as good as that of HFrEF. Consequently, effective management of patients with HFpEF is often more difficult to achieve. There are increasing data showing that HFpEF is not one clinical entity but instead comprises a diverse group of diseases with genetic, anatomical, and functional heterogeneity, not yet well defined [88]. Most prominent among the known causes of HFpEF is hypertension. Aggressive and effective blood pressure control can result in significant improvement of symptoms and well as in reducing end-organ damage. Amyloid and hypertrophic cardiomyopathy are also specific causes of HFpEF that may be improved with newer, specific approaches of therapy [89, 90]. Where the cause of HFpEF is not clear, the only medications that have been shown to be helpful in patients with HFrEF that is also clearly effective in patients with HFpEF are the SGLT-2 inhibitors [91].

While the modern cardiologist has to carefully choose amongst the many effective drugs to provide best individualized therapy for their patients with HFrEF there is only one class of drugs with proven efficacy in those with HFpEF. Because of the rapid advances in the science of pharmacotherapy it is expected that therapies for patients with HF regardless of the ejection fraction will continue to evolve. Thus, an important component of good PCC is close follow-up not only to monitor the patient's clinical changes but also to keep patients and families well informed on the latest therapeutic options, including their merits and limitations. The multidisciplinary medical team of the HFC headed by the treating cardiologist is ideal to accomplish these tasks following established optimal principles for effective PCC. The understanding, contribution, opinios, and preferences of patients and families should weigh heavily in the shared therapeutic decisions.

31.4.3 Acute Decompensated HF

Patients with either HFrEF or HFpEF are at risk of developing acute severe clinical symptoms ranging from pulmonary congestion and severe dyspnea to symptoms of low cardiac output, weakness, confusion, and shock. The causes are potentially multiple, some of them preventable. These include poor adherence to medications or/and diet, drug interaction, comorbidities, or progression of the primary cardiac disease. Therapy is largely symptomatic, together with management of the precipitating causes and comorbidities. A PCC approach is most important in this situation since only with good communication and clinical skills, patience, trust, using a systematic approach to uncover sometimes elusive precipitating causes, can the patient be optimally treated. If non-adherence is a problem, then personalized methods and solutions may be found by education, answering questions and concerns, and by step by step assistance in solving the patient's own individual barriers. This is specially important in addressing perceived or real side effects to medications. Only if the patient is satisfied with the answers he or she will agree to the treatment proposed. A shared-decision is most likely to result in optimal outcomes because the patient feels ownership of the strategy, with improved likelihood for adherence to medications, diet and life style. The role of PCC may be more rewarding and effective in preventing recurrences and rehospitalizations as exemplified by the multidisciplinary follow-up of these patients in HFCs [84, 86].

31.4.4 Potential Barriers for PCC in Persons with HF

There are a number of barriers to PCCC in persons with chronic CHF. They exist at several levels. The majority of patients with CHF are not treated by cardiologists or in HFCs. It has been shown that patients with chronic CHF have better outcomes when care is managed by cardiologists [92] and better yet when their outpatient care is in HFCs [86, 93]. Yet, even in affluent countries there is an insufficient number of heart failure cardiologists and only a small fraction of patients with chronic CHF are followed at a HFC. Moreover, not all HFCs have sufficient multidisciplinary human resources and/or technical support to function most effectively [83]. To solve these issues, there need to be political and administrative will. Physician advocacy for additional resources and quality control is necessary to deliver optimal PCC to patients with CHF.

Despite evidence-based guidelines (for patients with HFrEF) and best intentions, even in the early twenty-first century some degree of racial bias may be present when patients are admitted to hospital with decompensated HF [94]. As health care professionals in general, but more to the point if we want to provide PCCC we need to be aware of potential systemic inequities and must do what we think is appropriate to avoid inappropriate decisions based on racial or economic biases.

Because there are limited evidence-based guidelines to treat patients with HFpEF one of the potential barriers to practice PCCC is the lack of proven effective therapies. This fact however gives patients and families greater level of participation in the shared decisions for management and treatment.

The cost of drugs to treat persons with heart failure is not amongst the more expensive in the pharmacology arsenal of cardiology, but they add up. Considering the lifelong duration of drugs and other forms of care of the person with CHF, costs may be a significant burden for some patients.

31.5 The Person with Dyslipidemia

31.5.1 Secondary Prevention

Plasma low density lipoprotein (LDL) cholesterol is a measure of cholesterol mass carried by LDL particles. Numerous studies have demonstrated a log-linear relationship between the absolute levels of plasma LDL cholesterol and the risk of atherosclerosis [95, 96]. The remarkable consistency among these studies, in addition to biological and experimental evidence, provide compelling evidence that LDL cholesterol is causally associated with the risk of atherosclerosis. Randomized clinical trials have consistently shown that lowering LDL cholesterol levels reduces the risk of atherosclerotic cardiovascular disease proportionally to the absolute achieved reduction in LDL cholesterol [97, 98]. The importance of secondary prevention in atherosclerotic cardiovascular disease is undisputed [42]. Amongst the top achievements in clinical cardiology in the past century are the advances in the diagnosis and treatment of dyslipidemias, highlighted by the FDA approval for the clinical use of the first statin in 1987 [99]. The success in decreasing LDL cholesterol by life-style changes and particularly pharmacotherapy is in part responsible for the decreased cardiovascular morbidity and mortality seen over several decades [100, 101]. Lipid lowering reduction is cost-effective both in primary and secondary prevention [42, 102–105], and have been summarized in international guidelines for the diagnosis and management of dyslipidemias [42, 106, 107].

A PCC approach to the management of dyslipidemia is not only supported by the traditional motive of respect and consideration for the patient as a person, but also because of the considerable individual variability in the LDL-cholesterol response to dietary and drug treatments [108]. Moreover, LDL cholesterol reduction is only part of a tailored approach to total cardiovascular risk reduction that should be individualized. Recommendations for lifestyle and drug therapy are summarized in widely recognized guidelines with emphasis on achieving specific goals for each individual that is dependent on the person’s risk level [42]. Thus, the management of persons with dyslipidemia is a condition that is best suited for a PCC approach [109, 110]. A shared patient-health care provider decision on treatment goals reflects effective communication between both, that in turn supports optimum long-term adherence to treatment [111], with associated clinical benefits [112].

Some guidelines and recommendations contain comments regarding the value and the need of the PCC approach to manage dyslipidemias, and some include separate sections with specific recommendations for groups such as children, women, and seniors, others with co-morbidities (renal failure, diabetes, chronic inflammation, etc), and various ethnic and racial groups [109, 110]. Although studies on a team-based approach to manage some medical conditions have not always shown improved outcomes [113], most agree that care administered by specialized and motivated teams with sufficient resources, are most effective [83, 85]. The team to manage persons with dyslipidemia includes physicians, nurses, pharmacists, dietitians, and exercise physiologists, all of whom interact with patients for education, answer questions and concerns, to make sound share decisions. A team-based approach to manage dyslipidemias offer unique work strategies for effective care including: (1) Facilitate communication and coordination of care support among various team members. (2) Enhance use of evidence-based guidelines by providers. (3) Establish regular structured follow-up mechanisms to monitor patients’ progress and schedule additional visits as needed. (4) Actively engage patients in their own care by providing them with education about medications, adherence support, and tools and resources for self-management (including behavior change) [109, 110, 114].

The ESC guidelines [42] provide suggestions to optimize adherence but they fall short of suggesting meaningful PCC approaches such as shared decisions that, as noted above, may be one of best methods to maximize adherence.

In summary however, although more emphasis needs to be placed in the *patient-centered* aspect, it appears that guidelines and recommendations to manage persons with dyslipidemias are *effective, safe, timely, efficient, and equitable,* important characteristics of PCCC [2].

31.5.2 Primary Prevention

It is well established that lipid lowering measures are effective and are *cost-effective* in secondary prevention [42, 103]. Although several studies have also shown effectiveness of lipid lowering agents in primary prevention [115, 116], there are data suggesting that lipid lowering for primary prevention may not be *cost-effective* across all populations [117]. This point of view amongst the experts thus, gives the clinician treating the person with dyslipidemia for primary prevention, room for discussion and considerations of individual factors and preferences, ideal for PCC management strategies. The clinician should be well acquainted with the potential benefits, limitations and risks of prescribing medications such as statins, in addition to promoting optimal life style changes. Fortunately, there are quantitative methods to aid the clinician in the recommendations of when and how to treat patients with dyslipidemias for primary prevention, based on the premise that studies have shown a 20–22% relative risk reduction for each 1 mmol/L reduction in LDL cholesterol. The absolute risk reduction is thus dependent on baseline risk and baseline LDL cholesterol level. Reduction of LDL cholesterol levels for primary prevention may be limited to non-pharmacologic therapy in persons at low risk while persons at high risk will benefit from drugs such as statins, in addition to life style changes.

Instruments are available to estimate individual risks for cardiovascular events [103, 118] that are practical and useful. These instruments should be used in context of the unique clinical and laboratory characteristics of each patient. Discussions on management of dyslipidemia should consider the individual estimated risk as well as the patient's own preferences, following a PCC approach. The clinician's role is to help the patient understand the concept of risk versus benefits of life style and drug therapies. How to identify potential side effects and the mechanism to deal with them should clearly be outlined prior to initiating drug therapy. Then, a shared decision how to manage dyslipidemia for primary prevention should emerge. To accomplish this objective, it is important to recognize the need for superior communication skills and enough care giver's patience and time to educate and answer all questions and concerns of patients and families, following PCC principles.

31.5.3 Potential Barriers to PCC in Persons with Dyslipidemia

How well are elements of PCC, as stated by the ICPCM [119, 120], or the Picker Institute's eight principles of patient-centered care [26, 121], incorporated in the cholesterol guidelines? The guidelines are in our view, supportive of the notion not to just focus on the dyslipidemia, but on the whole person's biological, psychological, social and spiritual health. This however, is not emphasized enough in the specific recommendations of any of the reviewed lipid guidelines [42, 106, 107].

Access to care is another important feature of PCC. To achieve universal *access* (the last of the Picker's eight principles) to dyslipidemia care, especially for primary prevention, is a more complicated task that is best delivered by each country's health policy makers. The guidelines are certainly supportive of initiatives at international and global levels.

The cost of medications may be prohibitive for some persons. Since the treatment of dyslipidemias is a life-long commitment even low cost drugs may cause hardships, especially because the incremental costs of treatment for other conditions such as hypertension, coronary artery disease, and often diabetes.

Other potential barriers that apply to all patients, including those with cardiac disease, have been studied extensively with suggestions for policy makers and health authorities to remove those obstacles to make the implementation of optimal PCC possible [7, 122–124].

31.6 The Person with Hypertension

Hypertension (HTN) affects over one billion people and is one of the most common, readily identifiable, and reversible, risk factors for coronary artery disease, stroke, atrial fibrillation, heart failure, aortic dissection, peripheral arterial disease, renal failure, and cognitive decline [125]. Its prevalence is increasing due to the obesity epidemic and the increasing aging population and it is projected to affects 1.5 billion persons by 2025 [126]. HTN continues to be the largest single contributor to the global burden of disease, causing two-thirds of all strokes, and half of all ischemic heart disease, and an estimated 9.4 million deaths each year [125]. Substantial progress has been made in understanding the epidemiology and risk associated with HTN, and a wealth of evidence has demonstrated that lowering blood pressure (BP) can substantially reduce morbidity and mortality [127, 128]. The diagnosis, assessment and treatment of persons with HTN are well described in the most comprehensive, up-to-date hypertension guidelines [129–131]. The recommendations are based on the results of many RCTs. They recommend that treating HTN is best done considering the total risk of the patient and best accomplished by a multidisciplinary team. Every HTN guideline emphasizes life style improvements such as diet with sodium restriction, regular physical exercise, weight reduction, moderation in alcohol consumption, and abstinence from cigarette smoking. Specific recommendations are provided for the elderly, pregnant women, those taking oral contraceptives or hormone replacement therapy, different ethnic groups, and those with co-morbidities such as cardiac or renal dysfunction, diabetes, cerebral vascular disease, sleep apnea, peripheral arterial disease, obstructive lung disease. Most HTN guidelines however, fall short of strongly recommending that patients be involved in decision making including drug selection. In summary, HTN guidelines to manage persons with HTN appear to be *effective, safe, timely, efficient and equitable,* important characteristics of PCC [2], although the *patient-centered* aspect needs to be brought to a more prominent role as already suggested previously [132].

Do HTN guidelines and current practice follow the suggested principles of the ICPCM, as stated by Mezzich and collaborators [119, 120]? The guidelines are in our view, supportive of the notion that is not just the HTN that needs medical care, but they also promote focusing on other risk factors and, to a lesser extent to the whole person's biological, psychological, social and spiritual aspects of health. The focus on personalized care however, apart from specific suggestions for improving adherence, is not a prominent recommendation in any of the HTN guidelines. Moreover, they do not consider the patient as the principal decision-making member of the health care team to make sound shared decisions in establishing the goals and the specific treatment strategies to achieve those goals.

Despite the availability of a number of proven, highly effective, and well-tolerated lifestyle and drug treatment strategies, BP control remains poor worldwide, probably because of poor treatment adherence [133]. The excellent science in the management of persons with HTN thus, has been poorly translated into routine clinical practice. Non-adherence to prescribed life-style changes and pharmacotherapy is a problem encountered when treating practically any chronic medical conditions [134], and there is growing evidence that poor adherence to treatment - in addition to physician inertia - is the most important cause of inadequate BP control [135], and non-adherence is associated with higher risks for future cardiovascular events ([133, 136]. Up to 25% of patients do not fill their initial prescription for antihypertensive medications [137] and after 12 months only 40–50% are taking the prescribed medications [133, 138, 139]. Thus, a health professional treating persons with HTN needs to pay special attention to adherence as an essential step of treatment. Factors contributing to poor adherence are myriad, complex, and multilevel. Therefore, some guidelines have included long sections with recommendations of methods and techniques that are designed to improve medication adherence [130]. Barriers to optimal adherence may be linked with physician attitudes, patient beliefs and behavior, the complexity and tolerability of drug therapies, the healthcare system, and several other factors. Compared with the large number of trials for individual drugs and treatments, there are only a limited number of rigorous trials on adherence interventions. Thus, current recommendations to achieve sustained improvement in medication adherence have low level of evidence. Current guidelines suggest that patients should be encouraged to take responsibility for their own CV health, but fall short of recommending a PPC approach involving the patient as the most important element of the team making shared decisions.

Some guidelines recommend a systolic blood pressure goal of <140 mmHg while others a target of <130 mmHg. It has been found that the incremental benefit of BP lowering on events progressively decreased with lower target BPs [140] but, permanent treatment discontinuation due to adverse effects was more common in those with lower targets [141]. Therefore, advocating more intensive BP-lowering targets for all persons has to be viewed in the context of an increased risk of treatment discontinuation, which might offset, in part or completely, the small incremental reduction in CV risk [131]. These facts leave open a window of opportunity for treating physicians and patients to discuss these issues at length which, together with the patient's own preferences and believes, will be most valuable to make shared decisions in setting personal goals. It is our feeling that a shared decision made in this way regarding treatment goals, one that takes into account guideline recommendations as well as patient's preferences, is a decision which the patient can take ownership of and thus, is most likely to adhere to treatment. It is not surprising thus, that a PCC approach has been shown to improve adherence to medications after a myocardial infarction [31]. Whether a PCC approach will improve adherence in persons with HTN is a hypothesis that needs to be tested. The results of recent studies of treating HTN with the aid of the neighborhood barbershop strongly support the premise that PCC methods may indeed be associated with more success [142].

31.6.1 Potential Barriers for PCC in Persons with Hypertension

Hypertension most often is asymptomatic until complications develop. It is therefore often difficult for asymptomatic patients to adhere to long-term prescription of medications, especially if they cause side effects. Thus, educating patients as to the benefits of treatment is critical and should be reinforced from time to time, in addition to having effective strategies to manage possible side effects to full patient's satisfaction; otherwise there is a substantial risk that the patient would quietly stop taking the medications.

Hypertension is probably the single most important cardiovascular entity where compliance with drug therapies has been unacceptable. Most guidelines do not promote shared decisions with the patient. For most patients with hypertension, diuretics are considered the best first-line treatment in reducing morbidity and mortality [143] and indeed most physicians follow this recommendation [130]. How many busy persons stop taking this drug because of the need to interrupt their usual morning activities because they have to go to the washroom? Or get up at night for the same reason if they take the drug at bedtime? As described in previous paragraphs, appropriate PCC should improve patient's satisfaction and adherence, and thus achieve the goals of reducing clinical events associated with HTN. We feel that the care giver treating persons with HTN should provide the patients with the tools to make sound shared decisions to treat HTN and select the drugs that best suit their individual clinical status, life style, and preferences.

Another important potential barrier is physician availability to answer questions and deal with problems as they arise, such as efficacy of the therapeutic regimen or side effects. Close follow up to deal with these issues is of extreme importance to achieve not only good adherence but also to achieve targets. In our opinion, patients followed by pharmacists [144], nurses [145], and the neighborhood barbershop [142] have been reported to achieve better control than those followed by their physicians only, possibly because of the frequency of follow visits and the fact that each visit last as much as necessary, allowing time to deal with all issues, a classic and basic description of PCC.

31.7 The Person with Other Chronic Cardiac Conditions

Other chronic cardiac conditions include some which are very common, such as cardiac arrhythmias, and others not so common such as congenital, valvular, pericardial, endocardial, and congenital heart disease, cardiomyopathies, peripheral arterial or venous disease, etc. We included these clinical entities together in this section because of the similar PCC opportunities for the health care team. Guidelines for diagnosis and management of each of these conditions present up-to-date scientific data translated into recommendations that should be applied after appropriate education, discussion, and agreement with patient and families. Detailed discussions on the differences of each clinical entity are beyond the scope of this chapter. It is sufficient to state that in our opinion the same basic PCCC principles and methods are applicable, providing patients and families with the education necessary for them to actively participate in the shared decisions for management in their own terms. Systematic use of the six elements of PCC, as suggested by the Institute of Medicine [2], or the Picker Institute's eight principles of PCC [26], will help achieving these objectives. It is recognized there may be clinical situations with their own unique challenges that require unique responses but in general, the PCCC methods described here are applicable to most situations. Some of those unique situations are noted in the person centered palliative care chapter since they address unique and complex clinical scenarios, not exclusive of a particular disease or clinical syndrome, but applicable to several cardiac clinical conditions with common denominators usually at or near the end of life.

31.8 An Important Principle of Shared-Decisions in PCCC

Making shared-decision with patients and health care team working together is the pinnacle of PCC [146]. For some decisions, there is one clear best management strategy thus, patient preference is relegated to a secondary plane. An example is the management of persons with STEMI. For most decisions in patients with cardiovascular disorders however, more than one reasonable management option exists (including doing nothing, when appropriate), and different strategies entail different combinations of potential benefits and risks. An example is the use of lipid lowering agents for primary prevention. In these situations, patients need to be involved in determining the management strategy most consistent with their preferences, values, and goals [147]. The use of decision aids is encouraged [148], which in cardiology may take the form of videos about cardiac procedures, written or online documents. Turning the rhetoric of shared-decisions into reality may sometimes be challenging in modern health care settings [149]. Patients should be made aware of the essential role they play in decision-making and be given effective tools to help them understand their options and the consequences of their decisions. They should receive the emotional support they need to express their values and preferences and should receive answers to all their relevant questions, without censure or bias from their clinicians.

Once a shared-decision is reached it should be honored by the entire health care team. Because the clinical status of patients may change often dramatically, shared-decisions may need to be re-evaluated from time to time during follow-up. A patient who just sustained an electrical shock from an ICD, or was just admitted to hospital with decompensated CHF, may make a decision about EOL issues while he/she feels very ill, but may think and feel very differently when clinically improved. This is an example of carefully considering the appropriate timing of discussions regarding critical decision making. Thus, PCCC implies not only the periodic review of the clinical status and evolution of the patient but also a review of shared decisions made. Patients are entitled to change their minds, which in most cases is understandable because of the variability of emotional and physical state that is common in chronic cardiovascular diseases.

31.9 Practical Issues for the Implementation of Person Centered Care in Cardiology

The concept and benefits of PCC have been recognized by cardiologists more than 10 years ago [7] and its basic principles have been disseminated by the mainstream cardiology organizations worldwide. However, as of 2022, its implementation is still a work in progress. The extent to which current cardiology care is provided using PCC principles varies within practice areas of cardiology as noted in each section discussed earlier, and likely in different geographic regions. Most cardiology practice guidelines, which are based on the latest evidence-based knowledge, recommend considering each patient's set of values and preferences, but 99% of the content is focused on scientific advances and the ways to implement them. With some exceptions, how to practice PCC is not described in detail. Cardiology guideline would better promote and disseminate PCC by emphasizing how it benefits outcomes and patient satisfaction, and these should be described more extensive and prominently along with the results of the most influential RCTs. The benefits of practicing PCC, including enhanced treatment adherence, better clinical outcomes, lesser medication misuse, less use of diagnostic procedures, and lower health related costs, should be highlighted. In addition, future cardiology guidelines should include specific suggestions on how to provide optimal PCC at all levels of patient care, from member of the care team and the local health care institution, to community and national health care systems. To some extent, some of these processes are in place but they need to be extended more widely to all areas in cardiology.

One of the prominent barriers for PCC encountered by the cardiology care team is time constraints at all levels of interaction with patients, especially when conditions are acute or semi-acute. Such conditions may include an ACS, cardiogenic shock, serious arrhythmias, or acute heart failure. When dealing with chronic illnesses such as chronic heart failure, dyslipidemias, and hypertension, time constraints should not be problematic. Complex time-dependent cardiology interventions thus, are best accomplished by each member of the care team performing smaller tasks simultaneously in a coordinated and timely manner, while still providing comprehensive, efficient PCC. Time constraints unrelated to specific cardiac condition however exist in the real world. It appears that although cardiologists do well when treating patients with chronic heart failure in heart function clinics, management of subjects with other conditions such as hypertension and dyslipidemia, may be suboptimal in terms of PCC. This may, in part, be related to the way members of the team are compensated; for example, a fee-for-service model usually rewards quantity but not quality. Optimal PCC may be enhanced by an economical incentive model that rewards indicators of quality performance [150]. One of the principles for PCC is patient engagement with their on-treatment goals, which is easier to achieve by ready access to health care providers. Since this may be difficult for the busy cardiologist, a multi-disciplinary team approach has been promoted to provide better PCC, as exemplified in the heart function clinics. Similar clinics are being created to manage person with hypertension, dyslipidemia, and other cardiac conditions.

Recently, a panel of experts in PCC and other stakeholders in the USA identified other barriers for PCC common to all specialties including cardiology [124]: (1) information and communication, (2) trust and respect, (3) organizational and cultural (such as racial, social, and sexual discrimination), and (4) economical (from incentives to member of the cardiology team to costs to the regional health care system). To address these barriers in cardiology, regional health care systems need to adapt in creative and tailored ways at all levels, from social sensitivity and education to increasing human and economic resources where needed. Caring for persons with heart disease requires appropriate equipment and personnel for timely cardiac investigations and treatments. This implies the cooperation of health care systems and governments to support and organize regional cardiology resources for timely provision of care to persons with acute as well as chronic cardiac problems. Each member of the cardiology team should be trained in PCC and have enough time to provide appropriate comprehensive care, including shared decision-making in all aspects of investigation and treatment strategies. With this approach, one can optimize patient adherence, clinical outcomes, and patient/family satisfaction.

The many dimensions of PCC can be viewed from several perspectives; in cardiology, from the urgent and hectic scenario when seeing a patient with acute myocardial infarction in the emergency department to the person who comes to the office worried about his elevated cholesterol soon after his younger sibling sustained a cardiac event. These many dimensions of care have made it difficult to assess and monitor the implementation of PCC [151] since there are no accepted standardized forms of assessment. Recently, a group of investigators studied many instruments to validate PCC quality indicators and selected 26 evidence-based measures [152]. They suggest using these quality indicators to measure and evaluate quality incorporating patient perspectives, empowering jurisdictions to monitor healthcare system performance, and evaluate policy and practice related to PCC. Whether these suggested measures could be accepted as standard measures of quality PCC remains to be seen. From our perspective, these 26 PCC quality indicators may be used to assess the extent of implementation of PCC in cardiology practices in any setting.

Since the cornerstone objective of PCC in cardiology is to improve patient-related outcomes, it has been accepted that the best measure of optimal PCC implementation is a report from the patient. Thus, patient-derived report cards are being increasingly used to measure quality care and patient satisfaction, and its use is being encouraged by some medical credential/licensing bodies as a mean of self-assessment and continuing education, and they are also used by other health care organizations to monitor performance. Patient satisfaction surveys are evolving and, in one form or another, they will likely be common place in the future landscape of cardiology care. At this point in time however, there is no consensus on how to best measure and use patient-reported outcomes in heart failure [149] and in other areas of cardiology. Lastly, another important measure of PCC in cardiology is the documentation of shared decisions when planning investigation and treatment strategies. The value of shared decisions as a tool for better quality PCC manifested by patient and doctor satisfaction has been widely recognized and proven in RCTs [153, 154].

31.10 Summary and Future Directions

EXCELLENCE IN CARDIOLOGY CARE must include up to date evidence-based science delivered in a manner that is respectful of and responsive to individual patient preferences, needs, and values, which are the principles of person centered care (PCC). By educating patient and family and addressing their concerns and questions, shared clinical decisions emerge. This approach of care empowers patients to be active participants in their own health care, thus providing not only satisfaction, but also improved clinical outcomes.

In this chapter, specific cardiac conditions are discussed separately because of the different degrees of scientific certainty on their management recommendations, and the different time constrains to arrive to shared decisions.

More than in any other medical specialty, management of most cardiovascular conditions are summarized in well published guidelines from leading cardiac societies translating the latest scientific advances into sound recommendations for disease management. However, although every cardiology guideline states that the recommendations should be applied in accordance with individual patient's preferences and wishes, our review found that there is room for improvement by providing specific suggestions on how to best implement a truly person-centered cardiology care. This is especially true for guidelines to manage patients with hypertension or dyslipidemia, both which are associated with poor adherence to medications. Adherence, and thus clinical outcomes, might improve if patients take ownership of shared decisions on management, an important component of PCC.

Barriers for optimal PCC in cardiology have been recognized and potential solutions have been suggested, from education during cardiology training to regulated implementation. The future landscape in the practice of cardiology will be molded by more PCC research, resources, and incentives, for better dissemination and implementation of PCC principles.

Acknowledges and Disclosures Dante Manyari dedicates this paper to Debbie, his beloved not truly departed wife, who 35 years ago taught him the concept and importance of *person-centered care* and thus, remains present in every act of his professional work.

The authors do not report conflicts or interest.

References

1. Chassin MR, Galvin RW. The urgent need to improve health care quality. Institute of Medicine National Roundtable on Health Care Quality. JAMA. 1998;280(11):1000–5.
2. Institute of Medicine. Crossing the quality chasm: A new health system for the twenty-first century. Washington, DC: The National Academies Press; 2001. https://doi.org/10.17226/10027.
3. Berwick DM. What 'patient-centered' should mean: confessions of an extremist. Health Aff (Millwood). 2009;28(4):w555–65. https://doi.org/10.1377/hlthaff.28.4.w555.
4. ICPCM–International College of Person-Centered Medicine. https://www.personcenteredmedicine.org/index.html
5. ICPCM, Aims. 2019. https://www.personcenteredmedicine.org/index.html. Accessed 21 Oct 2019.
6. Reynolds A. Patient-centered care. Radiol Technol. 2009;81:133–47.
7. Walsh MN, Bove AA, Cross RR, Ferdinand KC, Forman DE, Freeman AM, Hughes S, Klodas E, et al. ACCF 2012 health policy statement on patient-centered care in cardiovascular medicine. J Am Coll Cardiol. 2012;59:2125–43. https://doi.org/10.1016/j.jacc.2012.03.016.
8. Hansson E, Ekman I, Swedberg KM, Wolf A, Dudas K, Ehlers L, Olsson LE. Person-centered care for patients with chronic heart failure—a cost-utility analysis. Eur J Cardiovasc Nurs. 2016;15(4):276–84.
9. Pirhonen L, Bolin K, Olofsson EH, Fors A, Ekman I, Swedberg K, Gyllensten H. Person-centered care in patients with acute coronary syndrome: cost-effectiveness analysis alongside a randomized controlled trial. Pharmacoecon Open. 2019;3(4):495–504. https://doi.org/10.1007/s41669-019-0126-3.
10. Pelzang R. Time to learn: understanding patient-centered care. Br J Nurs. 2010;19:912–7.
11. Stone S. A retrospective evaluation of the impact of the Planetree patient-centered model of care on patient quality outcomes. HERD. 2008;1:55–69.
12. Bohula EA, Morrow DA. ST_Segment elevation myocardial infarction: management. In: Zipes DP, Libby P, Bonow RO, Mann DL, Tomaselli GF, Braunwald E, editors. Braunwald's heart disease—a textbook of cardiovascular medicine. 11th ed. Boston, MA: Elsevier; 2019. p. 1123–72.

13. Ibanez B, James S, Agewall S, Antunes MJ, Bucciarelli-Ducci C, Bueno H, Caforio ALP, et al. 2017 ESC Guidelines for the management of acute myocardial infarction in patients presenting with ST-segment elevation. Eur Heart J. 2018;39:119–77. https://doi.org/10.1093/eurheartj/ehx393.
14. O'Gara PT, Kushner FG, Ascheim DD, Casey DE Jr, Chung MK, de Lemos JA, Ettinger SM, Fang JC, Fesmire FM, Franklin BA, et al. 2013 ACCF/AHA guideline for the management of ST-elevation myocardial infarction: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines. J Am Coll Cardiol. 2013;61:e78–140. https://doi.org/10.1016/j.jacc.2012.11.019.
15. Patel MR, Singh M, Gersh BJ, O'Neill W. ST-segment elevation myocardial infarction. In: Fuster V, Harrington RA, Narula J, Eapen ZJ, editors. Hurst's the heart, vol. 14e. New York, NY: McGraw-Hill; 2017. http://accessmedicine.mhmedical.com.www.proxy.cpsbc.ca/content.aspx?bookid=2046&sectionid=176556136.
16. Wong GC, Welsford M, Ainsworth C, Abuzeid W, Fordyce CB, Greene J, Huynh T, Lambert L, Le May M, Lutchmedial S, et al. 2019 CCS/Canadian Association of Interventional Cardiology guidelines on the acute management of ST-elevation myocardial infarction. Can J Cardiol. 2019;35:107–32. https://doi.org/10.1016/j.cjca.2018.11.031.
17. Daudelin DH, Sayah AJ, Kwong M, Restuccia MC, Porcaro WA, Ruthazer R, Goetz JD, Lane WM, Beshansky JR, Selker JP. Improving use of prehospital 12-lead ECG for early identification and treatment of acute coronary syndrome and ST-elevation myocardial infarction. Circ Cardiovasc Qual Outcomes. 2010;3:316–23.
18. Peterson ED, Ohman EM, Brindis RG, Cohen DJ, Magid DJ. Development of systems of care for ST-elevation myocardial infarction patients: evaluation and outcomes. Circulation. 2007;116:e64–7.
19. Kushner FG, Hand M, Smith SC Jr, King SB 3rd, Anderson JL, Antman EM, Bailey SR, et al. 2009 Focused updates: ACC/AHA guidelines for the management of patients with ST-elevation myocardial infarction (updating the 2004 guideline and 2007 focused update) and ACC/AHA/SCAI guidelines on percutaneous coronary intervention (updating the 2005 guideline and 2007 focused update): a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines. Circulation. 2009;74:E25–68.
20. Steg PG, James SK, Atar D, Badano LP, Blomstrom-Lundqvist C, Borger MA, Di Mario C, Dickstein K, Ducrocq G, Fernandez-Aviles F, et al. ESC Guidelines for the management of acute myocardial infarction in patients presenting with ST-segment elevation: the task force on the management of ST-segment elevation acute myocardial infarction of the European Society of Cardiology (ESC). Eur Heart J. 2012;33:2569–619.
21. Chew DP, Scott IA, Cullen L, French JK, Briffa TG, Tideman PA, Woodruffe S, Kerr A, Branagan M, Aylward PEG. National Heart Foundation of Australia & Cardiac Society of Australia and New Zealand: Australian clinical guidelines for the management of acute coronary syndromes 2016. Heart Lung Circ. 2016;25:895–951.
22. International Alliance of Patients' Organizations (IAPO). What is patient-centered health care? A review of definitions and principles. 2007. http://iapo.org.uk/sites/default/files/files/IAPO%20Patient-Centred%20Healthcare%20Review%202nd%20edition.pdf
23. Glickman SW, Boulding W, Manary M, Staelin R, Roe MT, Wolosin RJ, Ohman EM, Peterson ED, Schulman KA. Patient satisfaction and its relationship with clinical quality and inpatient mortality in acute myocardial infarction. Circ Cardiovasc Qual Outcomes. 2010;3:188–95.
24. Chen F-C, Lin Y-R, Kung C-T, Cheng C-I, Li C-J. The Association between Door-to-Balloon time of less than 60 minutes and prognosis of patients developing ST segment elevation myocardial infarction and undergoing primary percutaneous coronary intervention. Biomed Res Int. 2017;2017:1910934. https://doi.org/10.1155/2017/1910934.
25. Park J, Choi KH, Lee JM, Kim HK, Hwang D, Rhee T-M, Kim J, Park TK, et al. Prognostic implications of Door-to-Balloon time and onset-to-door time on mortality in patients with ST-segment-elevation myocardial infarction treated with primary percutaneous coronary intervention. J Am Heart Assoc. 2019;8:e012188. https://doi.org/10.1161/JAHA.119.012188.

26. Rawson JV, Moretz J. Patient and family-centered care: a primer. J Am Coll Radiol. 2016;13:1544–9. https://doi.org/10.1016/j.jacr.2016.09.003.
27. Browne JV, Sanchez E, Langlois A, Smith S. From visitation policies to family participation guidelines in the NICU: the experience of the Colorado consortium of intensive care nurseries. Neonatal Paediatr Child Health Nurs. 2004;7(2):16–23.
28. Ewait L, Moore J, Gibbs C, Crozier K. Patient' and family-centered care on an acute adult cardiac ward. Br J Nurs. 2014;23:213–8.
29. Ekman I, Swedberg K, Taft C, Lindseth A, Norberg A, Brink E, et al. Person centered care—ready for prime time. Eur J Cardiovasc Nurs. 2011;10(4):248–51.
30. Fors A, Ekman I, Taft C, Björkelund C, Frid K, Larsson ME, et al. Person-centered care after acute coronary syndrome, from hospital to primary care—a randomized controlled trial. Int J Cardiol. 2015;187:693–9.
31. Solemani F, Anbohi SZ, Esmaeili R, Pourhoseingholi MA, Borhani F. Person-centered nursing to improve treatment regimen adherence in patients with myocardial infarction. J Clin Diagn Res. 2018;12(1):1–4.
32. Anderson JL, Adams CD, Antman EM, Bridges CR, Califf RM, Casey DE Jr, Chavey WE II, Fesmire FM, Hochman JS, et al. ACC/AHA 2007 guidelines for the management of patients with unstable angina/non–ST-elevation myocardial infarction: a report of the ACC/AHA Task force on practice guidelines—developed in collaboration with the ACEP, ACP, SAEM, SCVAI, and STS. J Am Coll Cardiol. 2007;50:e1–157.
33. Bassand, J-P, Hamm CW, Ardissino D, Boersma E, Budaj A, Fernandez-Aviles F, Fox KAA, Hasdai D, Ohman EM, Wallentin L, Wijns W, Vahanian A, Camm J: Guidelines for the diagnosis and treatment of non-ST-segment elevation acute coronary syndromes The Task Force for the Diagnosis and Treatment of Non-ST-Segment Elevation Acute Coronary Syndromes of the European Society of Cardiology. Eur Heart J. 2007;28:1598–1660. https://doi.org/10.1093/eurheartj/ehm161.
34. Bavry AA, Kumbhani DJ, Rassi AN, Bhatt DL, Askari AT. Benefit of early invasive therapy in acute coronary syndromes: a meta-analysis of contemporary randomized clinical trials. J Am Coll Cardiol. 2006;48:1319–25. https://doi.org/10.1016/j.jacc.2006.06.050.
35. Fox KA, Damman P, Pocock SJ, de Winter RJ, Tijssen JG, Lagerqvist B, Wallentin L. Long-term outcome of a routine versus selective invasive strategy in patients with non-ST-segment elevation acute coronary syndrome—a meta-analysis of individual patient data. J Am Coll Cardiol. 2020;55(22):2435–45. https://doi.org/10.1016/j.jacc.2010.03.007.
36. O'Donoghue M, Boden WE, Braunwald E, Cannon CP, Clayton TC, de Winter RJ, Fox KA, Lagerqvist B, McCullough PA, et al. 2016 European Guidelines on cardiovascular disease prevention in clinical practice: the sixth joint task force of the European Society of Cardiology and other Societies on cardiovascular disease prevention in clinical practice (constituted by representatives of 10 societies and by invited experts) developed with the special contribution of the European Association for Cardiovascular Prevention & Rehabilitation (EACPR). Eur Heart J. 2016;37:2315–81.
37. Antman EM, Cohen M, Bermink PJ, McCabe CH, Horacek T, Papuchis G, Mautner B, Corbalan R, Radley D, Braunwald E. The TMI risk score for unstable angina/non-St-elevation MI: a method for prognostication and therapeutic decision making. JAMA. 2000;284:835–42.
38. Eagle KA, Lim LJ, Dabbous OH, Pieper KS, Goldberg RJ, Van de Werf F, Goodman SG, Granger CB, Steg G, Gore JM, et al. A validated prediction model for all forms of acute coronary syndrome estimating the risk of 6-month post discharge death in an international registry. JAMA. 2004;291:2727–33.
39. Neumann F-J, Sousa-Uva M, Ahlsson A, Alfonso F, Banning AP, Benedetto U, Byrne RA, Collet J-P, Falk V, Head SJ, et al. 2018 ESC/EACTS Guidelines on myocardial revascularization. The Task Force on myocardial revascularization of the European Society of Cardiology (ESC) and European Association for Cardio-Thoracic Surgery (EACTS). Developed with the special contribution of the European Association for percutaneous

Cardiovascular Interventions (EAPCI). Eur Heart J. 2019;40:87–165. https://doi.org/10.1093/eurheartj/ehy394.

40. Roffi M, Patrono C, Collet J-P, Mueller C, Valgimigli M, Andreotti F, Bax JJ, Borger MA, Brotons C, Chew DP, et al. For the Task Force for the Management of Acute Coronary Syndromes in Patients Presenting without Persistent ST-Segment Elevation of the European Society of Cardiology (ESC): 2015 ESC guidelines for the management of acute coronary syndromes in patients presenting without persistent ST-segment elevation. Eur Heart J. 2016;37:267–315. https://doi.org/10.1093/eurheartj/ehv320.
41. Bassand J-P, Hamm CW, Ardissino D, Boersma E, Buda A, Fernandez-Aviles F, Fox KAA, Hasdai D, Ohman M, Wallentin L, Wijns W. Guidelines for the diagnosis and treatment of non-ST-segment elevation acute coronary syndromes. The task force for the diagnosis and treatment of N-n-ST-segment elevation acute coronary syndromes of the European Society of Cardiology. Eur Heart J. 2007;28:1598–660. https://doi.org/10.1093/eurheartj/ehm161.
42. Mach F, Baigent C, Catapano AL, Koskinas KC, Casula M, Badimon L, Chapman MJ, De Backer GG, et al. 2019 ESC/EAS guidelines for the management of dyslipidaemias: lipid modification to reduce cardiovascular risk. Eur Heart J. 2019;41:111–88. https://doi.org/10.1093/eurheartj/ehz455.
43. Valgimigli M, Bueno H, Byrne RA, Collet J-P, Costa F, Jeppsson A, Juni P, Kastrati A, Kolh P, Mauri L, et al. 2017 ESC focused update on dual antiplatelet therapy in coronary artery disease developed in collaboration with EACTS. Eur Heart J. 2018;39:213–54. https://doi.org/10.1093/eurheartj/ehx419.
44. Khatib R, Lee G, Marques-Sule E, Hopstock L, O'Donnell S, Svavarsdottir M, Andreae C, Vellone E, Goossens E, Stromberg A, Kjellstrom B, Jaarsma T, Stewart C. Evaluating the extent of patient-centred care in a selection of ESC guidelines. Eur Heart J Qual Clin Outcomes. 2019;6:55–61. https://doi.org/10.1093/ehjqcco/qcz025.
45. Bowe AA. President's page: patient-centered care and health care reform. J Am Coll Cardiol. 2009;53:1242–3.
46. Brindis R, Walsh MN. President's page: patient-centered cardiovascular care: an ACC initiative. J Am Coll Cardiol. 2010;56:155–7.
47. Zoghbi WA. President's page: The ACC in 2012: transforming cardiovascular care, step by step. J Am Coll Cardiol. 2012;59:1330–2.
48. Labots G, Jones A, de Visser SJ, Rissmann R, Burggraaf J. Gender differences in clinical registration trials: is there a real problem? Br J Clin Pharmacol. 2018;84(4):700–7. PMCID: PMC5867082. https://doi.org/10.1111/bcp.13497.
49. Downing NS, Shah ND, Neiman JH, Aminawung JA, Krumholtz HM, Ross JS. Participation of the elderly, women, and minorities in pivotal trials supporting 2011-2013 U.S. Food and Drug Administration approvals. Trials. 2016;17:199. https://doi.org/10.1186/s13063-016-1322-4.
50. Knuuti J, Wijns W, Saraste A, Capodanno D, Barbato E, Funck-Brentano C, Prescott E, et al. 2019 ESC Guidelines for the diagnosis and management of chronic coronary syndromes. The Task Force for the diagnosis and management of chronic coronary syndromes of the European Society of Cardiology (ESC). Eur Heart J. 2019;41:1–71. https://doi.org/10.1093/eurheartj/ehz425.
51. Morrow DA, De Lemos JA. Stable ischemic heart disease. In: Zipes DP, Libby P, Bonow RO, Mann DL, Tomaselli GF, Braunwald E, editors. Braunwald's heart disease. A textbook of cardiovascular medicine. 11th ed. Philadelphia, PA: Elsevier; 2019. p. 1209–70.
52. Rothberg MB, Sivalingam SK, Kleppel R, Schweiger M, Hu B, Sepucha KR. Informed decision making for percutaneous coronary intervention for stable coronary disease. JAMA Intern Med. 2015;175:1199–206.
53. Fihn SD, Gardin JM, Abrams J, Berra K, Blankenship JC, Dallas AP, Douglas PS, Foody JM, et al. ACCF/AHA/ACP/AATS/PCNA/SCAI/STS guideline for the diagnosis and management of patients with stable Ischemic heart disease. J Am Coll Cardiol. 2012;2012(60):e44–e164. https://doi.org/10.1016/j.jacc.2012.07.013.

54. Mancini GBJ, Gosselin G, Chow B, Kostuk W, Stone J, Yvorchuk KJ, Abramson BL, Cartier R, Huckell V, Tardif J-C, Connelly K, Ducas J, Farkouh ME, Gupta M, Juneau M, O'Neil B, Raggi P, Teo K, Verma S, Zimmermann R. Canadian cardiovascular society guidelines for the diagnosis and management of stable Ischemic heart disease. Can J Cardiol. 2014;30:837–49. https://doi.org/10.1016/j.cjca.2014.05.103.
55. Maron BA, Gersh BJ, O'Gara PT. The evaluation and management of stable ischemic heart disease. In: Fuster V, Harrington RA, Narula J, Eapen ZJ, editors. Hurst's the heart, vol. 14e. New York, NY: McGraw-Hill; 2017. http://accessmedicine.mhmedical.com.www.proxy.cpsbc.ca/content.aspx?bookid=2046&sectionid=176556990.
56. Boden WE, O'Rourke RA, Teo KK, Hartigan PM, Maron DJ, Kostuk WJ, Knudtson M, Dada M, Casperson P, et al. Optimal medical therapy with or without PCI for stable coronary disease. N Engl J Med. 2007;356:1503–16. https://doi.org/10.1056/NEJMoa070829.
57. Chaitman BR, Hardison RM, Adler D, Gebhart S, Grogan M, Ocampo S, Sopko G, Ramires JA, Schneider D, Frye RL, For the BARI 2D Study Group. The bypass angioplasty revascularization investigation 2 diabetes randomized trial of different treatment strategies in type 2 diabetes mellitus with stable ischemic heart disease: impact of treatment strategy on cardiac mortality and myocardial infarction. Circulation. 2009;120:2529–40.
58. Pitt B, Waters D, Brown WV, van Boven AJ, Schwartz L, Title LM, Eisenberg D, Shurzinske L, McCormick LS. Aggressive lipid-lowering therapy compared with angioplasty in stable coronary artery disease. Atorvastatin versus revascularization treatment investigators. N Engl J Med. 1999;341:70–6. https://doi.org/10.1056/NEJM199907083410202.
59. Weintraub WS, Spertus JA, Kolm P, et al. Effect of PCI on quality of life in patients with stable coronary disease. N Engl J Med. 2008;359:677–87.
60. Acharya T, Deedwania P. Cardiovascular outcome trials of the newer anti-diabetic medications. Prog Cardiovasc Dis. 2019;62:342–8. https://doi.org/10.1016/j.pcad.2019.08.003.
61. Sheahan KH, Wahlberg EA, Gilbert MP. An overview of GLP-1 agonists and recent cardiovascular outcomes trials. Postgrad Med J. 2020;96:156–61. https://doi.org/10.1136/postgradmedj-2019-137186.
62. Teo YH, Teo YN, Syn NL, Kow CS, Yoong CSY, Tan BYQ, Yeo T-C, Lee C-H, Lin W, Sia C-H. Effects of Sodium/Glucose cotransporter 2 (SGLT2) inhibitors on cardiovascular and metabolic outcomes in patients without Diabetes Mellitus: a systematic review and meta-analysis of randomized-controlled trials. J Am Heart Assoc. 2021;10:e019463. https://doi.org/10.1161/JAHA.120.019463.
63. Farkouh ME, Sharma SK, Tomey MI, Puskas J, Fuster V. Coronary artery by-pass grafting and percutaneous interventions in stable ischemic heart disease. In: Fuster V, Harrington RA, Narula J, Eapen ZJ, editors. Hurst's the heart, vol. 14e. New York, NY: McGraw-Hill; 2017. http://accessmedicine.mhmedical.com.www.proxy.cpsbc.ca/content.aspx?bookid=2046&sectionid=176557150.
64. Capers Q, Sharalaya Z. Racial disparities in cardiovascular care: a review of culprits and potential solutions. J Racial Ethn Health Disparities. 2014;1:171–80. https://doi.org/10.1007/s40615-014-0021-7.
65. Chen J, Rathore SS, Radford MJ, Wang Y, Krumholz HM. Racial differences in the use of cardiac catheterization after acute myocardial infarction. N Engl J Med. 2001;344:1443–9. https://doi.org/10.1056/NEJM200105103441906.
66. Aggarwal R, Chiu N, Loccoh EC, Kazi DS, Yeh RW, Wadhera RK. Rural-urban disparities. J Am Coll Cardiol. 2021;77:1480–1. https://doi.org/10.1016/j.jacc.2021.01.032.
67. Carnethon MR, Pu J, Howard G, Albert MA, Anderson CAM, Bertoni AG, Mujahid MS, Palaniappan L, Taylor HA, Willis M, Yancy CW. Cardiovascular health in African-Americans: a scientific statement from the AHA: endorsed by the ACC. Circulation. 2017;136:e393–423. https://doi.org/10.1161/CIR.0000000000000534.
68. Ahmad T, Butler J, Borlaug B. The diagnosis and management of chronic heart failure. In: Fuster V, Harrington RA, Narula J, Eapen ZJ, editors. Hurst's the heart, vol. 14e. New York,

NY: McGraw-Hill; 2017. http://accessmedicine.mhmedical.com.www.proxy.cpsbc.ca/content.aspx?bookid=2046&sectionid=176557150.

69. Mann DL. Management of heart failure patients with reduced ejection fraction. In: Zipes DP, Libby P, Bonow RO, Mann DL, Tomaselli GF, Braunwald E, editors. Braunwald's heart disease—a textbook of cardiovascular medicine. 11th ed. Boston, MA: Elsevier; 2019. p. 490–522.
70. McDonald M, Virani S, Chan M, Ducharme A, Ezekowitz JA, Giannetti N, Heckman GA, et al. CCS/CHFS Heart failure guidelines update: defining a new pharmacologic standard of care for heart failure with reduced ejection fraction. Can J Cardiol. 2021;37:531–46. https://doi.org/10.1016/j.cjca.2021.01.017.
71. McDonagh TA, Metra M, Adamo M, Gardner RS, Baumbach A, Böhm M, Burri H, Butler J, Čelutkienė J, Chioncel O, et al. 2021 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure: Developed by the Task Force for the diagnosis and treatment of acute and chronic heart failure of the European Society of Cardiology (ESC) of the ESC. Eur Heat J. 2021;42:3599–726. https://doi.org/10.1093/eurheartj/ehab368.
72. Ho K, Pinsky J, Kannel WB, Levy D. The epidemiology of heart failure: the Framingham study. J Am Coll Cardiol. 1993;22(4 Suppl A):6A–13A. https://doi.org/10.1016/0735-1097(93)90455-A.
73. Mosterd A, Hoes AW. Clinical epidemiology of heart failure. Heart. 2007;93(9):1137–46. https://doi.org/10.1136/hrt.2003.025270.
74. Chun S, Tu JV, Wijeysundera HC, Austin PC, Wang X, Levy D, et al. Lifetime analysis of hospitalizations and survival of patients newly admitted with heart failure. Circ Heart Fail. 2012;5(4):414–21. https://doi.org/10.1161/CIRCHEARTFAILURE.111.964791.
75. Gheorghiade M, Vaduganathan M, Fonarow GC, Bonow RO. Rehospitalization for heart failure: problems and perspectives. J Am Coll Cardiol. 2013;61(4):391–403. https://doi.org/10.1016/j.jacc.2012.09.038.
76. Stewart S, Ekman I, Ekman T, Oden A, Rosengren A. Population impact of heart failure and the most common forms of cancer: a study of 1 162 309 hospital cases in Sweden (1988 to 2004). Circ Cardiovasc Qual Outcomes. 2010;3(6):573–80. https://doi.org/10.1161/CIRCOUTCOMES.110.957571.
77. Stewart S, Macintyre K, Hole DJ, Capewell S, Mcmurray JJ. More 'malignant' than cancer? Five-year survival following a first admission for heart failure. Eur J Heart Fail. 2001;3:315–22. https://doi.org/10.1016/S1388-9842(00)00141-0.
78. Solomon SD, Dobson J, Pocock S, Skali H, Mcmurray JJ, Granger CB, et al. Influence of nonfatal hospitalization for heart failure on subsequent mortality in patients with chronic heart failure. Circulation. 2007;116(13):1482–7. https://doi.org/10.1161/CIRCULATIONAHA.107.696906.
79. Stewart S, Jenkins A, Buchan S, Mcguire A, Capewell S, Mcmurray JJ. The current cost of heart failure to the National Health Service in the UK. Eur J Heart Fail. 2002;4(3):361–71. https://doi.org/10.1016/S1388-9842(01)00198-2.
80. Braunschweig F, Cowie MR, Auricchio A. What are the costs of heart failure? Europace. 2011;13(Suppl 2):ii13–7.
81. Bennett SJ, Huster GA, Baker SL, Milgrom LB, Kirchgassner A, Birt J, et al. Characterization of the precipitants of hospitalization for heart failure decompensation. Am J Crit Care. 1998;7(3):168–74.
82. Michalsen A, Konig G, Thimme W. Preventable causative factors leading to hospital admission with decompensated heart failure. Heart. 1998;80:437–41. https://doi.org/10.1136/hrt.80.5.437.
83. Gustafsson F, Arnold JMO. Heart failure clinics and outpatient management: review of the evidence and call for quality assurance. Eur Heart J. 2004;25:1596–604.
84. Moertl D, Altenberger J, Bauer N, Berent R, Berger R, Boehmer A, Ebner C, Fritsch M, et al. Disease management programs in chronic heart failure Position statement of the Heart Failure Working Group and the Working Group Of The Cardiological Assistance and Care

Personnel of the Austrian Society of Cardiology. Wien Klin Wochenschr. 2017;129:869–78. https://doi.org/10.1007/s00508-017-1265-0.

85. Rich MW, Beckham V, Wittenberg C, Leven CL, Freedland KE, Carney RM. A multidisciplinary intervention to prevent the readmission of elderly patients with congestive heart failure. N Engl J Med. 1995;333:1190–5.
86. Kane PM, Murtagh FEM, Ryan K, Mahon NG, McAdam B, McQuillan R, Ellis-Smith C, Tracey C, Howley C, Raleigh C, O'Hara G, Higginson IJ, Daverson BA. The gap between policy and practice: a systematic review of patient-centred care interventions in chronic heart failure. Heart Fail Rev. 2015;20(6):673–87. https://doi.org/10.1007/s10741-015-9508-5.
87. Mcdonagh TA, Blue L, Clark AL, Dahlstrom U, Ekman I, Lainscak M, et al. European Society of Cardiology Heart Failure Association standards for delivering heart failure care. Eur J Heart Fail. 2011;13(3):235–41. https://doi.org/10.1093/eurjhf/hfq221.
88. Sharma K, Ying W, Editorial Comment. Is PARAGON a paragon Example of an HFpEF clinical trial? A call for deep phenotyping. J Am Coll Cardiol. 2019;74:2874–7. https://doi.org/10.1016/jack.2019.10.024.
89. Olivotto I, Oreziak A, Barriales-Villa R, Abraham TP, Masri A, Garcia-Pavia P, et al. Mavacamten for treatment of symptomatic obstructive cardiomyopathy (EXPLORER-HCM): A randomized, double-blind, placebo-controlled, phase 3 trial. Lancet. 2020;396:759–69. https://doi.org/10.1016/S0140-6736(20)31792-X.
90. Garcia-Pavia P, Rapezzi C, Adler Y, Arad M, Basso C, Brucato A, Burazor I, Caforio A, Damy T, Eriksson U, et al. Diagnosis and treatment of cardiac amyloidosis. A position statement of the European Society of Cardiology Working group on myocardial and pericardial diseases. Eur J Heart Fail. 2021;23(4):512–26. https://doi.org/10.1002/ejhf.2140.
91. Vaduganathan M, Docherty KF, Claggett BL, Jhund PS, de Boer RA, Hernandez AF, Inzucchi SE, Kosiborod MN, Lam CSP, Martinez F, Shah SJ, Desai AS, McMurray JJV, Solomon SD: SGLT-2 inhibitors in patients with heart failure: a comprehensive meta-analysis of five randomized controlled trials. The Lancet. 2022;400:757–67. https://doi.org/10.1016/S0140-6736(22)01429-5.
92. Ansari M, Alexander M, Tutar A, Bello D, Massie BM. Cardiology participation improves outcomes in patients with new-onset heart failure in the outpatient setting. J Am Coll Cardiol. 2003;41:62–8. https://doi.org/10.1016/S0735-1097(02)02493-2.
93. Avaldi VM, Lenzi J. The role of cardiologists in the management of patients with heart failure. In: Islam M, editor. Heart failure: from research to clinical practice. Advances in experimental medicine and biology, vol. 1067. Cham: Springer; 2017.
94. Eberly LA, Richterman A, Beckett AG, Wispelwey B, Marsh RH, Cleveland Manchanda EC, Chang CY, Glynn RJ, Brooks KC, et al. Identification of racial inequities in access to specialized inpatient heart failure care at an Academic medical center. Circ Heart Fail. 2019;12:e006214. https://doi.org/10.1161/CIRCHEARTFAILURE.119.006214.
95. Cholesterol Treatment Trialists Collaboration, Baigent C, Blackwell L, Emberson J, Holland LE, Reith C, Bhala N, Peto R, et al. Efficacy and safety of more intensive lowering of LDL cholesterol: a meta-analysis of data from 170,000 participants in 26 randomised trials. Lancet. 2010;376(9753):1670–81. https://doi.org/10.1016/S0140-6736(10)61350-5.
96. Silverman MG, Ference BA, Im K, Wiviott SD, Giugliano RP, Grundy SM, Braunwald E, Sabatine MS. Association between lowering LDL-C and cardiovascular risk reduction among different therapeutic interventions: a systematic review and meta-analysis. JAMA. 2016;316:12891297.
97. Baigent C, Keech A, Kearney PM, Blackwell L, Buck G, Pollicino C, Kirby A, Sourjina T, Peto R, Collins R, Simes R, Cholesterol Treatment Trialists' (CTT) Collaborators. Efficacy and safety of cholesterol-lowering treatment: prospective meta-analysis of data from 90,056 participants in 14 randomised trials of statins. Lancet. 2005;366:12671278.
98. Ference BA, Ginsberg HN, Graham I, Ray KK, Packard CJ, Bruckert E, Hegele RA, Krauss RM, Raal FJ, Schunkert H, et al. Low-density lipoproteins cause atherosclerotic cardiovascular disease. 1. Evidence from genetic, epidemiologic, and clinical studies. A con-

sensus statement from the European Atherosclerosis Society Consensus panel. Eur Heart J. 2017;38:2459–72.

99. Endo A. A historical perspective on the discovery of statins. Proc Jpn Acad Ser B Phys Biol Sci. 2010;86:484–93. https://doi.org/10.2183/pjab.86.484.
100. Aspelund T, Gudnason V, Magnusdottir BT, Andersen K, Sigurdsson G, Thorsson B, Steingrimsdottir L, Critchley J, Bennett K, O'Flaherty M, Capewell S. Analysing the large decline in coronary heart disease mortality in the Icelandic population aged 25–74 between the years 1981 and 2006. PLoS One. 2010;5:e13957.
101. Pereira M, Azevedo A, Lunet N, Carreira H, O'Flaherty M, Capewell S, Bennett K. Explaining the decline in coronary heart disease mortality in Portugal between 1995 and 2008. Circ Cardiovasc Qual Outcomes. 2013;6:634–42.
102. Cholesterol Treatment Trialists Collaboration, Fulcher J, O'Connell R, Voysey M, Emberson J, Blackwell L, Mihaylova B, Simes J, Collins R, Kirby A, et al. Efficacy and safety of LDL-lowering therapy among men and women: meta-analysis of individual data from 174,000 participants in 27 randomised trials. Lancet. 2015;385:13971405.
103. Piepoli MF, Hoes AW, Agewall S, Albus C, Brotons C, Catapano AL, Cooney MT, Corra U, Cosyns B, Deaton C, et al. 2016 European Guidelines on cardiovascular disease prevention in clinical practice: the Sixth Joint Task Force of the European Society of Cardiology and Other Societies on Cardiovascular Disease Prevention in Clinical Practice (constituted by representatives of 10 societies and by invited experts): developed with the special contribution of the European Association for Cardiovascular Prevention & Rehabilitation (EACPR). Eur J Prev Cardiol. 2016;23(11):NP1–NP96. Epub 2016 Jun 27. https://doi.org/10.1177/2047487316653709.
104. Sabatine MS, Giugliano RP, Keech AC, Honarpour N, Wiviott SD, Murphy SA, Kuder JF, Wang H, Liu T, Wasserman SM, Sever PS, Pedersen TR, FOURIER Steering Committee and Investigators. Evolocumab and clinical outcomes inpatients with cardiovascular disease. N Engl J Med. 2017;376:17131722.
105. Schwartz GG, Steg PG, Szarek M, Bhatt DL, Bittner VA, Diaz R, Edelberg JM, et al. Alirocumab and cardiovascular outcomes after acute coronary syndrome. N Engl J Med. 2018;379:20972107.
106. Grundy SM, Stone NJ, Bailey AL, Beam C, Birtcher KK, Blumenthal RS, Braun LT, de Ferranti S, Faiella-Tommasino J, et al. 2018 AHA/ACC/AACVPR/AAPA/ABC/ACPM/ADA/AGS/APhA/ASPC/NLA/PCNA guideline on the management of blood cholesterol: a report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. Circulation. 2019;139:e1082–143. https://doi.org/10.1161/CIR.0000000000000625.
107. Pearson GJ, Thanassoulis G, Anderson TJ, Barry AR, Couture P, Dayan N, Francis G, Genest J, Gregoire J, et al. 2021 Canadian Cardiovascular Society guidelines for the management of dyslipidemia for the prevention of cardiovascular disease in the adult. Can J Cardiol. 2021;37(8):1129–50. https://doi.org/10.1016/j.cjca.2021.03.016.
108. Boekholdt SM, Hovingh GK, Mora S, Arsenault BJ, Amarenco P, Pedersen TR, LaRosa JC, Waters DD, et al. Very low levels of atherogenic lipoproteins and the risk for cardiovascular events: a meta-analysis of statin trials. J Am Coll Cardiol. 2014;64:485494.
109. Jacobson TA, Ito MK, Maki KC, Orringer CE, Bays HE, Jones PH, McKenney JM, et al. National lipid association recommendations for patient-centered management of Dyslipidemia: part 1—full report. J Clin Lipodol. 2015a;9:129–69. https://doi.org/10.1016/j.jacl.2015.02.003.
110. Jacobson TA, Maki KC, Orringer CE, Jones PH, Kris-Etherton P, Sikand G, La Forge R, Daniels SR, et al. National lipid association recommendations for patient-centered management of Dyslipidemia: part 2. J Clin Lipodol. 2015b;9:S1–S122. https://doi.org/10.1016/j.jacl.2015.09.002.

111. Wei MY, Ito MK, Cohen JD, Brinton EA, Jacobson TA. Predictors of statin adherence, switching, and discontinuation in the USAGE survey: understanding the use of statins in America and gaps in patient education. J Clin Lipidol. 2013;7:472–83.
112. Simpson RJ, Mendys P. The effect of adherence and persistence on clinical outcomes in patients treated with statins: a systematic review. J Clin Lipidol. 2010;4:462–71.
113. Pape GA, Hunt JS, Butler KL, Siemienczuk J, LeBlanc BH, Gillanders W, Rozenfeld Y, Bonin K. Team-based care approach to cholesterol management in diabetes mellitus: two-year cluster randomized controlled trial. Arch Intern Med. 2011;171:1480–6.
114. Proia KK, Thota AB, Njie GJ, Finnie RKC, Hopkins DP, Mukhtar Q, Pronk NP, et al. Team-Based care and improved blood pressure control: a community guide systematic review. Am J Prev Med. 2014;47:86–99. http://refhub.elsevier.com/S1933-2874(15)00380-3/sref807
115. Sever PS, Dahlof B, Poulter NR, Wedel H, Beevers G, Caulfield M, Collins R, et al. Prevention of coronary and stroke events with atorvastatin in hypertensive patients who have average or lower-than-average cholesterol concentrations, in the Anglo-Scandinavian Cardiac Outcomes Trial-Lipid Lowering Arm (ASCOT-LLA): a multi centre randomised controlled trial. Lancet. 2003;361:1149–58. https://doi.org/10.1016/S0140-6736(03)12948-0.
116. Shepherd J, Cobbe SM, Ford I, Isles CG, Lorimer AR, Macfarlane PW, McKillop JH, Packard CJ. Prevention of coronary heart disease with pravastatin in men with hypercholesterolemia. West of Scotland coronary prevention study group. N Engl J Med. 1995;333:1301–8.
117. Byrne P, Cullinan J, Smith A, Smith SM. Statins for primary prevention of cardiovascular disease: an overview of systematic reviews. BMJ Open. 2019;367:I1574. https://doi.org/10.1136/bmj.l5674.
118. Goff DC, Lloyd-Jones DM, Bennett G, Coady S, D'Agostino RB, Gibbons R, Greenland P, et al. 2013 ACC/AHA guideline on the assessment of cardiovascular risk: a report of the American College of Cardiology/American Heart Association Task Force on practice guidelines. J Am Coll Cardiol. 2014;63:2935–59. https://doi.org/10.1016/j.jacc.2013.11.005.
119. Mezzich J, Snaedal J, van Weel C, Heath I. Mission of the International College of person-centered medicine. 2019. https://personcenteredmedicine.org/mission.html. Accessed 15 Oct 15.
120. Mezzich J, Snaedal J, van Weel C, Heath I. Toward person-centered medicine: from disease to patient to person. Mt Sinai J Med. 2010;77:304–6. https://doi.org/10.1002/msj.20187.
121. Picker Institute. Principles of patient-centered care. 2019. http://pickerinstitute.ipfcc.org/about/picker-principles/. Accessed 16 Oct 2019.
122. Alnasir FA, Jaradat A. Patient-centered care; physicians' view of obstacles against and ideas for implementation. Int J Med Res Health Sci. 2016;5(4):161–8.
123. Moore L, Britten N, Lydahl D, Naldemird O, Elam M, Wolf A. Barriers and facilitators to the implementation of person-centered care in different healthcare contexts. Scand J Caring Sci. 2017;31:662–73. https://doi.org/10.1111/scs.12376.
124. Sinaiko AD, Szumigalski K, Eastman D, Chien AT. Delivery of patient centered care in the U.S. Health Care System: what is standing in its way? Academy Health; Robert Wood Johnson Foundation. 2019. https://www.academyhealth.org/sites/default/files/deliverypatientcenteredcare_august2019.pdf
125. Blacher J, Levy BI, Mourad J-J, Safar ME, Bakris G. From epidemiological transition to modern cardiovascular epidemiology: hypertension in the 21st century. Lancet. 2016;388:530–2.
126. Poulter NR, Prabhakaran D, Caulfield M. Hypertension. Lancet. 2015;386:801–12.
127. Ettehad D, Emdin CA, Kiran A, Anderson SG, Callender T, Emberson J, Chalmers J, Rodgers A, Rahimi K. Blood pressure lowering for prevention of cardiovascular disease and death: a systematic review and meta-analysis. Lancet. 2016;387:957–67.
128. Rapsomaniki E, Timmis A, George J, Pujades-Rodriguez M, Shah AD, Denaxas S, White IR, Caulfield MJ, Deanfield JE, Smeeth L, Williams B, Hingorani A, Hemingway H. Blood pressure and incidence of twelve cardiovascular diseases: lifetime risks, healthy life-years lost, and age-specific associations in 1.25 million people. Lancet. 2014;383:1899–911.
129. Nerenberg KA, Zamke KB, Leung AA, Dasgupta K, Butalia S, McBrien K, Harris KC, et al. Hypertension Canada's 2018 guidelines for diagnosis, risk assessment, prevention, and treat-

ment of hypertension in adults and children. Can J Cardiol. 2018;34:506–25. https://doi.org/10.1016/j.cjca.2018.02.02.

130. Whelton PK, Carey RM, Aronow WS, Casey DE, Collins KJ, Himmelfarb CD, DePalma SM, et al. 2017 ACC/AHA/AAPA/ABC/ACPM/AGS/APhA/ASH/ASPC/NMA/PCNA guideline for the prevention, detection, evaluation, and management of high blood pressure in adults: a report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. J Am Coll Cardiol. 2018;71:2199–269. https://doi.org/10.1016/j.jacc.2017.11.005.
131. Williams B, Mancia G, Spiering W, Rosei EA, Azizi M, Burnier M, Clement DL, Coca A, de Simone G, Dominiczak A, et al. 2018 ESC/ESH Guidelines for the management of arterial hypertension. Eur Heart J. 2018;39:3021–104. https://doi.org/10.1093/eurheartj/ehy339.
132. Rabi DM. Barriers to patient-centered care in hypertension. Can J Cardiol. 2017;33:586–90. https://doi.org/10.1016/j.cjca.2017.03.003.
133. Lee H, Yano Y, Cho SMJ, Heo JE, Kim D-W, Park S, Lloyd-Jones DM, Kim HC. Adherence to antihypertensive medication and incident cardiovascular events in young adults with hypertension. Hypertension. 2021;77:1341–9. https://doi.org/10.1161/HYPERTENSIONAHA.120.16784.
134. Kleinsinger F. The unmet challenge of medication nonadherence. Perm J. 2018;22:18–033. https://doi.org/10.7812/TPP/18-033.
135. Krousel-Wood M, Joyce C, Holt E, Muntner P, Webber LS, Morisky DE, Frohlich ED, Re RN. Predictors of decline in medication adherence: results from the cohort study of medication adherence among older adults. Hypertension. 2011;58:804–10. https://doi.org/10.1161/HYPERTENSIONAHA.111.176859.
136. Burnier M, Wuerzner G, Struijker-Boudier H, Urquhart J. Measuring, analyzing, and managing drug adherence in resistant hypertension. Hypertension. 2013;62:218–25. https://doi.org/10.1161/HYPERTENSIONAHA.113.00687.
137. Fischer MA, Stedman MR, Lii J, Vogeli C, Shrank WH, Brookhart MA, Weissman JS. Primary medication non-adherence: analysis of 195,930 electronic prescriptions. J Gen Intern Med. 2010;25(4):284–90. https://doi.org/10.1007/s11606-010-1253-9.
138. Abegaz TM, Shehab A, Gebreyohannes EA, Bhagavathula AS, Elnour AA. Nonadherence to antihypertensive drugs: a systematic review and meta-analysis. Medicine (Baltimore). 2017;96(4):e5641. https://doi.org/10.1097/MD.0000000000005641.
139. Naderi SH, Bestwick JP, Wald DS. Adherence to drugs that prevent cardiovascular disease: meta-analysis on 376,162 patients. Am J Med. 2012;125:882–887.e1.
140. Thomopoulos C, Parati G, Zanchetti A. Effects of blood pressure lowering on outcome incidence in hypertension: 7. Effects of more vs. less intensive blood pressure lowering and different achieved blood pressure levels—updated overview and meta-analyses of randomized trials. J Hypertens. 2016a;34:613–22.
141. Thomopoulos C, Parati G, Zanchetti A. Effects of blood pressure lowering treatment in hypertension: 8. Outcome reductions vs. discontinuations because of adverse drug events—meta-analyses of randomized trials. J Hypertens. 2016b;34:1451–63.
142. Victor RG, Blyler CA, Li N, Lynch K, Moy NB, Rashid M, Chang LC, Handler J, Brettler J, Rader F, Elashoff RM. Sustainability of blood pressure reduction in black barbershops. Circulation. 2019;139:10–9. https://doi.org/10.1161/CIRCULATIONAHA.118.038165.
143. Wright JM, Musini VM, Gill R. First line drugs for hypertension. Cochrane Database Syst Rev. 2018;4(4):CD001841. https://doi.org/10.1002/14651858.CD001841.
144. Tsuyuki RT, Houle SKD, Charrois TL, Kolber MR, Rosenthal MM, Lewanczuk R, Campbell NRC, Cooney D, McAlister FA. Randomized Trial of the Effect of Pharmacist Prescribing on Improving Blood Pressure in the Community The Alberta Clinical Trial in Optimizing Hypertension (RxACTION). Circulation. 2015;132:93–100. https://doi.org/10.1161/CIRCULATIONAHA.115.015464.

145. Andersen UO, Simper AM, Ibsen H, Svendsen TL. Treating the hypertensive patient in a nurse-led hypertension clinic. Blood Press. 2010;19:182–7. https://doi.org/10.3109/08037051003606405.
146. Barry MJ, Edgman-Levitan S. Shared decision making–the pinnacle of patient-centered care. N Engl J Med. 2012;366:780–1. https://doi.org/10.1056/NEJMp1109283.
147. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). Soc Sci Med. 1997;44:681–92.
148. Stacey D, Leegare F, Lewis K, Barry MJ, Bennett CL, Eden KB, Holmes-Rovner M, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev. 2017;4:CD001431. https://doi.org/10.1002/14651858.CD001431.pub5.
149. Castro EM, Van Regenmortel T, Vanhaecht K, Sermeusd W, Van Heckef A. Patient empowerment, patient participation and patient-centeredness in hospital care: a concept analysis based on a literature review. Patient Educ Couns. 2016;99:1923–39. https://www.sciencedirect.com/science/article/abs/pii/S0738399116303214.
150. Heidenreich PA, Fonarow GC, Breathett K, Jurgens CY, Pisani BA, Pozehl BJ, Spertus JA, Taylor KG, Thibodeau JT, Yancy CW, Ziaeian B. 2020 ACC/AHA Clinical Performance and quality measures for adults with heart failure: a report of the American College of Cardiology/American Heart Association Task Force on performance measures. J Am Coll Cardiol. 2020;76:2527–64. https://doi.org/10.1016/j.jacc.2020.07.023.
151. Edvardson D, Innes A. Measuring person-centered care: a critical comparative review of published tools. Gerontologist. 2010;50(6):834–46. https://doi.org/10.1093/geront/gnq047.
152. Santana M-J, Manalili K, Zelinsky S, Brien S, Gibbons E, King J, Frank L, Wallstrom S, Fairie P, Leeb K, Quan H, Sawatzky R. Improving the quality of person-centred healthcare from the patient perspective: development of person-centred quality indicators. BMJ Open. 2020;10:e037323. https://doi.org/10.1136/bmjopen-2020-037323.
153. Ahmed AT, Akeroyd JM, Mahtta D, Street R, Slagle J, Navar AM, Stone NJ, Ballantyne CM, Petersen LA, Virani SS. Shared decision: a qualitative study on clinician and patient perspectives on statin therapy and statin-associated side effects. J Am Heart Assoc. 2020;9:e017915. https://doi.org/10.1161/JAHA.120.017915.
154. Kunneman M, Branda ME, Hargraves IG, Sivly AL, Lee AT, Gorr H, Burnett B, Suzuki T, Jackson EA, Hess E, et al. Assessment of shared decision-making for Stroke prevention in patients with atrial fibrillation—a randomized clinical trial. JAMA Intern Med. 2020;180(9):1215–24. https://doi.org/10.1001/jamainternmed.2020.2908.

Chapter 32
Person-Centered Pulmonary Medicine

Christopher M. Dennis

32.1 Introduction

This chapter provides a contextual analysis of how Pulmonary Medicine is practiced in our modern world. It explores the challenges and limitations of our models of care and discusses how a "Person-centered approach" may be developed and formulated in the future with reference to key historical figures from our profession.

32.2 Patients

The patients encountered in the practice of Pulmonary Medicine fall broadly into three categories. All of these patients may be approached by the physician and the health system using the "age old" principle of *cura personalis (individual care).*

The first group consists of people who attend the Outpatient Department or Clinics and have long-standing or sub-acute symptoms such as chronic cough, increasing dyspnea or chest discomfort. These patients require clinical assessment and subsequent investigation to establish the cause of their symptoms and then a plan of management to alleviate the symptoms if possible. Much of this work may be done in a graduated fashion with outpatient investigation and return visits to see the Pulmonary Physician in the clinic.

C. M. Dennis (✉)
Royal North Shore Hospital, Sydney, NSW, Australia

Northern Clinical School 2014–2021, University of Sydney and the Royal Australasian College of Physicians, Sydney, NSW, Australia
e-mail: christopher.dennis@sydney.edu.au

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_32

The second group of patients consists of those suffering more acute and sometimes life-threatening illnesses such as pneumonia, severe asthma or respiratory failure from other causes. These patients require admission to hospital and more urgent investigation and treatment of their respiratory complaints.

The third group includes patients with lung cancer or other malignancies involving the chest or respiratory system. Such patients may require extensive investigation and treatment that involves both outpatient and in-patient services.

> "*The witch-doctor succeeds for the same reason all the rest of us succeed. Each patient carries his own doctor inside him. They come to us not knowing that truth. We are at our best when we give the doctor who resides within each patient a chance to go to work".* Albert Schweitzer [1].

32.3 Current Practice

In Pulmonary Medicine, as in most specialty areas of modern medicine these days, there is a strong tendency for pulmonologists to focus carefully and often exclusively on the presenting medical problem. The history taking is often abbreviated and the physical examination by some physicians may be limited to the chest. There may be preferential emphasis on examination of x-rays, scans, pulmonary function tests and blood tests that have performed prior to or after the consultation. This information is then often synthesized into a working diagnosis with subsequent confirmatory investigations and management plan.

There is often very little time for the pulmonary physician to undertake (with the patient and family), an explanation of his/her thoughts on the diagnosis and the thinking behind how and why further investigation may be necessary. Opportunity for patients and family members or friends to ask questions of clarification may be quite limited. There is often abbreviated discussion around important issues such as the intended treatment regimen and the overall prognosis.

> *"Knowledge is an extraverted element in the doctor's psyche; it comes from without; it is what he acquires during his long & demanding education in order that he may direct it outward upon his patients. It is what he brings to bear upon the disease that confronts him in his patients. Wisdom is an introverted element in the doctor's psyche; it has its origin within. It is what makes the doctor look not at the disease, but at the bearer of the disease. It is what creates the link that unites the healer with the patient. It is what makes him a true physician. It is wisdom that tells the physician how to make the patient a partner in his own cure".* Bernard Lown, Harvard Medical School [2].

32.4 Health Systems

In most health systems of today's world there are practical considerations which impact heavily upon the interaction of the patient with the doctor. Indeed these considerations also involve the patient's family and friends, as well as other members of the health care team, including nurses and allied health professionals.

The two critical elements, which impinge upon the patient-doctor relationship in a practical sense, are time and patient numbers. In the modern world of Pulmonology (as well as other specialties or disciplines) the time available to the physician is limited. Together with this are relentless increases in patient numbers, which involve both outpatient clinics and presentations to the hospital emergency departments. These pressures are a reality for medical staff working in well-resourced tertiary referral hospitals in the developed world as well as institutions less well-resourced in many countries in the developing world.

An example of this phenomenon includes the limited time (perhaps 30 min) available for Pulmonary Physicians in Australia to see new patients with complex respiratory problems in the hospital outpatients or private clinic setting. In the developing world (Vietnam—personal correspondence) it is not uncommon for Pulmonary Physicians to be expected to see similar patients in a 5 or 10-min consultation.

In her recent article in the New England Journal of Medicine "A Good Physician—On Complacency and Communication", Michelle Kittleson refers to the practicalities of working in a complex health care system and the impact this has on our relationships with patients, particularly certain types of patients with special needs [3]. She makes reference to Anne Fadiman's highly influential book "The spirit catches you and you fall down" wherein the author makes the observation that "every illness is not a set of pathologies but a personal story" [4].

32.5 Case Study 1

The patient is a 50-year old male with neuro-sarcoidosis. He initially presented in 2001 with impotence, bladder and bowel dysfunction. In addition, there were problems with cough and dyspnea. These symptoms were investigated and a lesion of the conus in the spinal cord was identified with MRI. Concurrent findings included pulmonary infiltrates, skin lesions (erythema nodosum), lymphadenopathy and bone lesions.

A lymph node biopsy confirmed the presence of non-caseating granulomata and the diagnosis of sarcoidosis was made.

Treatment with prednisone (1 mg/kg) and azathioprine was commenced. This resulted in dramatic improvement in most manifestations of the disease, but there was very limited recovery in bladder function. This required insertion of a permanent supra-pubic catheter.

Subsequent reduction in the dose of prednisone resulted in relapse of the disease and the patient developed iatrogenic Cushing's Syndrome with multiple complications. These included recurrent bladder infections and several episodes of life-threatening systemic sepsis. Eventually mycophenylate was substituted for azathioprine and the dose of prednisone has been gradually reduced over the years.

The patient has also suffered a number of psycho-social problems resulting from his illness. Depression and anxiety were problems in the early years and on occasions there were issues with adherence to medical care and medical advice. The patient married and had several children, which produced considerable joy but was accompanied by the usual financial and emotional pressures encountered in family life. He worked long hours as a sports coach and this made it difficult at times for him to attend his "never-ending" series of medical appointments.

His care has required "pain-staking" co-ordination of multiple specialists and health care facilities. Geographical dislocation has also been an issue as he lived and worked in a small coastal town, which was 200 km from the University Teaching Hospital in the city where he received his therapy. His general practitioner worked hard to co-ordinate his care but at times this was beyond his capacity.

In this particular case, the patient's pulmonologist became the central figure coordinating and overseeing the patient's care. This required considerable input from the physician himself, but the work also involved nursing staff, allied health staff and administrative staff at the University Hospital and in other parts of the health system. This process was not perfect and there were times when mistakes were made because of the complexity of the problems and the patient's personal circumstances.

32.5.1 Comment

This case demonstrates some of the challenges of providing comprehensive *person-centered care* in patients with complex pulmonary problems. In these situations, such care is often beyond the capability of a single physician and requires the efforts of a well-coordinated, highly motivated team of health professionals. These people need to share a common philosophy centered on humanism and compassion.

The main challenge as a physician in the early years of this patient's care was to maintain a good relationship with him and try to keep him engaged with his many doctors and other health professions who were providing the various elements of his care. This included physiotherapy, psychiatry, urology and the "Bladder Care" team, dermatology, the metabolic bone team, neurology, endocrinology, hepatology and infectious diseases. I don't think we would have been successful in our efforts to provide all these individual components of his care if we had not adopted a "person centered approach" which also involved his wife and family as well and his general practitioner of course.

This man has been able to lead a productive, useful, enjoyable life during the many years since the original presentation. There have been some difficult periods, but he has "weathered the storms" that he has encountered with the assistance of the medical profession and the health care system. I am not sure that this would have been the case, had we not adopted a "person centered approach" to his care. He is exceedingly grateful for all our efforts and I am very proud of what our "person centered team" has been able to achieve here.

> *"The first objective is to allow doctors to reflect on their own thoughts, feelings, inclinations, practice and experience. This process of reflection offers them the opportunity to gain new insights into the strengths and weaknesses of their own practice"* [5].

32.5.2 "The Common Cold"

David Watts writes about the medical profession suffering from "*too many cold and distant doctors"* in his NEJM article in 2012 [6]. He describes how our profession slowly but surely becomes worn down by challenging clinical work and that over time we lose our "sense of goodwill" which is present in large quantities when we set out as medical students.

He makes the point, "the art of medicine can't be taught. Good doctors realize that compassion arises not from will, but from a deep sense of goodness". He explores the idea that we need to work on how we personally deal with these challenges in modern medicine. The high workload and pressure of time, and how we maintain our "balance" to enable us to provide compassionate, comprehensive care for our patients.

As Sir William Osler said to his students around the turn of the nineteenth century, "*We hope to see you acquire knowledge of disease and its cure, and knowledge of yourself. The former will make you a practical and useful doctor. The latter will make you a truly good person. You may of course have the first without the second. So we hope to infect you with a desire to have a due proportion of each!"* [7].

32.6 Case Study 2

A 48 year-old male who was known to be an asthmatic was brought to the Emergency Department of a major teaching hospital in a large city by ambulance at 7 am. The patient was receiving cardio-pulmonary resuscitation by the paramedic staff when the ambulance arrived.

The paramedics had been called to the patient's home in a nearby suburb soon after 6 am. They found the patient's wife administering CPR when they arrived. They took over the resuscitation process but were unable to intubate the patient.

The paramedics obtained a rapid, limited history from the patient's wife and children during the resuscitation process. He had complained of increasing dyspnea, wheeze and cough over the previous few days. There were also some "flu-like" symptoms of fever, myalgia and lethargy. He had been using nebulized salbutamol frequently on the previous day and had started himself on oral Prednisone and an inhaled corticosteroid sometime over the previous 36 h. He had a very disturbed night prior to this incident. Around 6 am he went to the shower and became very distressed. Upon returning to the bedroom he called to his wife saying he "could not breath" and collapsed to the floor. He became cyanosed, unresponsive and suffered a brief seizure. His wife commenced CPR and had one of the teenage sons call the ambulance. The ambulance arrived around 6.20 am.

Fortunately following administration of adrenalin in the resuscitation process there was return of cardiac output and the patient was moved to the ambulance for transfer to hospital. There was a subsequent cardiac arrest en-route to hospital and resuscitation measures were reinstituted during the journey.

In the Emergency Department the patient was intubated and there was return of cardiac function within 4 min of arrival. Physical examination at that time revealed subcutaneous emphysema over the upper chest and neck, a silent chest and dilated pupils.

Imaging of the chest showed bilateral pneumo-thoraces and subcutaneous emphysema. The lung parenchyma and airways appeared unremarkable.

Arterial blood gases revealed severe acidosis (respiratory and metabolic) related to respiratory failure and the cardiac arrest. Blood tests confirmed acute cardiac injury (raised troponin), renal and hepatic damage. ECG showed atrial fibrillation but no signs of acute ischemia.

The patient was treated for acute severe asthma with bronchodilators, corticosteroids and antibiotics. Bilateral intercostal drains were inserted for the pneumothoraces. He was transferred to the Intensive Care Unit for ongoing management.

Further history was then obtained from the patient's wife and family. The patient had suffered from asthma since early childhood. There had been multiple hospital admissions for asthma throughout the course of his life. In adult life he had become reluctant to seek medical advice and tended to "self-medicate". He generally took no regular medications for his asthma and his usual exercise tolerance was one flight of stairs.

Otherwise his past medical history was of fractured ribs (from a fall down some stairs) several years earlier, and low-back pain for which he used an anti-inflammatory agent and various analgesics. He worked in the film industry and was married with two teenage children. His family described him as "a difficult person" who smoked heavily, drank to excess and used recreational drugs. He had apparently experienced considerable "life stress" in the six or nine months leading up to this presentation to hospital.

Over the following 24 h in hospital the patient made a dramatic recovery and was able to extubated successfully. He did not seem to have any neurological deficit and soon engaged in normal conversation. He was irritable, somewhat aggressive and contrary, but his family confirmed that this was often how he was in everyday life. He was transferred to the regular ward and converted to oral medications and inhalers within 48 h of admission to hospital.

He soon became insistent that he wanted to leave hospital and did not wish to comply with some of his treatment. The medical staff did not think he was psychotic or delirious. He refused a Psychiatric assessment and would not co-operate with the Social Worker. Discussions took place between the hospital staff and the family. Arrangements were made for discharge and follow-up with the General Practitioner as well as the Pulmonary Physician. The patient did not attend these appointments and he did not respond to attempts to contact him made by the hospital staff following discharge. He has subsequently been lost to follow-up.

32.6.1 Comment

This case demonstrates the limits to what is possible with patient care in certain circumstances. On occasions it becomes very difficult to achieve what we believe is ideal (or even adequate) care for certain patients. Our best efforts as a team of health professionals may be compromised by the wishes of the patient and his or her family. In these circumstances one could argue that we should take a pragmatic approach and try to do the best we can under difficult conditions.

I am not sure if our "person-centered" approach to this patient's care made any difference to his outcome or prognosis. I like to think that the input from the medical staff, nursing and allied health teams during his hospitalization may have caused him to re-evaluate the way he was approaching his life, but I don't know about this. I am most concerned that he did not appear for follow-up with his General Practitioner or our Clinic.

Despite these important reservations, I do think that the "patient centered" approach to his care provided support for his family in their struggle to deal with him. I also felt that our coordinated, team-based, "person-centered" approach helped support the members of our team in their attempts to provide care for such a difficult patient and helped them resolve their own personal reservations and concerns about his behavior and management. My own feelings about the case were those of frustration, impotence, dissatisfaction and concern.

We may find solace in the words of Rene Leriche [8], *Every doctor carries within himself (herself) a small cemetery; where he/she goes from time to time to pray.*

32.7 Practical Implications for Person Centered Care

Looking towards the years to come, one can envisage the challenge of delivering high quality "person-centered care" for complex patients with pulmonary disorders such as those described above. In my opinion this will not be possible without two essential components of medical practice and health care delivery.

The first is philosophy. There needs to exist a way of thinking which considers the patient as a "complete" human being, and entails consideration of physical, emotional, psychological and social factors which have a bearing on his condition or disease.

This contrasts with an approach that looks instead at the patient as an "organism" with a problem or problems affecting the lungs or the respiratory system. The question confronting us at present is how we cultivate this philosophy in our medical students, young doctors and the profession as a whole? There is no easy answer to this, but part of the solution may lie in Oliver Sacks suggestion that we need to expose medical students, junior doctors and other young health professionals to the humanities during their study and training. *"Many of us live with the scientific and the sacred; the medical and the mystical; both at once"*. Oliver Sacks [9].

The second element is resources. In today's world of modern medicine, it is very difficult for one professional (doctor, nurse or allied health worker) to take sole responsibility for a patient with a complex respiratory problem. Increasingly the task of delivering excellent person-centered care now comes to rest with a team of health professionals who combine in a coordinated and highly disciplined fashion to provide what is necessary to manage the patient effectively.

This multidisciplinary, inter-professional "team-based" approach is the secret of success in managing patients with complex medical problems as we move towards the second half of the twenty-first century. Such comprehensive care comes at a cost and health budgets are tight everywhere. Effective delivery of these models of care involves training of health professions to be able to work together in an effective, cooperative fashion. This type of training needs to be adopted and implemented in the early days of the health professional's educational journey. This means we need to start in the early years of Medical School for the doctors and at University for the nurses and the allied health professionals.

32.8 Conclusions

It seems that over the past three or four decades, the tide has slowly turned against the delivery of "person-centered care" in our specialty of Pulmonary Medicine. The practical reality of modern medicine has pushed many of our colleagues into a form of practice that focuses heavily on the respiratory system rather than the patient as a whole. Our scientific conferences, craft group meetings and journals are heavily weighted in favor of emphasizing and exploring the technical or biomedical aspects of what we do. It has become increasingly difficult for Respiratory Physicians to practice our "art" modeled on the likes of William Osler or Bernard Lown.

We may find inspiration and guidance in the words of Professor Francis Weld Peabody [10], from Harvard Medical School, *The secret of the care of the patient is in caring for the patient*. The writings of the great physicians quoted in this chapter may stimulate and energize pulmonologists facing challenges in the years ahead across the world.

Acknowledgements and Disclosures The author does not report any conflicts of interest in the preparation of this manuscript.

References

1. Schweitzer A. African Notebook. New York: Henry Holt and Co; 1939.
2. Lown B. The lost art of healing. Houghton Mifflin Co: New York NY; 1996.
3. Kittleson MM. A good physician—on complacency and communication. N Engl J Med. 2019;381:1798–9.

4. Fadiman A. The spirit catches you and you fall down: a hmong child, her american doctors, and the collision of two cultures. New York NY: Farrar, Straus and Giroux; 1997.
5. Kirklin D, Richardson R. Medical humanities: a practical introduction. London: Royal College of Physicians; 2001.
6. Watts D. Cure for the common cold. N Engl J Med. 2012;367:1184–5.
7. Verney RE. The student life. The philosphy of Sir William Osler. Livingstone Ltd: Edinburgh and London E. & S; 1957.
8. Leriche R. The philosophy of surgery. Paris: Flammarion bibliothèque de philosophie scientifique; 1951.
9. Sacks OW. Gratitude, Picador. Pan Macmillan UK. 2015. ISBN: 9781743548936.
10. Peabody FW. The care of the patient. JAMA. 2015;313:1868.

Chapter 33
Person-Centered Intensive Care Medicine

Mark R. Tonelli

33.1 Introduction

Intensive care units (ICUs) are best characterized as the site of delivery of the most invasive and burdensome interventions to the most severely ill of patients within a hospital. The majority of deaths in Western acute care hospitals occur in patients admitted to, or recently discharged from, an ICU. While all are severely ill, patients in the ICU otherwise represent a heterogenous group, with a wide-variety of maladies, admitted from the emergency department, acute care floors, and operative suites. In industrialized nations, medical care is generally provided by specially trained nursing staff under the guidance of an intensivist, a specialist with advanced training in critical care. Care also typically includes a variety of consultants and ancillary support providers. ICU decision-making begins with whether admission to an ICU is appropriate and often evolves to whether to continue such care in the setting of a worsening prognosis. While the decisions made in the ICU often directly relate to core values, goals, and experiences of patients, multiple barriers make delivery of truly person-centered care extremely difficult, but not impossible. Dehumanization and depersonalization are hallmarks of critical illness, affecting both patients and providers in the ICU.

Critically ill patients, compromised by disease and dependent upon a variety of technological interventions for survival, often cease to even physically resemble persons. (This point was brought home to me years ago when my then 6-year old daughter, accompanying me while I was meeting in the ICU with a colleague, looked into a patient room and asked, "*What* is that?" while gazing upon an intubated, ventilated patient receiving hemodialysis.) Depersonalization affects a large

---

M. R. Tonelli (✉)
Department of Medicine and Department of Bioethics and Humanities,
University of Washington, Seattle, WA, USA
e-mail: tonelli@uw.edu

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_33

percentage of patients with critical illness, who experience a very high incidence of cognitive impairment, hallucinations, and delirium [1]. While the critically ill remain persons they, temporarily or permanently, are likely to have lost the ability to exercise the hallmarks of personhood, agency and autonomy.

Providers of intensive care themselves are also at high risk to develop symptoms of depersonalization, as multiple studies of intensivist physicians and critical care nurses have demonstrated [2, 3]. Feelings of exhaustion related to both the physical and emotional burdens of providing care to sick and often dying patients may lead clinicians in the ICU to not only fail to recognize their patients as persons, but to lose their own sense of personhood.

The ICU necessarily introduces several other specific barriers to the provision of person-centered medicine (PCM) [4]. Many decisions in critical care medicine must be made under significant time constraints and in the setting of great uncertainty, contributing to the difficulty of making care person-centered. Considered judgment and the shared decision-making embraced by PCM are generally time intensive, with time being necessary for both for the sharing of information as well as deliberation on the part of physician and patient alike [5]. Complicating matters further, decision-making in the ICU is often dependent upon pathophysiologic reasoning and highly technical knowledge, with significantly less empirical evidence available to guide treatment choices compared to other aspects of medicine [6]. Technical knowledge and understanding complex physiology are often difficult for patients and family to process and consider. These features create additional barriers to incorporating the personal experiences, goals and values of individual patients into the ICU care plan.

Providing person-centered healthcare in an ICU environment requires understanding the nature of these barriers and then devising and implementing specific strategies to help overcome or ameliorate these limitations.

33.2 Barriers to Person-Centered Care in the ICU

33.2.1 Patient Loss of Autonomy and Agency

The vast majority of critically ill patients cannot participate directly and fully in medical decision-making. Communication, cognition, and capacity are all compromised by the severity of illness itself as well as the effect of interventions aimed at providing support, analgesia, and anxiolysis [7]. Even patients who remain responsive and interactive in the ICU generally have compromised autonomy [8] Critical illness interferes directly with a person's agency, their ability to accomplish self-identified goals. While a primary goal of medical care is to restore agency to those who have lost it [9], doing so in the context of severe illness generally proves to be impossible. This loss of autonomy and agency renders patients incapable of expressing personal choice and demanding the respect due to persons.

33.2.2 Difficulty Knowing Patients as Persons

Critically ill patients generally present acutely, in need of urgent and emergent medical interventions, and are unable to fully participate in medical decision-making. Those who practice intensive care medicine rarely have had the opportunity to know patients as persons prior to their arrival to the ICU. Direct attempts to learn from and about the patient as person are severely hampered by patients' inability to communicate. The impact of the loss of the ability of critically ill patients to participate directly in their care is compounded by the nature of the decisions that need to be made in the ICU, decisions that often literally relate to life and death. Questions regarding what constitutes an acceptable quality of life and whether the burdens of interventions are worth the potential benefits permeate the ICU. Properly answering such questions requires a deep understanding of the individual patient.

33.2.3 Provider Burnout

Work in the ICU setting, characterized by unpredictability and high levels of uncertainty, can be especially stressful even relative to other high stress medical specialties [10]. Given the high mortality associated with ICUs, clinicians practicing in this environment are exposed constantly to emotionally-laden situations. At times, death is viewed as a failure and at other times prolonging death induces moral distress. In either circumstance, ICU clinicians are subject to constant doubts regarding the value of their work, potentially leading to feeling of limited worth. Providing care in an ICU is both physically and emotionally challenging. Not surprisingly then, working in an ICU is associated with high rates of burnout, a syndrome characterized by not only exhaustion and a reduced sense of personal accomplishment, but also by depersonalization. Depersonalization, in this context, represents a distant and indifferent attitude toward caring for patients. Depersonalization in clinicians may lead to callous behavior and the inability to relate to patients as persons. This further dehumanizes ICU patients, a cycle that leads to both poor self-care for clinicians and poor medical care for patients. The ICU, then, represents an environment in medicine where the personhood of both the patient and the clinician are likely to be compromised. Such a situation undermines the ideals of PCM, which calls for the engagement of both patients and clinicians as persons.

33.2.4 Acuity and Time Constraints

Time for thoughtful consideration tends to be a luxury in the ICU, particularly early in a patient's course. Patients generally arrive to an ICU acutely ill, with multiple diagnostic and therapeutic interventions that need to take place in relatively short order. Given the high risk of death in many ICU patients, a strong inclination toward action permeates the ICU, where uncertainty often elicits preparations and treatments for the "worst case scenario." As in an emergency department, engagement with patients and/or surrogate decision makers may be brief and cursory, limited to a quick exchange of limited information and request for assent, rather than fully informed consent, for interventions.

33.2.5 Complexity of ICU Decisions

The results of clinical research provide very limited value for decisions made in the ICU, where clinicians must rely on pathophysiologic rationale and clinical experience in arriving at the best course of action for an individual patient [11]. Adding to the complexity, clinical decisions and treatment plans must be assessed at frequent intervals, occasionally minute-by-minute in highly unstable patients. The complexity of clinical decision-making in the ICU renders the clinician's reasoning difficult to convey to patients and surrogates. In the setting of the barriers already outlined above, ICU clinicians are often left making multiple medical decisions with little direct involvement of patients or their loved ones.

33.3 Bringing Person-Centered Medicine to the Intensive Care Unit

Given the loss of agency and autonomy experienced by the vast majority of critically ill patients, intensive care providers must turn to family members and friends in order to try and understand their patients as persons. Family members feel compelled to impart some understanding of their loved one as a person, an individual who had loves, dreams and experiences prior to becoming critically ill, to the health care team. Loved ones allowed to share such knowledge about the patient-as-person tend to be more satisfied with the care provided [12]. Unfortunately, attempts to know the patient-as-person even with the well-meaning input of engaged surrogates will necessarily result in an imperfect understanding. Even close family members are often not willing or able to communicate accurate treatment preferences for their loved ones [13, 14]. The substituted judgement of another always lacks the ethical and epistemic imperative of a contemporaneous decision of a patient with full capacity.

Still, the challenge of knowing a critically ill patient as a person does not excuse the tremendous variability that exists among intensivists regarding whether and how they seek and incorporate surrogate input regarding patient goals and values into their medical decision-making [15, 16]. While there is an emphasis on research and education to encourage intensivists to improve their communication skills and to view family members as representatives of patients [17], the most crucial step in practicing a person-centered intensive care medicine is to maintain the sense that critically ill patients are persons.

The dehumanizing aspect of critical care medicine cannot be completely ameliorated, as the severity of illness and the technology employed to treat it will conspire to render patients inert, often devoid of spontaneous action, and separated from the world by a wall of equipment. Relatively simple interventions and practices, however, can serve to remind caregivers that their patients are persons. Our ICU encourages family members to display photographs of the patient at the bedside and has a large wall poster for the patient or family to complete telling the staff what name they like to be called, something about their family, outside interests and things that are most important to them. Rounding in the patient's room (rather than the hallway), including family members in rounds, and referring to the patient by name and other unique identifiers (for example, "William, a gentleman recently retired from his job as a high school teacher" rather than "A 64 year-old male with COPD") all serve to remind clinicians that the patient had a life and specific goals prior to becoming seriously ill. ICU clinicians should prioritize meeting with families of patients, early and often. At family conferences, clinicians should spend more time listening than talking, soliciting information regarding the patient's life, not only to improve family satisfaction, but to allow for person-centered decision-making [18].

To have any chance of recognizing their patients as persons, caregivers must maintain their own personhood. One of the key insights of PCM is the recognition of the importance of the clinician-as-person. Intensive care providers who do not care for themselves cannot hope to deliver optimal medical care. And yet burnout rates, with subsequent depersonalization, are extremely high in among nurses and physicians providing ICU care. Of late, professional organizations in North America have gone beyond recognizing this increased risk of burnout to calling for interventions to decrease the frequency [10]. Strategies to prevent or ameliorate burnout and depersonalization may be targeted on the ICU environment or focused on helping individuals deal with that environment. In the former category, limiting duty hours, structuring shifts in a manner that facilitates outside activities, team debriefs and team-building activities may all help improve the workplace. Our institution engages our palliative care service for medical team debriefs and education and provides moral distress counseling in real-time through our ethics consultation service. For individual practitioners, wellness programs can offer access to stress reduction, relaxation techniques, and mindfulness training. Together, individuals and institutions should work to change the culture of ICU care to explicitly value work-life balance. Caring for the well-being of ICU clinicians supports a structure that can provide care to patients as individual persons.

33.3.1 Person-Centered Decision-Making in the ICU

Person-centered care in intensive care, which begins with the decision regarding whether a patient should be admitted to the ICU, generally embraces a default position that can be understood as the Reasonable Person Supposition. The Reasonable Person Supposition asserts that intensive care is appropriate and indicated so long as it offers a meaningful chance of returning an individual to an acceptable quality of life. This general supposition is subject to rebuttal when the burdens of such care are too high, either for the system or the individual, to bear.

Given the barriers related to loss of autonomy and the typically high acuity and time pressure related to initial decisions, this initial starting point will rely upon a clinician's understanding of what an average, reasonable patient would likely want. But within the general supposition several elements eventually require understanding the patient-as-person. What constitutes a "meaningful chance" of some outcome varies from individual to individual, particularly as the burdens of treatment are considered. For instance, individuals with advanced cancer at a cancer research facility, who have already agreed to highly burdensome therapies with little chance for cure, may also agree to intensive care for complications. Another patient with the same malignancy may opt for hospice treatment, which precludes intensive care. In the former case, even a small statistical chance for survival is deemed meaningful, while in the latter case it is not. Similarly, what constitutes an "acceptable quality of life" differs among individuals. Those whose self-assessed quality of life is marginal prior to the development of serious illness may not want intensive care under any circumstance, as they recognize that their quality of life will be even worse than that baseline if they survive to hospital discharge. Individuals may have strong views of the kind of life that falls below an acceptable minimum for them, often related to dependency and permanent, severe neurologic impairment. Intensive care is not appropriate if the result of such care leaves a person in a state she clearly finds worse than death.

So while illness severity will hamper efforts, an ICU clinician must reliably and efficiently seek ways to understand individual patients as persons. As patients will generally have lost their ability to directly make themselves known, information regarding the person's previous experience, goals and values must be actively sought. This effort must be prioritized along with the diagnostic and therapeutic interventions being considered and implemented, not dismissed as a secondary consideration. When appropriate, clinicians will need to resist the urge to the therapeutic imperative to act in order to find time to appreciate who the patient was prior to the illness. Deliberate clinical inertia, a pause in clinical momentum, allows the opportunity to seek out knowledge of the patient as a person [19].

Prior discussion and documentation of patient goals and values may be helpful. Advance care planning will have best been undertaken with a primary care physician who already knows the patient as a person and can share in the decision-making. Conditions under which the need for intensive care would most likely be anticipated (e.g. respiratory failure in a patient with advanced lung disease) should be discussed specifically. For some diseases with predictable courses, advance care planning can be facilitated with the use of disease-specific tools [20]. Instructive directives, such as ‘living wills’ or Physician Orders for Life Sustaining Treatment (POLST) forms, can provide some insight into a patient’s previous preferences and goals of care. But alone, these documents often do not provide enough information to determine the best treatment plan for a particular individual [21].

Even when advance care planning has taken place, and certainly when it has not, intensive care physicians will usually need to rely on input from family and friends in attempt to elucidate the goals, values and preferences of individual patients. In addition, intensivists will need to make sure that surrogates for the patient understand the salient medical information, including physician assessments of prognosis, necessary for decision-making. Several practices and strategies can help facilitate this exchange of information. Including family members on rounds helps ensure their understanding and gives them a chance to ask questions, improving communication, though not necessarily satisfaction with care [22]. Scheduling “family meetings” early in the ICU stay and at regular intervals after that allows intensive care providers to solicit input from loved ones and learn about the patient as a person. All those who wish to participate in such meetings should be welcomed, as many times the people who know a patient best are not blood relatives. Even if no formal advance care planning has occurred, primary care providers who have known the patient prior to the development of serious illness are often very helpful in establishing goals and limits of care. In institutions with a dedicated palliative care service, early involvement of that service can improve outcomes as well as patient/family satisfaction [23]. All of these approaches share an aim to provide ICU clinicians with the knowledge of a particular patient that would allow for the plan of care to be guided by the experience, values, and goals of that person. Such knowledge will be imperfect, but that is not an excuse to not seek it out or to fail to act upon it.

Decision-making for the critically ill should focus on trying to elicit and understand the individual patient’s broad goals and values regarding medical care, rather than on specific medical interventions. Offering patients and/or families a list of potential interventions, such as mechanical ventilation, cardiopulmonary resuscitation (CPR) or dialysis, and asking whether or not to employ them does not constitute person-centered decision-making. Rather, a clinician who understands the experiences, goals and values of a patient can characterize interventions as likely or unlikely to advance that patient’s goals. PCM in the ICU puts a large burden on intensivists to actively solicit the information, generally from third parties, necessary to understand the relevant experiences and values of a patient they have never met previously and then to place medical information, including prognosis regarding not only survival but likely quality of life if the patient survives, in the proper context of the individual patient. Such an approach is time-consuming and often emotionally draining, but ultimately respects the personhood of patient and provider alike.

33.4 Conclusions

Providers of intensive care medicine face many barriers to providing person-centered care to critically ill patients. Clinicians working in the ICU must make special efforts to ensure that their patients are still seen as persons and to ameliorate the challenges of the work environment that might lead to clinician depersonalization. At a distinct disadvantage compared to their colleagues in primary care, intensivists must take an active role in soliciting information, generally from available friends and family, in order to understand the personal experiences, goals and values of the patient relevant to the decisions-at-hand. In caring for patients who are no longer autonomous, intensivists must take responsibility for contextualizing medical information for surrogate decision makers and for making difficult decisions regarding the provision and continuation of intensive care with the person who is their patient in mind. Perhaps nowhere else in healthcare is it more difficult to practice person-centered medicine. The difficulty of the endeavor, however, does not obviate the responsibility of intensive care clinicians to pursue it.

Acknowledgements and Disclosures The author does not report conflicts of interest in the preparation of this manuscript.

References

1. Miller RR, Ely EW. Delirium and cognitive dysfunction in the intensive care unit. Semin Respir Crit Care Med. 2006;27(3):210–20.
2. Embriaco N, Papazian L, Kentish-Barnes N, Pochard F, Azoulay E. Burnout syndrome among critical care healthcare workers. Curr Opin Crit Care. 2007;13(5):482–8.
3. Guntupalli KK, Fromm REJ. Burnout in the internist-intensivist. Intensive Care Med. 1996;22(7):625–30.
4. Tonelli MR. Person-centered care in intensive care medicine. Intensive Crit Care Nurs. 2013;3(1):23–6.
5. Curtis JR, Tonelli MR. Shared decision-making in the ICU: value, challenges, and limitations. Am J Respir Crit Care Med. 2011;183(7):840–1.
6. Vincent J. Evidence-based medicine in the ICU: Important advances and limitations. Chest. 2004;126(2):592–600.
7. Cassell E, Leon A, Kaufman S. Preliminary evidence of impaired thinking in sick patients. Ann Intern Med. 2001;134(12):1120–3.
8. Tonelli MR, Misak CJ. Compromised autonomy and the seriously ill patient. Chest. 2010;137(4):926–31.
9. Sullivan MD. The patient as agent of health and Health Care. Oxford: Oxford University Press; 2016.
10. Moss M, Good VS, Gozal D, Kleinpell R, Sessler CN. An official critical care societies collaborative statement: burnout syndrome in critical care health care professionals: a call for action. Am J Crit Care. 2016;25(4):368–76.
11. Tonelli MR, Curtis JR, Guntupalli KK, Rubenfeld GD, Arroliga AC, Brochard L, Douglas IS, Gutterman DD, Hall JR, Kavanagh BP, Mancebo J, Misak CJ, Simpson SQ, Slutsky AS, Suffredini AF, Thompson BT, Ware LB, Wheeler AP, Levy MM. An official multi-society

statement: The role of clinical research results in the practice of critical care medicine. Am J Respir Crit Care Med. 2012;185(10):1117–24.

12. McDonagh JR, Elliott TB, Engelberg RA, Treece PD, Shannon SE, Rubenfeld GD, Patrick DL, Curtis JR. Family satisfaction with family conferences about end-of-life care in the intensive care unit: increased proportion of family speech is associated with increased satisfaction. Crit Care Med. 2004;32(7):1484–8.
13. Suhl J, Simons P, Reedy T, Garrick T. Myth of substituted judgment: Surrogate decision making regarding life support is unreliable. Arch Int Med. 1994;154:90–6.
14. Torke AM, Alexander GC, Lantos J. Substituted judgment: the limitations of autonomy in surrogate decision making. J Gen Intern Med. 2008;23(9):1514–7.
15. Boumendil A, Angus DC, Guitonneau AL, Menn AM, Ginsburg C, Takun K, Davido A, Masmoudi R, Doumenc B, Pateron D, Garrouste-Orgeas M, Somme D, Simon T, Aegerter P, Guidet B. Variability of intensive care admission decisions for the very elderly. PLoS One. 2012;7(4):e34387.
16. Curtis JR, Vincent JL. Ethics and end-of-life care for adults in the intensive care unit. Lancet. 2010;376(9749):1347–53.
17. Curtis JR. Communicating about end-of-life care with patients and families in the intensive care unit. Crit Care Clin. 2004;20(3):363–80, viii
18. Hurd CJ, Curtis JR. The intensive care unit family conference. Teaching a critical intensive care unit procedure. Ann Am Thorac Soc. 2015;12(4):469–71.
19. Keijzers G, Fatovich DM, Egerton-Warburton D, Cullen L, Scott IA, Glasziou P, Croskerry P. Deliberate clinical inertia: Using meta-cognition to improve decision-making. Emerg Med Australas. 2018;30(4):585–90.
20. Benditt J, Smith T, Tonelli M. Empowering the individual with ALS at the end-of-life: disease-specific advance care planning. Muscle Nerve. 2001;24(12):1706–9.
21. Tonelli MR. Pulling the plug on living wills: A critical analysis of advance directives. Chest. 1996;110:816–22.
22. Jacobowski NL, Girard TD, Mulder JA, Ely EW. Communication in critical care: family rounds in the intensive care unit. Am J Crit Care. 2012;19(5):421–30.
23. Schaefer KG, Block SD. Physician communication with families in the ICU: evidence-based strategies for improvement. Curr Opin Crit Care. 2009;15(6):569–77.

Chapter 34
Person-Centered Oncology

Rajiv Agarwal, Zoran Rakusic, Ana Misir Krpan, Trinh Le Huy, and Andrew S. Epstein

34.1 Introduction

Person-centered care in oncology is comprehensive care that addresses all aspects of health and personhood for people living with and affected by cancer. Herein in this chapter, we will discuss modern-day components for successful and high-quality person-centered care in oncology. Such topics are categorical, in that they span across all stages of disease, all types of cancers, and all variations in clinical presentation. Given the heterogeneity of populations affected by cancer, it is important to note that person-centered care in oncology can and should be applied globally and universally. High-quality person-centered care should acknowledge age, gender, racial, cultural, religious, socioeconomic, and community differences, along with many others; yet it should be fixed in providing an overall umbrella of care that is tailored and focused on the individual as a human [1]. As the field of oncology continues to evolve, with improved understanding of cancer biology leading to rapid changes in drug development, the philosophy of person-centered cancer care

---

R. Agarwal
Vanderbilt-Ingram Cancer Center, Nashville, TN, USA
e-mail: rajiv.agarwal@vumc.org

Z. Rakusic · A. M. Krpan
University of Zagreb, School of Medicine, Zagreb, Croatia
e-mail: zrakusic@kbc-zagreb.hr

T. Le Huy
Department of Oncology, Hanoi Medical University, Hanoi, Vietnam
e-mail: trinhlehuy@hmu.edu.vn

A. S. Epstein (✉)
Memorial Sloan Kettering Cancer Center, New York, NY, USA
e-mail: epsteina@mskcc.org

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_34

has simultaneously developed. With the emergence of new cancer therapies, there is a greater recognition for the value of focusing on the person—and not just the patient—facing cancer.

34.2 A Brief Word on Our Science

It would be remiss to not at least acknowledge the radical changes in precision oncology and what this means for oncologists and patients, as it relates to person-centered care. For oncologists across the world, treatment of many types of cancers is now intimately tied to the underlying mutational profile of a person's cancer [2–6]. In the most rudimentary sense, one patient with metastatic non-small cell lung cancer is not the same as another patient with metastatic non-small cell lung cancer, and therefore, first-line treatment for metastatic non-small cell lung cancer is not the same for each patient. The same logic can be applied for nearly every cancer type. Even though there may be variation in the degree to which tumor mutations can be acted upon, the awareness of the potential impact from next-generation sequencing results has changed how oncologists and patients discuss treatment planning in clinic. Similarly, advancements in immune-oncology and improved methods to identify which patients, agnostic of tumor type, could respond to immune checkpoint inhibitors adds another dynamic in personalizing care [7].

Overall, these twenty-first century breakthroughs along with ongoing laboratory cancer research cannot be isolated from the larger context of person-centered oncology, as oncologists cannot simply treat a specific cancer type as a collective disease entity. To consider a cancer diagnosis without testing or even thinking of the mutational makeup of each person is outdated. Oncologists instead must consider the cancer genomics of each person when formulating cancer treatment recommendations. Each patient must be approached as a unique person, with unique genetics and potentially unique biological drivers behind their cancer development, mechanisms of resistance, and progression. Each person's mutational fingerprint contributes to how we apply clinical judgment and how we individualize treatment. In effect, our current science and practice of oncology demonstrates that mutations matter, even in person-centered care.

34.3 Beyond Biology and Overall Survival

Typically, cancer treatments are approved and subsequently offered to patients if they have shown in randomized clinical trials that they can improve survival outcomes. Survival or prolongation of life has always been, and will continue to be, a metric by which oncologists judge if a new cancer treatment is non-inferior or superior to existing standards of care. However, it is far too simple to formulate a patient's cancer treatment based on such outcomes alone. Even after a patient's biological makeup is incorporated into personalized treatment planning, person-centered care in oncology encompasses much more [8–10]. The goal is not simply to recommend treatments that can extend life, but to do so in a manner that preserves what is important to the patient as a person. This signifies a comprehensive approach that acknowledges and places value on the many facets of each person's life—including the physical, spiritual, religious, cultural, emotional, psychological, role-functioning, economic, familial, and social domains of being human.

A musician or a painter may not want to receive oxaliplatin for their colorectal cancer due to the potential for peripheral neuropathy. An immigrant may want to return to their country of origin to be closer to family upon receiving a cancer diagnosis, even if there may be limitations in what drugs can be procured and administered. A person may decide that receiving a cancer drug to extend their quantity of life is not worth the potential side effects and possible negative impact on their quality of life. Cases such as these indicate that oncologists have to look beyond cancer biology and beyond survival outcomes, and preferably, have to focus conversations with patients on who they are as people and what matters to them.

With this in mind, there have been greater efforts to capture the patient's experience and symptoms while receiving cancer treatment. Measuring and eliciting patient reported outcomes (PROs) are important when patients are treated with both standard of care and investigational drugs, as it gives patients the opportunity to periodically report how they are feeling at home and in between treatment [11]. Moreover, active engagement in symptom monitoring has been shown to improve health-related quality of life, with patients having fewer emergency-room visits and also remaining on chemotherapy for longer periods of time [12, 13]. In examining new combinations of drugs, more phase III studies are emphasizing the importance of PROs in addition to survival outcomes. For example, the BEACON study recently showed that in patients with metastatic BRAF mutated colorectal adenocarcinoma who have progressed on one or more lines of systemic treatment, time to definitive deterioration in quality of life was significantly delayed when patients received encorafenib with cetuximab with or without binimetinib, when compared to the current standard of care [14, 15]. Likewise, in patients with unresectable hepatocellular carcinoma, there is promising data from the IMbrave150 study to suggest that atezolizumab with bevacizumab not only improves survival outcomes compared to sorafenib in the first-line setting, but also improves maintenance of patient-reported quality of life and reduces clinically meaningful deterioration [16]. Understanding what patients experience and how patients feel during cancer treatment, regardless of whether such treatment is approved or still under investigation, is a key component of person-centered cancer care.

Along with PROs, recognition and advocacy for value-based care in oncology is rising [17]. The pace of drug discovery has undoubtedly led to improvements in survival and patient outcomes, resulting in tangible benefits for patients. But we define the value of any product or service as a dynamic relationship between benefit and cost, and oncologists must consider the value of each cancer treatment for each person they intend to treat. From chimeric antigen receptor T-cells (CAR T-cells) to immune checkpoint inhibition to targeted molecular therapies, the costs of such agents can be a limiting factor for patients who may not be able to afford modern-day cancer treatment. Furthermore, financial distress may impair overall well-being, quality of care, and treatment adherence [18–21].

As newer drugs enter the market, financial toxicity and long-term financial sequelae of cancer treatment cannot be overlooked. Person-centered oncologic care should acknowledge this growing challenge in our field, with emphasis on how it pertains to each person receiving cancer treatment and how cost of treatment may impact a person's future life. Oncologists and patients should both feel comfortable in having informed and candid discussions about the value of cancer drugs, and should know where to find accurate information on drug pricing and available resources.

34.4 Person-Centered Communication and Patient Participation

At the core of practicing person-centered care in oncology lies effective communication [22, 23]. For high-quality care that centers on the personhood of patients, oncologists are tasked with educating patients about their cancer diagnoses and treatments, while also attending to the non-biomedical needs of patients as human beings coping and living with cancer. The clinical encounter is key for not only conveying factual information, but also for eliciting personal values and preferences, in order to preserve and respect what matters for patients as individuals. Communication strategies that promote patient inclusion are essential for person-centered care and tailored decision-making, ultimately helping to establish trust and leading to stronger therapeutic alliances [24–26]. Dedicated attention to patient involvement can remind patients of their fundamental autonomy as people in the context of living with serious illness, and enable patients to have an active role, to the extent that they want such a role, in the management of their cancer [27].

Communication in oncology can have significant impact on patient perceptions of care and health-related quality of life. Among breast cancer survivors at 2, 5, and 10 years post-diagnosis, perceived initial involvement in decision-making about cancer treatment and follow-up care was associated with improved quality of life scores [28]. When patients perceive that breakdowns in care have occurred, most report that the underlying problem is communication. In a qualitative analysis of 78 patients with early stage breast or gastrointestinal cancers, 47% reported a communication problem alone, 28% reported a problem in medical care such as delay in treatment, and 24% reported that there were problems in both communication and medical care such that poor delivery of information made delays worse. Specifically, for those patients who reported communication breakdowns, they reported having feelings of being uninformed regarding treatment options, receiving incomplete or inaccurate information, and feeling not cared for or not heard. When a communication breakdown was felt or identified in the clinical encounter, patients reported negative impact on their emotional and psychological wellbeing, with 53% of patients viewing the relationship with their oncologist now damaged, 39% reporting disruptions to their life activities, and 58% reporting relationship consequences with family members due to distress [29]. In fact, patients who perceive that they have received complete information about their cancer care, inclusive of the risks and benefits of cancer treatment, also report that they have received person-centered care [30].

Early evidence on the importance of patient involvement in cancer-related decisions and communication largely stem from the experiences of women living with and being treated for breast cancer. One study that examined factors contributing to patient involvement in treatment planning for Stage I or II breast cancer showed that patients were more likely to participate if they were simply invited and encouraged to do so by their treating oncologist [25]. In a qualitative analysis of eleven women who were interviewed with early-stage breast cancer, positive communication experiences were characterized by themes of patient vulnerability, physician response to such vulnerability by focusing on information sharing and relationship-building, patient participation and ownership in their care to create an experience of control, and physicians providing both hope and compassion to enable patients to master their experience of illness and to learn how to live with cancer [31]. Acknowledgement of the patient's voice, inviting input, and placing value on the human experience in oncology are paramount for developing meaningful relationships and helping patients feel that they are being cared for beyond their tumor biology.

34.5 Highlighting the Patient Voice and Personal Values

Ongoing research efforts in the last decade have focused on how to improve person-centered care and communication. Prior data have mainly utilized patient reported outcomes and survey responses, albeit there remains concern that this may be insufficient to identify areas for improvement without accounting for the patient narrative and conducting a qualitative analysis of the patient experience [32–34]. In a study population of patients with non-small cell lung cancer in the Netherlands, patient questionnaires revealed that improvement was needed within the domains of emotional and psychosocial support, physical support, and supply of information. This research group concluded that person-centered indicators must be based on guideline recommendations, but should also incorporate patient opinion for developing a comprehensive approach [33]. For patients with newly diagnosed breast and lung cancer in the UK, those with lung cancer reported receiving less information about support services pertaining to psychological or emotional support compared to those with breast cancer, and also indicated less receipt of information about complementary therapies or support groups [32].

One effective person-centered approach to reduce suffering and address the emotional, spiritual, and psychosocial needs of people with advanced cancer is

Meaning-Centered Psychotherapy (MCP). MCP, as developed by Breitbart et al., is a weekly psychotherapy program which utilizes didactic teaching, hypothetical exercises, and other psychotherapeutic techniques to allow patients to focus on the themes of one's meaning in the context of one's whole life, asking patients to reflect on their legacy, relationships, and other sources of purpose in life [35, 36]. Initially MCP was tested with group interventions (Meaning-Centered Group Psychotherapy, MCGP) in adult patients diagnosed with stage III or IV solid tumor cancers or non-Hodgkin's lymphoma; however due to logistical difficulties with scheduling and patient death, study attrition remained high. Nonetheless, MCGP resulted in improved spiritual well-being and sense of meaning when compared to supportive group psychotherapy, in which the latter primarily encouraged patients to share their concerns and experiences related to their cancer diagnosis and treatment [36]. In order to adapt MCGP for the individual, a randomized study compared individual MCP (IMCP) to therapeutic massage in patients diagnosed with advanced solid tumors or non-Hodgkin's lymphoma. Participants who received IMCP had greater short-term improvement after treatment in primary outcomes of spiritual well-being, sense of meaning and faith, and quality of life; and greater improvement in secondary outcomes of physical symptom burden and physical symptom-related distress [35]. A follow-up study has shown that IMCP compared to usual care can help treat psychological, existential, and spiritual distress for patients with advanced cancer [37].

Other interventions, such as the VOICE study or Dana Farber's Serious Illness Care Program, dually focus on communication training for oncologists with pre-specified topics, while encouraging patients to express their goals and values [38–40]. Combined intervention strategies that target both oncologists and patients offers hope to maximize person-centered care and can enrich clinic conversations so that the patient's voice is heard. That said, documenting and finding a person's values in various electronic health records can be challenging, and remains non-standardized [41, 42]. More work and tools are needed to effectively summarize who the person is the medical record, and to emphasize a person's narrative as it relates to his or her medical care.

34.6 Primary Palliative Care and Person-Centered Advance Care Planning

For all patients who have cancer, advance care planning is an essential component for person-centered care. Advance care planning (ACP) is the process by which to elicit and document patient's values, goals, and preferences to guide decisions for their future care, including their end-of-life care. While this chapter will not address the principles of person-centered palliative or supportive care (see Palliative Care Chapter), it is important to note how interventions that seamlessly incorporate palliative care elements in routine cancer care embody the spirit of person-centeredness. As there is no gold standard for ACP in oncology, one person-centered approach is to provide patients with an informational video on their end-of-life care options while also conducting interviews that empower patients to reflect on and communicate their values. This process has been proven to be acceptable by patients in clinic, although may result in transient increases in distress [43–45]. Another method for optimizing person-centered ACP aims to integrate and normalize ACP as part of standard outpatient cancer care. Memorial Sloan Kettering's 1–2–3 primary palliative care program offers a stepwise mechanism led by oncology nurses for patients to report symptoms, provide their information and decision-making preferences, and freely articulate their personal values and understanding of their illness. Summaries of nurse-led discussions are then reviewed periodically, to boost the iterative nature of ACP. In a preliminary study, patients reported that engaging in values discussions with their nurses and verifying their personal values summaries, while actively receiving cancer treatment, was feasible and useful [46, 47].

34.7 Person-Centered Survivorship

In addition to involving patients in treatment decision-making, practices and strategies that are person-centered should focus on the sequelae of cancer treatment and long-term impact on patients' social, physical, psychological, and emotional well-being. For example, in breast cancer survivors who completed treatment for their cancer, one study indicated that while patients felt satisfied with the level of detail regarding their treatment information, they reported significantly less satisfaction about survivorship information, such as the long-term side effects of treatment, follow-up care, risk of recurrence, and how to communicate with family members. Patients were more satisfied with the information provided if they perceived that their physician's communication style reflected patient-centeredness and an acknowledgment of who they are as whole people [48]. In a cohort of leukemia, bladder, and colorectal cancer survivors, assessment of the quality of cancer-related follow-up care revealed that 59% of survivors reported less than optimal quality regarding health promotion and 77% reported poor quality in their physician's knowledge of them as a whole person [49]. Moreover, survivorship conversations that are less symptom specific and are more focused on what it means to be a cancer survivor within the context of one's life have been shown to be associated with greater perceptions of person-centeredness [50]. In order to promote self-efficacy and self-functioning in society, personal coaching, survivorship care planning, and whole-person interventions have been proven to be effective strategies for continuing person-centered care for patients in remission or cured from their cancer [51–53].

34.8 Cancer Care in Croatia and the European Union (EU)

While the above themes are not unique to a specific geographic area, it is worth highlighting some international differences in clinical practice and care delivery, which may influence person-centered care in oncology.

In the EU, availability and access to cancer drugs remains a challenge. Approval of new anti-cancer drugs in the EU differs from that in the U.S. For example, the FDA granted bevacizumab an accelerated approval in 2009 as monotherapy for patients with recurrent glioblastoma. The approval was based on two single arm phase II trials, AVF3708g and NCI 06-C-0064E. In contrast, the European Medicines Agency (EMA) postponed registration of the drug. Two additional clinical studies, RTOG0825 and AVAglio, were conducted in the first line setting, but neither showed a statistically significant prolongation of overall survival; as such, the drug was not approved within the EU for newly diagnosed glioblastoma. The EORTC 26101 study, which investigated the combination of bevacizumab and lomustine in recurrent glioblastoma, led to full approval in the U.S. because it reduced the risk of disease progression or death by 48%. However, the study did not meet its primary endpoint, prolongation of overall survival, and thus per EU approval standards, it was deemed a negative study [54].

Within the EU itself, there are also major differences in the availability of cancer drugs, largely due to delays from approval to access, delays in reimbursement, drug pricing, and drug shortages. This is especially relevant for Eastern and Southeastern European countries. Time to drug access and delay in reimbursement ranges from 0 days in Switzerland to 1458 days in Bosnia and Herzegovina [55]. Although most patients live in countries with self-proclaimed universal healthcare, it is nonetheless challenging to explain to patients and their families why such disparities exist and how this impacts their ability to receive new and potentially more effective cancer treatments. In addition, older and cheaper cancer medicines are not always readily available, and unfortunately, this is often more pronounced for patients living in poorer countries. Common drug shortages in the EU include: 5-flourouracil, carboplatin, cisplatin, doxorubicin (liposomal), etoposide, melphalan, methotrexate, oxaliplatin, and vincristine [56]. This problem is particularly true for rare diseases, where there may be less enthusiasm for drug production by pharmaceutical companies.

Despite these issues with drug access, person-centered care for patients with cancer in the EU, such as in Croatia, is maintained with attention to the needs and values of each person and his or her family unit. For instance, few Croatian patients seek treatments in other European countries, and almost never do in the U.S. Even when financial options allow patients to be treated somewhere else in the world, patients generally choose to stay within the family, community, and environment in which they live. Therefore, the availability of a drug elsewhere, especially in the case of metastatic disease, is not as much of a priority as being treated in a person's native land with his or her relatives nearby. The family unit is incredibly important in Croatia, with family members often having an active role in treatment decisions, including those related to advance care planning and end-of-life care. Along with incorporating a patient's family for decision-making, cancer care in Croatia must bear in mind a patient's daily-life activities and values, including one's occupation and religious beliefs. For patients who are working, treatment infusions can be scheduled on weekends to maintain normal weekday routines. Lastly, religion and spirituality are deeply part of one's experience as a person living with and being treated for cancer. As over 90% of the Croatian population identify as Christian, it is common for hospitals to have a priest as a regular support member for patients [57]. The priest is available and present almost daily, especially for the sickest patients and those at the end of life. In this manner, oncologists can practice person-centered medicine for their patients, by continuing to support meaningful aspects of patients' lives—their family, their occupation, their religion—alongside providing cancer treatment [58].

34.9 Cancer Care in Vietnam and Asia

As in the U.S. and EU, oncologists in Asia dedicate their time and effort to deliver person-centered care. Using Vietnam as an example, patient-centered principles in Asia focus on eliciting patient preferences and respecting language differences, adapting to important religious and cultural values, and customizing treatment to address other medical, psychosocial, or familial needs.

Of note, there are 53 minority ethnicities in Vietnam, each with their own language. Many patients thus have to learn Vietnamese in order to communicate with their oncologists. Still, many oncologists tend to spend more time with such patients to overcome language barriers, even explaining the same issue several times to ensure they fully understand their disease and treatment options. Additionally, patients are given opportunities to provide feedback and voice symptoms and concerns at each clinic visit. Open-ended questions help patients express their individual preferences, and oncologists encourage patients to take part in determining their own treatment after being fully informed about the pros and cons of all available therapeutic options. Family members are also proactively encouraged to participate if the patient desires, by assisting in the decision-making process and sometimes by informing healthcare professionals of reactions during chemotherapy.

With this said, information disclosure between physicians and patients is not always as complete or transparent. Vietnamese physicians traditionally do not discuss all information to patients about their disease, especially for those with poorer expected prognoses. Likewise, family members often ask oncologists not to inform patients about the severity of their illness, thereby hindering oncologists in their efforts to recognize patients' desires and what really matters to them in their last days of life. This type of therapeutic privilege, in combination with some patients in Asia feeling uncomfortable expressing their private matters such as cancer-related sexual dysfunction, limits how oncologists can tailor care to meet the unique needs of each person.

In Asia, the domains of religion and culture are diverse and warrant attention. For example, it is not uncommon for a breast cancer patient who receives weekly paclitaxel and trastuzumab to desire to attend church throughout her treatment. Routine chemotherapy appointments are accordingly scheduled to allow such patients to recover as much as possible after infusion, so that they can continue to engage in religious activities. Similarly, patients often request forgoing treatment during the holiday of Tet, the Vietnamese Lunar New Year. In Vietnam, Tet is the most special occasion in the year—a time in which all companies provide employees with weeks off to allow for families to gather. Spiritually, Vietnamese people believe that bad or unexpected events (including adverse events from cancer treatment) that occur during Tet will determine their luck for the remainder of the year. Given its magnitude, it is normal for oncologists to make treatment adjustments at the time of Tet. Some patients with ovarian cancer who are initially scheduled for debulking surgery may instead receive neoadjuvant chemotherapy during Tet, so that they can enjoy their holiday at home with loved ones instead of being hospitalized.

Other medical and societal factors are also taken into consideration for Vietnamese patients starting cancer treatment. First, as Thalassemia is very common in some minority ethnic populations, patients who present with microcytic anemia are directed to Benign Hematology clinics to rule out Thalassemia before receiving chemotherapy [59]. Second, financial toxicity can impede patients from receiving the most optimal treatment available. One example is the affordability of pembrolizumab in low-income countries in Asia, despite data showing that pembrolizumab improves overall survival in patients with metastatic non-small cell lung cancer [60, 61]. Consequently, oncologists, along with patients and their families, have to spend more time finding the most suitable regimen with maximal benefit and acceptable cost. Finally, the majority of patients in Vietnam do not have a general practitioner (GP), as Vietnam's GP healthcare system is underdeveloped. In 2013, according to the Vietnam Ministry of Health, there were only 570 GPs in the entire country [62, 63]. To address this issue, the Vietnam Ministry of Health aims to cover 80% of provinces with GP clinics in 2020 [64], which will greatly facilitate care delivery. Still, the workforce of other healthcare professionals, such as social workers, psychologists, and psychiatrists remain limited. As a result, oncologists have more ownership of every aspect of a patient's health during their cancer treatment, which increases provider workload and makes it difficult to thoroughly attend to all social, psychological, and non-cancer health-related issues. Delivery of comprehensive person-centered care is thus restricted by time and lack of additional resources and personnel to assist Vietnamese oncologists in their efforts.

34.10 Practical Implications for Person-Centered Care

In day-to-day clinical practice, there is an increasing trend to treat the person who has cancer and not simply the pathology. More oncologists have incorporated person-centered care principles in their daily approach, yet this is not established as a standard of care. Our field's momentum to develop drugs and better understand our science must be equally matched with a goal to provide care that concentrates on the person within the patient. In the U.S., lack of standardization and acceptance, variability in communication training for oncologists and nurses, and time constraints in clinic represent some of the leading barriers to put person-centered medicine into practice. Although there may be a conceptual acceptance and appreciation for person-centered care among oncologists and nurses, its practical application is still limited. In Croatia and the EU, obstacles include: disparities in access to newer cancer treatments, lack of awareness of the medical staff about the need for higher levels of communication, lack of well-developed supportive care and hospice services, less than ideal patient resources for supplementary information, insufficient medical education on person-centered issues, and a free circulation of the healthcare workforce which results in a constant outflow of doctors and nurses to more-developed countries. Challenges in Vietnam and other Asian countries include: cultural acceptance of and training for transparent medical communication, especially as it relates to private subject matters or prognosis; prohibitive costs of newer drugs and suboptimal health insurance coverage; lack of an electronic health record system and shortages of ancillary support staff and general practitioners, all of which overload oncologists with multiple tasks to be performed in a single clinic visit; and an imbalanced distribution of cancer patients at national hospitals in Hanoi and Ho Chi Minh City due to mistrust in the quality of cancer care at district and provincial levels. To help reduce inconvenient patient travel, scheduling modifications of treatment regimens, and overcrowded facilities, there are now increasing efforts to build oncology-specialized centers at provincial levels in Vietnam. Overall, oncologists across the globe need innovative system-level changes, additional resources that are standardized and acceptable for all cultures and socioeconomic strata, and sustainable designs to restructure clinic and make time for the personhood of our patients.

34.11 Conclusions

Person-centered care therefore represents an underlying philosophy that guides all aspects of cancer care: from refining treatment plans on the basis of who the person is, inclusive of their unique tumor biology, to advance care planning and survivorship, and all done with communication skills that ensure that the patient's voice is heard and that the human experience is honored. Fundamental themes that guide person-centered cancer care and best clinical practices include (a) ensuring that the patient or person is the center of focus and of conversation, (b) inviting patient participation to the extent that he or she may desire, (c) tailoring care to meet the unique needs of each person, and (d) providing care with empathy [65]. To help standardize person-centered care in oncology, Cancer Care Ontario's Person-Centered Care Guideline and associated educational video has been disseminated globally, with viewers reporting improvement in their understanding of person-centered care concepts and its relevance to the care they provide. This evidence-based guideline provides 65 recommendations for person-centered care in oncology, distributed across five main domains: (1) knowing the patient as an individual, (2) essential requirements of care, (3) tailoring healthcare service for each patient, (4) continuity of care and relationships, and (5) enabling patients to actively participate [66]. Further research is needed to study implementation and acceptance of these person-centered care guidelines on a broader scale.

In summary, individualized person-centered care in oncology is truly predicated on the person who is receiving the care. It spans all medical and non-medical aspects of living with a serious illness [67]. In oncology, we must always remember to care for our patients as fellow people, who deserve a framework that concentrates on their personal values and addresses their personal needs, both within and outside of their cancer experience.

Acknowledgements and Disclosures The authors do not report conflicts of interest in preparing this manuscript.

References

1. Epner DE, Baile WF. Patient-centered care: the key to cultural competence. Ann Oncol. 2012;23(Suppl 3):33–42.
2. Dy GK, Nesline MK, Papanicolau-Sengos A, Depietro P, Levea CM, Early A, Chen H, Grandmaison A, Boland P, Ernstoff MS, Edge S, Akers S, Opyrchal M, Chatta G, Odunsi K, Pabla S, Conroy JM, Glenn ST, Defedericis HT, Burgher B, Andreas J, Giamo V, Qin M, Wang Y, Kanehira K, Lenzo FL, Frederick P, Lele S, Galluzzi L, Kuvshinoff B, Morrison C. Treatment recommendations to cancer patients in the context of FDA guidance for next generation sequencing. BMC Med Inform Decis Mak. 2019;19:14.
3. Frampton GM, Fichtenholtz A, Otto GA, Wang K, Downing SR, He J, Schnall-Levin M, White J, Sanford EM, An P, Sun J, Juhn F, Brennan K, Iwanik K, Maillet A, Buell J, White E, Zhao M, Balasubramanian S, Terzic S, Richards T, Banning V, Garcia L, Mahoney K, Zwirko Z, Donahue A, Beltran H, Mosquera JM, Rubin MA, Dogan S, Hedvat CV, Berger MF, Pusztai L, Lechner M, Boshoff C, Jarosz M, Vietz C, Parker A, Miller VA, Ross JS, Curran J, Cronin MT, Stephens PJ, Lipson D, Yelensky R. Development and validation of a clinical cancer genomic profiling test based on massively parallel DNA sequencing. Nat Biotechnol. 2013;31:1023–31.
4. Hyman DM, Solit DB, Arcila ME, Cheng DT, Sabbatini P, Baselga J, Berger MF, Ladanyi M. Precision medicine at Memorial Sloan Kettering Cancer Center: clinical next-generation sequencing enabling next-generation targeted therapy trials. Drug Discov Today. 2015;20:1422–8.
5. Meric-Bernstam F, Brusco L, Shaw K, Horombe C, Kopetz S, Davies MA, Routbort M, Piha-Paul SA, Janku F, Ueno N, Hong D, De Groot J, Ravi V, Li Y, Luthra R, Patel K, Broaddus R, Mendelsohn J, Mills GB. Feasibility of large-scale genomic testing to facilitate enrollment onto genomically matched clinical trials. J Clin Oncol. 2015a;33:2753–62.
6. Meric-Bernstam F, Johnson A, Holla V, Bailey AM, Brusco L, Chen K, Routbort M, Patel KP, Zeng J, Kopetz S, Davies MA, Piha-Paul SA, Hong DS, Eterovic AK, Tsimberidou AM, Broaddus R, Bernstam EV, Shaw KR, Mendelsohn J, Mills GB. A decision support framework for genomically informed investigational cancer therapy. J Natl Cancer Inst. 2015b;107
7. Le DT, Uram JN, Wang H, Bartlett BR, Kemberling H, Eyring AD, Skora AD, Luber BS, Azad NS, Laheru D, Biedrzycki B, Donehower RC, Zaheer A, Fisher GA, Crocenzi TS, Lee JJ, Duffy SM, Goldberg RM, De La Chapelle A, Koshiji M, Bhaijee F, Huebner T, Hruban RH, Wood LD, Cuka N, Pardoll DM, Papadopoulos N, Kinzler KW, Zhou S, Cornish TC,

Taube JM, Anders RA, Eshleman JR, Vogelstein B, Diaz LA Jr. PD-1 blockade in tumors with mismatch-repair deficiency. N Engl J Med. 2015;372:2509–20.

8. Mezzich J, Snaedal J, Van Weel C, Heath I. Toward person-centered medicine: from disease to patient to person. Mt Sinai J Med. 2010;77:304–6.
9. Price AI, Djulbegovic B, Biswas R, Chatterjee P. Evidence-based medicine meets person-centred care: a collaborative perspective on the relationship. J Eval Clin Pract. 2015;21:1047–51.
10. Richards T. Patient commentary: Consider the person alongside the pathology. BMJ. 2015;351:h4878.
11. Basch E, Barbera L, Kerrigan CL, Velikova G. Implementation of patient-reported outcomes in routine medical care. Am Soc Clin Oncol Educ Book. 2018;38:122–34.
12. Basch E, Deal AM, Dueck AC, Scher HI, Kris MG, Hudis C, Schrag D. Overall survival results of a trial assessing patient-reported outcomes for symptom monitoring during routine cancer treatment. JAMA. 2017;318:197–8.
13. Basch E, Deal AM, Kris MG, Scher HI, Hudis CA, Sabbatini P, Rogak L, Bennett AV, Dueck AC, Atkinson TM, Chou JF, Dulko D, Sit L, Barz A, Novotny P, Fruscione M, Sloan JA, Schrag D. Symptom monitoring with patient-reported outcomes during routine cancer treatment: a randomized controlled trial. J Clin Oncol. 2016;34:557–65.
14. Kopetz S, Grothey A, Cutsem EV, Yaeger R, Wasan HS, Yoshino T, Desai J, Ciardiello F, Loupakis F, Hong YS, Steeghs N, Guren TK, Arkenau H-T, Garcia-Alfonso P, Gollerkeri A, Maharry K, Christy-Bittel J, Keir CH, Pickard MD, Tabernero J. Encorafenib plus cetuximab with or without binimetinib for BRAF V600E-mutant metastatic colorectal cancer: Quality-of-life results from a randomized, three-arm, phase III study versus the choice of either irinotecan or FOLFIRI plus cetuximab (BEACON CRC). J Clin Oncol. 2020;38:8–8.
15. Kopetz S, Grothey A, Yaeger R, Van Cutsem E, Desai J, Yoshino T, Wasan H, Ciardiello F, Loupakis F, Hong YS, Steeghs N, Guren TK, Arkenau HT, Garcia-Alfonso P, Pfeiffer P, Orlov S, Lonardi S, Elez E, Kim TW, Schellens JHM, Guo C, Krishnan A, Dekervel J, Morris V, Calvo Ferrandiz A, Tarpgaard LS, Braun M, Gollerkeri A, Keir C, Maharry K, Pickard M, Christy-Bittel J, Anderson L, Sandor V, Tabernero J. Encorafenib, binimetinib, and cetuximab in BRAF V600E-mutated colorectal cancer. N Engl J Med. 2019;381:1632–43.
16. Galle PR, Finn RS, Qin S, Ikeda M, Zhu AX, Kim T-Y, Kudo M, Breder VV, Merle P, Kaseb AO, Li D, Mulla S, Verret W, Xu D-Z, Hernandez S, Liu J, Huang C, Lim HY, Cheng A-L, Ducreux M. Patient-reported outcomes (PROs) from the Phase III IMbrave150 trial of atezolizumab (atezo) + bevacizumab (bev) vs sorafenib (sor) as first-line treatment (tx) for patients (pts) with unresectable hepatocellular carcinoma (HCC). J Clin Oncol. 2020;38:476.
17. Saltz LB. The value of considering cost, and the cost of not considering value. J Clin Oncol. 2016;34:659–60.
18. De Souza JA, Yap BJ, Wroblewski K, Blinder V, Araujo FS, Hlubocky FJ, Nicholas LH, O'Connor JM, Brockstein B, Ratain MJ, Daugherty CK, Cella D. Measuring financial toxicity as a clinically relevant patient-reported outcome: The validation of the COmprehensive Score for financial Toxicity (COST). Cancer. 2017;123:476–84.
19. Green AK, Saltz LB. Can we afford that car? Confronting the effect of novel immunotherapies on future health care costs. J Clin Oncol. 2018;36:1381–2.
20. Tran G, Zafar SY. Financial toxicity and implications for cancer care in the era of molecular and immune therapies. Ann Transl Med. 2018;6:166.
21. Zafar SY. Financial toxicity of cancer care: it's time to intervene. J Natl Cancer Inst. 2016;108:djv370.
22. Mazor KM, Beard RL, Alexander GL, Arora NK, Firneno C, Gaglio B, Greene SM, Lemay CA, Robinson BE, Roblin DW, Walsh K, Street RL Jr, Gallagher TH. Patients' and family members' views on patient-centered communication during cancer care. Psychooncology. 2013a;22:2487–95.
23. Mazor KM, Gaglio B, Nekhlyudov L, Alexander GL, Stark A, Hornbrook MC, Walsh K, Boggs J, Lemay CA, Firneno C, Biggins C, Blosky MA, Arora NK. Assessing patient-centered communication in cancer care: stakeholder perspectives. J Oncol Pract. 2013b;9:e186–93.
24. Redmond K. Assessing patients' needs and preferences in the management of advanced colorectal cancer. Br J Cancer. 1998;77(Suppl 2):5–7.

25. Street RL Jr, Voigt B, Geyer C Jr, Manning T, Swanson GP. Increasing patient involvement in choosing treatment for early breast cancer. Cancer. 1995;76:2275–85.
26. Williams SW, Hanson LC, Boyd C, Green M, Goldmon M, Wright G, Corbie-Smith G. Communication, decision making, and cancer: what African Americans want physicians to know. J Palliat Med. 2008;11:1221–6.
27. Kvale K, Bondevik M. What is important for patient centred care? A qualitative study about the perceptions of patients with cancer. Scand J Caring Sci. 2008;22:582–9.
28. Andersen MR, Bowen DJ, Morea J, Stein KD, Baker F. Involvement in decision-making and breast cancer survivor quality of life. Health Psychol. 2009;28:29–37.
29. Mazor KM, Roblin DW, Greene SM, Lemay CA, Firneno CL, Calvi J, Prouty CD, Horner K, Gallagher TH. Toward patient-centered cancer care: patient perceptions of problematic events, impact, and response. J Clin Oncol. 2012;30:1784–90.
30. Van Vliet LM, De Veer AJE, Raijmakers NJH, Francke A. Is information provision about benefits and risks of treatment options associated with receiving person-centered care?: A survey among incurably Ill cancer patients. J Palliat Med. 2019;22:797–803.
31. McWilliam CL, Brown JB, Stewart M. Breast cancer patients' experiences of patient-doctor communication: a working relationship. Patient Educ Couns. 2000;39:191–204.
32. Davies E, Madden P, Coupland V, Griffin M, Richardson A. Comparing breast and lung cancer patients' experiences at a UK Cancer Centre: implications for improving care and moves towards a person centered model of clinical practice. Int J Pers Cent Med. 2011;1:177–89.
33. Ouwens M, Hermens R, Hulscher M, Vonk-Okhuijsen S, Tjan-Heijnen V, Termeer R, Marres H, Wollersheim H, Grol R. Development of indicators for patient-centred cancer care. Support Care Cancer. 2010;18:121–30.
34. Tsianakas V, Maben J, Wiseman T, Robert G, Richardson A, Madden P, Griffin M, Davies EA. Using patients' experiences to identify priorities for quality improvement in breast cancer care: patient narratives, surveys or both? BMC Health Serv Res. 2012;12:271.
35. Breitbart W, Poppito S, Rosenfeld B, Vickers AJ, Li Y, Abbey J, Olden M, Pessin H, Lichtenthal W, Sjoberg D, Cassileth BR. Pilot randomized controlled trial of individual meaning-centered psychotherapy for patients with advanced cancer. J Clin Oncol. 2012;30:1304–9.
36. Breitbart W, Rosenfeld B, Gibson C, Pessin H, Poppito S, Nelson C, Tomarken A, Timm AK, Berg A, Jacobson C, Sorger B, Abbey J, Olden M. Meaning-centered group psychotherapy for patients with advanced cancer: a pilot randomized controlled trial. Psychooncology. 2010;19:21–8.
37. Breitbart W, Pessin H, Rosenfeld B, Applebaum AJ, Lichtenthal WG, Li Y, Saracino RM, Marziliano AM, Masterson M, Tobias K, Fenn N. Individual meaning-centered psychotherapy for the treatment of psychological and existential distress: A randomized controlled trial in patients with advanced cancer. Cancer. 2018;124:3231–9.
38. Bernacki R, Paladino J, Neville BA, Hutchings M, Kavanagh J, Geerse OP, Lakin J, Sanders JJ, Miller K, Lipsitz S, Gawande AA, Block SD. Effect of the serious illness care program in outpatient oncology: a cluster randomized clinical trial. JAMA Intern Med. 2019;179:751–9.
39. Epstein RM, Duberstein PR, Fenton JJ, Fiscella K, Hoerger M, Tancredi DJ, Xing G, Gramling R, Mohile S, Franks P, Kaesberg P, Plumb S, Cipri CS, Street RL Jr, Shields CG, Back AL, Butow P, Walczak A, Tattersall M, Venuti A, Sullivan P, Robinson M, Hoh B, Lewis L, Kravitz RL. Effect of a patient-centered communication intervention on oncologist-patient communication, quality of life, and health care utilization in advanced cancer: The VOICE randomized clinical trial. JAMA Oncol. 2017b;3:92–100.
40. Paladino J, Bernacki R, Neville BA, Kavanagh J, Miranda SP, Palmor M, Lakin J, Desai M, Lamas D, Sanders JJ, Gass J, Henrich N, Lipsitz S, Fromme E, Gawande AA, Block SD. Evaluating an intervention to improve communication between oncology clinicians and patients with life-limiting cancer: a cluster randomized clinical trial of the serious illness care program. JAMA Oncol. 2019;5:801–9.

41. Coats H, Meek PM, Schilling LM, Akard TF, Doorenbos AZ. "Connection": The integration of a person-centered narrative intervention into the electronic health record: an implementation study. J Palliat Med. 2020;23(6):785–91.
42. Desai A, Kuperman G, Michael C, Agarwal R, Connor MA, Epstein A, Kramer D, Bernal C, Nelson J. Designing a “Patient Values Tab” for the Electronic Health Record (EHR): an investigation of the needs and perspectives of key stakeholders at a dedicated cancer center (FR461B). J Pain Symptom Manag. 2020;59:479.
43. Agarwal R, Shuk E, Romano D, Genoff M, Li Y, O'reilly EM, Breitbart W, Volandes AE, Epstein AS. A mixed methods analysis of patients’ advance care planning values in outpatient oncology: Person-Centered Oncologic Care and Choices (P-COCC). Support Care Cancer. 2020;28:1109–19.
44. Epstein AS, O’Reilly EM, Shuk E, Breitbart W, Shah MA, Ly M, Tayler R, Volandes AE. Development of an advance care planning paradigm for advanced cancer: person-centered oncologic care and choices (P-COCC). Psychooncology. 2017a;26:866–9.
45. Epstein AS, O’Reilly EM, Shuk E, Romano D, Li Y, Breitbart W, Volandes AE. A Randomized trial of acceptability and effects of values-based advance care planning in outpatient oncology: person-centered oncologic care and choices. J Pain Symptom Manag. 2018;56:169–177.e1.
46. Desai AV, Klimek VM, Chow K, Epstein AS, Bernal C, Anderson K, Okpako M, Rawlins-Duell R, Kramer D, Romano D, Goldberg JI, Nelson JE. 1-2-3 project: a quality improvement initiative to normalize and systematize palliative care for all patients with cancer in the outpatient clinic setting. J Oncol Pract. 2018;14:e775–85.
47. Epstein AS, Desai AV, Bernal C, Romano D, Wan PJ, Okpako M, Anderson K, Chow K, Kramer D, Calderon C, Klimek VV, Rawlins-Duell R, Reidy DL, Goldberg JI, Cruz E, Nelson JE. Giving voice to patient values throughout cancer: a novel nurse-led intervention. J Pain Symptom Manag. 2019;58:72–79.e2.
48. Mallinger JB, Griggs JJ, Shields CG. Patient-centered care and breast cancer survivors’ satisfaction with information. Patient Educ Couns. 2005;57:342–9.
49. Arora NK, Reeve BB, Hays RD, Clauser SB, Oakley-Girvan I. Assessment of quality of cancer-related follow-up care from the cancer survivor's perspective. J Clin Oncol. 2011;29:1280–9.
50. Clayton MF, Dudley WN. Patient-centered communication during oncology follow-up visits for breast cancer survivors: content and temporal structure. Oncol Nurs Forum. 2009;36:E68–79.
51. Kvale EA, Huang CS, Meneses KM, Demark-Wahnefried W, Bae S, Azuero CB, Rocque GB, Bevis KS, Ritchie CS. Patient-centered support in the survivorship care transition: outcomes from the patient-owned survivorship care plan intervention. Cancer. 2016;122:3232–42.
52. Loonen JJ, Blijlevens NM, Prins J, Dona DJ, Den Hartogh J, Senden T, Van Dulmen-Den Broeder E, Van Der Velden K, Hermens RP. Cancer survivorship care: person centered care in a multidisciplinary shared care model. Int J Integr Care. 2018;18:4.
53. Shippee ND, Shippee TP, Mobley PD, Fernstrom KM, Britt HR. Effect of a whole-person model of care on patient experience in patients with complex chronic illness in late life. Am J Hosp Palliat Care. 2018;35:104–9.
54. Wick W, Gorlia T, Bendszus M, Taphoorn M, Sahm F, Harting I, Brandes AA, Taal W, Domont J, Idbaih A, Campone M, Clement PM, Stupp R, Fabbro M, Le Rhun E, Dubois F, Weller M, Von Deimling A, Golfinopoulos V, Bromberg JC, Platten M, Klein M, Van Den Bent MJ. Lomustine and bevacizumab in progressive glioblastoma. N Engl J Med. 2017;377:1954–63.
55. Wilking N, Bucsics A, Kandolf Sekulovic L, Kobelt G, Laslop A, Makaroff L, Roediger A, Zielinski C. Achieving equal and timely access to innovative anticancer drugs in the European Union (EU): summary of a multidisciplinary CECOG-driven roundtable discussion with a focus on Eastern and South-Eastern EU countries. ESMO Open. 2019;4:e000550.
56. A Report By The Economist Intelligence Unit 2017. Cancer medicines shortages in Europe, Policy recommendations to prevent and manage shortages. The Economist Intelligence Unit (EIU).

57. Croatian Bureau of Statistics. 2013 Census of Population, Households and Dwellings 2011, Population by Citizenship, Ethnicity, Religion and Mother Tongue, Statistical Reports. ISSN 1333-1876. Zagreb, Croatia: Croatian Bureau of Statistics.
58. Rakusic Z, Krpan A, Bišof V, Samardjic K. Croatian perspectives for person centered care in oncology. Int J Pers Cent Med. 2014;4:19–22.
59. Nguyen HN. AB035. Thalassemia in Vietnam. Ann Transl Med. 2015;36:AB035.
60. Gandhi L, Rodriguez-Abreu D, Gadgeel S, Esteban E, Felip E, De Angelis F, Domine M, Clingan P, Hochmair MJ, Powell SF, Cheng SY, Bischoff HG, Peled N, Grossi F, Jennens RR, Reck M, Hui R, Garon EB, Boyer M, Rubio-Viqueira B, Novello S, Kurata T, Gray JE, Vida J, Wei Z, Yang J, Raftopoulos H, Pietanza MC, Garassino MC. Pembrolizumab plus chemotherapy in metastatic non-small-cell lung cancer. N Engl J Med. 2018;378:2078–92.
61. Paz-Ares L, Luft A, Vicente D, Tafreshi A, Gumus M, Mazieres J, Hermes B, Cay Senler F, Csoszi T, Fulop A, Rodriguez-Cid J, Wilson J, Sugawara S, Kato T, Lee KH, Cheng Y, Novello S, Halmos B, Li X, Lubiniecki GM, Piperdi B, Kowalski DM. Pembrolizumab plus chemotherapy for squamous non-small-cell lung cancer. N Engl J Med. 2018;379:2040–51.
62. Ministry of Health 2013a. Decision No.92/QĐ-TTg January 9, 2013, Approval of the project for reducing overcrowding at hospitals in period 2013–2020.
63. Ministry of Health 2013b. Decision No.935/QĐ-BYT March 22, 2013, Approval of the project for the building and development of the family medicine clinic model in the period 2013–2020.
64. Ministry of Health 2016. Decision No. 1568/BYT on approving the plan of developing the general practice clinic model in a larger scale in Vietnam in the 2016–2020 period.
65. Calisi R, Boyko S, Vendette A, Zagar A. What is person-centred care? a qualitative inquiry into oncology staff and patient and family experience of person-centred care. J Med Imaging Radiat Sci. 2016;47:309–14.
66. Moody L, Nicholls B, Shamji H, Bridge E, Dhanju S, Singh S. The person-centred care guideline: from principle to practice. J Patient Exp. 2018;5:282–8.
67. Schellinger SE, Anderson EW, Frazer MS, Cain CL. Patient self-defined goals: essentials of person-centered care for serious illness. Am J Hosp Palliat Care. 2018;35:159–65.

Chapter 35
Person-Centered Surgery and Anesthesiology

Rebecca Martin, Pringl Miller, Gheorghe Borcean, Oscar Cluzet, and Ghassan Shahrour

35.1 Introduction

In the past, surgery was primarily focused on the 'procedural management of localised disease' and struggled to contextualise a part or section of the body part within a holistic understanding of the person. Nowadays, the surgeon's tool kit includes treating the system and aberrant physiology within the whole person outside of a diseased organ or tissue area. Yet, the invasive and potentially life-threatening nature of surgery fundamentally shapes the relationship between the patient and the surgeon. An emphasis on technical competencies and increasing subspecialisation of highly precise technical skills further endangers the capacity of surgical 'service providers' to also provide person-centred clinical care. In this chapter, we are including the field of anaesthesiology under the broad umbrella of person-centred

---

R. Martin (✉)
Department of Pain Management, Royal North Shore Hospital, St Leonards, NSW, Australia
e-mail: Rebecca.Martin@health.nsw.gov.au

P. Miller
General Surgery, Hospice & Palliative Medicine and Clinical Medical Ethics,
Chicago, IL, USA

G. Borcean
Romanian Medical Association, Victor Babes Medical and Pharmaceutical University,
Timisoara, Romania
e-mail: gheorghe.borcean@cmr.ro

O. Cluzet
Surgery, Intensive Medicine and Bio Ethics, Latin American Network of Person Centered Medicine, Montevideo, Uruguay

G. Shahrour
Syrian Medical Syndicate, Palestinian Otolaryngological Society, and the Kuwait Medical Association, Hawalli, Kuwait

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_35

surgery, as developments in the provision of anaesthesia means that surgery can be offered in any circumstance, not just emergently.

The professional standards for surgeons are prescribed by organizations such as the American College of Surgeons (ACS) and can be seen to be squarely focused on the surgeon's relationship with the person they are treating. Fellows of the ACS pledge "to pursue the practice of surgery with honesty and to place the welfare and the rights of my patient above all else" [1]. In particular, they promise to deal with each patient as if they were in the patient's position, and to respect the patient's autonomy and individuality. The Statement of Principles of the ACS goes on to state that surgeons need to acknowledge that they interact with patients when they are most vulnerable. Their patients' trust and the privileges surgeons enjoy depend on "individual and collective participation in efforts to promote the good of both our patients and society" [1]. Surgeons must treasure the trust that is placed in them because trust is integral to the practice of surgery in particular and medicine at large.

The responsibilities of the trustworthy surgeon include:

- Serve as effective advocates of patients' needs.
- Communicate effectively and empathetically with patients and their families.
- Disclose therapeutic options, including their risks, benefits, complications, and alternatives.
- Disclose and resolve any conflict of interest that might influence decisions regarding care.
- Be sensitive and respectful of patients, understanding their vulnerability during the perioperative period.
- Fully disclose adverse events and medical errors.
- Acknowledge patients' psychological, social, cultural, and spiritual needs.
- Encompass within our surgical care the special needs of terminally ill patients.
- Acknowledge and support the needs of patients' families.

In return for the trust of patients, their families and society, surgeons undertake to:

- Provide the highest quality surgical care.
- Abide by the values of honesty, confidentiality, and altruism.
- Participate in lifelong learning.
- Maintain competence throughout their surgical careers.
- Participate in self-regulation by setting, maintaining, and enforcing practice standards.
- Improve care by evaluating its processes and outcomes.
- Inform the public about subjects within our expertise.
- Advocate for strategies to improve individual and public health through communication with government, health care organizations, and industry.
- Work with society to establish just, effective, and efficient distribution of health care resources.
- Provide necessary surgical care without regard to gender, race, disability, religion, social status, or ability to pay.
- Participate in educational programs addressing professionalism.

35.2 The Surgeon-Patient Relationship

The American College of Surgeons [1] has identified the following features of the relationship between the surgeon and the person they are treating. These include:

- Informed consent.
- Scope of surgical care.
- Preoperative diagnosis and care.
- The operation—Intraoperative responsibility of the primary surgeon.
- Postoperative care.
- Continuity of care.
- Freedom of choice.
- Confidentiality of medical records.
- Conflict of Interest
- Unnecessary operations
- Quality assurance
- Surgical fees
- The invasive and potentially life-threatening nature of surgery fundamentally shapes the relationship between the patient and the surgeon [2].
- Patients must have deep trust in the surgeon on two counts. Firstly, they must trust the surgeon's recommendation to remove a body part. Unlike taking a medication or engaging with a therapist, removal of a body part is generally not reversible, giving the calculus of benefit vs harm a much heavier weighting when choosing whether to have a surgery. Secondly, there is the trust that underlies the complete, albeit temporary, transfer of power and control by the patient to the surgeon and anesthesiologist while they are being surgerized. Certainly, some surgery occurs awake and some interventionalists who heavily sedate their patients to perform procedures are non-surgical (e.g. cardiologists) but when it comes to major operative procedures, the relationship between surgeon, anesthesiologist and patient is fundamentally different from other medical specialities and primary care. However, even though the patient relinquishes all control to the anesthesiologist and puts their life in the hands of the surgeon for the duration of the surgery, in the case of non-emergent surgery there is a gradual transition from the normal physician-patient relationship to what Axelrod and Goold have called the "dramatic surgical crescendo" [2]. The patient is in full control as they decide to: consult a surgeon; be evaluated; choose from among the various treatment options offered; enter into a therapeutic relationship with the surgeon. Therefore, as with other fields of medicine, a general consideration of the physician-patient relationship applies to much of the surgeon-patient relationship.

Since the 1960's, the four bioethical principles put forward by Beauchamp and Childress—autonomy, beneficence, non-maleficence, and justice—have been applied to outlining how clinicians should behave towards their patients [3]. Respect for autonomy is explicitly mentioned in the Preamble to the ACS Statement [1].

Despite this exalted status, it seems the principles are too abstract for decision making in individual cases, [4–6] where situational information acquires greater importance [5]. There is empirical evidence that surgeons reason more from a relational ethics perspective, focusing on dialogue, openness, and involvement in their relationships with patients and colleagues. [7].

35.3 Principles of Person-Centered Medicine as Applied to Surgery

Next, and starting from the analysis of the principles that sustain Person-Centered medicine [8], as they have been established by its founders, we will expose the specificities of the current surgical practice.

35.3.1 Ethical Commitment

This is the most important principle in general [9], and also as applied to surgery and anesthesiology. Within such principles we will give pre-eminence to those situations that, if not timely detected and corrected, could even prevent a real advance in the effective and growing practice of Person-Centered Surgery (PCS) itself. At each relevant point, the aspects that we understand will have to be corrected as a cultural change that will guide their future clinical practice will be pointed out. As it is a healthcare area with special demands such as the surgical sector, this cultural change requires that the participants have the presence of the corresponding instructors who accompany them in the early stages of their training.

35.3.2 Holistic Approach of the Patient's Personhood

The Surgeon is not formed with a comprehensive orientation of the totality of the person of their patient and not even of the main aspects that constitute the complexity of the human being, particularly in their psychological sphere. Consequently, it is ill-prepared for the challenges posed by this momentous issue. Therefore, in the undergraduate program of any University that has adopted this paradigm of incorporating Person-Centered medicine in its curriculum, due curricular emphasis must be made to obtain a deep mastery of these crucial aspects on their part. But also, once the medical degree is reached, upon entering the corresponding Postgraduate Degree, the future Surgeon must resume the practice of these communicational and psychological skills, as important themes acquiring a good command of the most complex technical details of their specialty [10].

35.3.3 Cultural Sensitivity

Aspect of a hierarchy variable, according to the ethnic and cultural integration of each country. There is a consensus that, in our modern multicultural societies, health professionals should be able to adapt to a higher degree in terms of processing a true decoding of the words of the person who consults. In this way, knowing their cultural contexts would be facilitated enough to allow them to effectively explore their desires, aspirations and scale of values [11]. Conducting a mini-ethnography on every patient seen through the Cultural Formulation outline would be one practical way of operationalizing cultural sensitivity in the practice of person-centred surgery. [12].

35.3.4 Relationship Focus

Every surgeon should be warned about the appearance in their clinical relationship of what we could call the "fallacy of technical leadership", consisting of interpreting on his part that his mastery of the very complex technical aspects that their specialty involves, authorizes them to dispense with providing the corresponding explanations to the people and their families. By doing so, the surgeon would be invading center stage and displacing the person of their patient from the place that has been legitimately assigned to them by Person-Centered medicine paradigm. Also crucial is the need for the surgeon to contextualize their knowledge and actions. The words of the Spanish philosopher Ortega y Gasset are apt here: "I am I and my circumstance, and if I do not save it, I do not save myself" [13].

35.3.5 Collaborative Care and Shared Decision Making

A collaboration between the patient and physician is important for achieving Person-Centered care in surgery and anesthesiology, perhaps even more than in other specialities. Indeed, patients who have not been properly informed or have not correctly understood the multiple aspects of a complex surgical situation could hardly make decisions regarding their own life. It is that the surgeon and anaesthesiologist, even without being aware of it, in addition to overpowering the autonomy of the person involved, would be affecting their dignity, as this person feels excluded from nothing less than the surgical decision made on them. The final decision must always be reached to be assumed by a duly informed person-patient, accompanied by their consulting physician, which is known as "shared decision-making" [14]. At the end of life, a similar scenario arises, now carried out by a person who, by the time loses their autonomy, intends to leave directives, known as advance care planning.

35.3.6 *Empathic, Complete and Transparent Communication*

In Surgery it is increasingly necessary to be able to count on the strong vocational roots of the Surgeon in terms of explaining the complex in simple, clear, and transparent terms. In addition, such skill is currently required for any other member of the surgical team, now configured into true surgical work units, gradually replacing the former primary surgeon. It can be argued that the primary surgeon still has the primary responsibility of communication with patients and loved ones, even though there's delegation and other members of the team that represent other service lines and different expertise that the primary surgeon cannot speak to. Teams should also communicate effectively with each other so as to be propagating the same message to prevent confusion about the treatment plan. The objective continues to be to try to establish a firm commitment to the quality, clarity and empathy of information and advice, so that the patient is optimally informed to make the best decision for their goals and values.

35.3.7 *Personalization of Care*

As relational frameworks continue to improve their effectiveness, efficiency, and quality of results, and as various modern therapies are tailored to the individual characteristics of each person, this personalization of care emerges. This situation of desideratum can be sought voluntarily between the parties of the clinical relationship but not infrequently it responds to the need to adjust to the situation of the biological characteristics of the affected person. Such is, by way of example, the case of the use of monoclonal antibodies against various oncological or rare pathologies. The relationship maturity that this personalization will require, once again, from the members of the clinical relationship is evident.

35.3.8 *Organization of Services Focused on the Person and the Community*

It constitutes an example of the use of directives to be applied in the field of Public Health and requires a high level of social and academic acceptance of the Person-Centered medicine paradigm, which today we are far from reaching (despite the efforts of strenuous colleagues from various corners of the world). However, continuing to integrate members of the community from each geographic constituency into the aforementioned efforts, we believe that it will substantially boost these difficult achievements.

35.3.9 People-Centered Health Education and Research

Another example of public policies that should undergo substantial transformations due to the properly applied Person-Centered medicine paradigm follows. It requires continuing to develop these policies in Public Health plans and programs, as well as in their corresponding counterparts in the universities that adhere to this concept and that are usually present and trying to collaborate in meetings such as those of the Latin American Network of Person Centered Medicine. In surgical areas that were greatly affected by the COVID-19 pandemic, adjustments will have to be made to encourage surgical practice in advanced simulators. It has been firmly demonstrated that such a surgical skill training modality has a real impact on clinical outcomes, which constitutes a verification of the benefits of applying the Person-Centered medicine postulates, now in the surgical environment.

35.4 Implementation of Person-Centeredness Through Surgical Care Phases

The care provided to the patient by the surgeon and anesthesiologist has three phases: pre-operative, operative and post-operative. There are key aspects of person centeredness at each phase.

35.4.1 Person-Centered Pre-operative Phase

In the nineteenth century, the surgical specialty emerged as pioneers such as Billroth improvised aggressive and ambitious surgeries in order to treat horrific battlefield injuries. Interventions were by necessity reserved for life threatening situations, when the pain and trauma of such things as a limb amputation, the closing a wound or perhaps reducing a fractured bone was offset by the dire need. In modern times only rare situations are of such precipitant need that alternative choices are not available or discussed. With the advantage of modern anaesthesia there is now opportunity for surgical procedures to be offered prior to a person reaching such a severe state of need. In doing so we can now dramatically improve life expectancy by intervening much earlier in the course of conditions such as malignancies, infections and vascular occlusions. Furthermore, we can now electively intervene to improve function, with procedures such as joint replacements, laser refractive eye surgery and bariatric surgery, or for cosmetic intent. The decision whether ‘to operate’ or ‘not to operate’ is no longer limited by clear clinical indicators but also heavily influenced by patient choice that aligns their goals and values with a surgical intervention vs request surgery. It should be emphasized that clinicians today are frequently exposed to expectations from both patients and the community, that anything that can be done should in fact be done, with little recognition or tolerance of potentially sub-optimal outcomes.

In this scenario of high expectations, with patients often willing to submit themselves to elective surgical procedures with significant actual and potential harm, it is necessary to ask, "who benefits?" A Person-Centered approach aids reflection of the ethical balance and value conflicts that are often encountered between surgeon-as-person and patient-as-person. Conflicting goals of technical accomplishment, financial renumeration and the personal satisfaction achieved by a 'successful operation' can influence willingness to undertake elective procedures that may not be best suited to achieving the desired outcome sought by the person for whom the operation is designed to benefit.

Surgeons need to be educated about the ethics of shared decision making and be willing to consider them during clinical care. Ego and bias may sway surgeons away from following the ethical tenants that are well documented as references. Conflicts exist but need to be addressed from a patient-centered perspective. The paternalistic approach which is a surgeon-centered—surgeon value-based approach has been superseded by a patient-centered approach. In this way, a Person-Centered preoperative decision making framework that balances benefits and harms for the individual contextualised person, with an understanding of the motivations of both clinician and patient, is necessary to ensure fully informed consent.

One such helpful toolkit developed to facilitate a Person-Centered approach to decision making is the SHARE Approach (Fig. 35.1), https://www.ahrq.gov/health-literacy/professional-training/shared-decision/index.html It suggests a clear 5 step approach and is a straightforward framework to prompt good surgical preoperative discussions.

1. Seek the person's participation.
2. Help them explore and compare treatment options.
3. Assess their values and preferences.
4. Reach a decision with the person.
5. Evaluate the decision.

A person's motivations are however complex and dynamic, influenced by social, cultural and personality factors, information and education, opportunity and responsibilities. Often a person has little insight into their own motivations and eliciting an understanding of their goals in seeking health care will require carefully implemented skills. The answers to true open-ended questions may surprise the clinician-person when the values expressed differ from those expected, but this is the value of Person-Centered pre-operative discussions. Ensuring adequately detailed explicit information is communicated, utilizing culturally and linguistically appropriate resources, is imperative to informing the person to allow for informed discussion. Realistic estimates of expected positive and negative outcomes, including risks of chronic post-surgical pain, return to prior function and work, wound care and psychological impacts may well alter a person's motivation to proceed with the surgery.

Fig. 35.1 The SHARE approach to decision making

In 1992 the Australian High Court, in the Rogers v. Whitaker case, affirmed that doctors must discuss material risk particular to the individual patient, meaning risks that a reasonable person in similar circumstances would attach significance to. It is not enough for a doctor to discuss risks in general common to most people, they must also discuss risks specific to the situation of the individual person consenting to the procedure, and they should be cognizant of such personalized risks.

In this case, Maree Whitaker became essentially blind after an unsuccessful operation on her right eye caused sympathetic ophthalmia in her left eye. Although there was no question that the surgery had been performed with the requisite skill and care, Ms. Whitaker petitioned the court for relief due to the failure of the ophthalmologist, Dr. Christopher Rogers, to warn her of the possibility (approximately 1 in 14,000) that the sympathetic ophthalmia condition could develop. The trial court's award of damages was affirmed because, in spite of Ms. Whitaker's expressed specific concern that her "good eye" not be harmed, Dr. Rogers did not inform her of the potential risks associated with the surgery [15].

35.4.2 Person-Centered Operative Care

With the need for an emphasis on skill acquisition whilst training, more junior surgical team members are often insulated from the person of the patient when they first meet the patient on the surgical day long after the decision to proceed with an operation has been made. By then the person has been disguised and labelled in their role as patient by the costume of a surgical gown and context of a hospital bed, and the clinician equally role deployed wearing their surgical scrubs, their mind distracted by the imminent need to plan for the surgical technicalities. There is much to be gained in establishing an understanding a person's decision-making context by conversing with them, fully dressed, sitting across from oneself who is also normally dressed and not time pressured. Alas, especially for the surgeon in training, many preoperative interactions are hurried by the bed side of an unwell person and efforts to understand them as persons must be deliberately added to the interaction rather than inherently included by default. Increasing our surgeons-in-training involvement in the preoperative shared deliberations between a person consenting to a procedure and their surgeon will enhance their training and aid the development of a surgical cohort with a Person-Centered ethos. Even when the patient is first met by the operative team on the day of surgery, the surgeon responsible for the shared decision to embark on the planned operation should choose to share the person specific goals with the team. A team pre-operative huddle, usually implemented to improve peri-operative safety, can accommodate inclusion of the personalized context of the decision to proceed and remind the operative team of the person status of their patient who will soon be rendered into unique state of vulnerability and loss of dignity that anesthesia and surgical exposure brings to the patient.

The anesthesiologist is also often meeting the conscious patient in a brief and clinically intense interaction required to fulfill the biomedical assessment criteria necessary for planning the imminent anesthesia. Yet with the goal of anesthesia being to facilitate the physical insults (i.e. the surgical operation) to the body of the person, and reduce or eliminate the experience of these insults by the person, some understanding of how the person experiences their world is inherently clinically relevant. Personality traits influence the choice of agent, a needle phobic person may choose a gas induction, an anxious person may choose general anesthesia over local.

An anaesthetized person is still a person with personhood, even though they are temporarily disabled and vulnerable with no awareness, memory or capacity to defend self or express their autonomy to their operative team, only some of whom have even met them prior to this anaesthetized condition. Operative staff are frequently exposed to traumatic events and can lead to psychological distress including the development of PTSD-type symptoms [16]. Consequences can include such problems as compassion fatigue and de-personalization of the patient which is often a self-protective psychological tool, which is on a continuum with burnout phenomenon. Intentional attention to behavior consistently respectful of the vulnerability of the anesthetized person must be ensured, to avoid the risk of becoming desensitized to the profound trust and responsibility placed by the anesthetized person submitting to their care. Whilst the team may be desensitized to bodily exposure, the patient-person may prefer their modesty is protected even whilst unaware. Wise anesthesiologists and operative staff will presume that an anaesthetized person is aware, at least of auditory phenomena, and will often talk to their patients during a case as if they were present, despite knowing that the incidence of awareness is very low. Such behavior serves as a reminder to the team of the personhood of the individual undergoing a surgery, and facilitates attitudes of respect, with a presumption of awareness a tool for recollecting the team to the dignity of the body-person bond.

35.4.3 Optimizing Care of Persons Post-operatively

There is a large variability in people's tolerance of the inconvenience and vulnerability experienced whilst recovering from a procedure, not only related to the differences in the type of surgery but due to factors inherent to the persons involved. Recognition of these differing experiences of patients traversing the same operative procedures, especially in their length of stay and analgesic requirements, has led to worthy attempts to characterize traits of an individual that may predict poorer outcomes. Psychological factors such as catastrophizing and anxiety are well-established as predictors of poor post operative outcomes [17]. Relevant contextual exploration of these traits are now expectations of preoperative assessment to guide the ideal perioperative management plan. Whilst reducing these traits to quantifiable indices or score cards using questionnaires or toolkits may allow for more individualized biomedical decision making (e.g. choice of anesthesia/analgesia), it ideally will also encourage efficient investment and adjustment of interpersonal communication style to cater to this person's needs. However, such an adjustment requires the clinician to have the skill, desire and emotional energy to utilize their own 'bedside manner' resources to optimize the patient-as-person experience of the operative journey. Even the compassionate and skilled communicator clinician may at times find their own capacity to meet the patient's needs exhausted, influenced by their own day to day complexities of 'clinician-as-person'. Often such patient support defaults to nursing staff and the surgeons and anesthesiologists who lack the natural inclination to excel at this tend to self-select away from careers with such high intensity interactions. The roles of an Acute Pain Service and Peri-operative Medicine teams have developed in recognition that excellent surgeons, with their need to attend to technical competencies, cannot also fully cater to all the complex needs of the person recovering from a procedure. A team approach, with recognition of multidisciplinary skills to cater to various components of recovery is desirable. Efforts to integrate routine use of standardized simple assessment tools to assist insight into personalized variables that may influence recovery and routine provision of patient educational resources to optimize patient expectations, in addition to enlisting appropriate team approaches aim to protect patients from clinician variation in skill, capacity and inclination to consider person variables.

In scenarios where difficulties have been encountered, complications, poor outcomes and/or patient safety incidents have occurred, then open disclosure processes should be implemented in a Person-Centered approach. Acknowledgement, with effective truthful, clear and timely communication about the incident or complication, active listening and providing opportunity for the person to recount their own experiences, concerns and feelings, and the provision of respect, support and ongoing care are the principles of an open disclosure process. Health services will often have formalized policies on how to care for persons impacted by such incidents and risk management and quality improvement processes in recognition of the gravity of the consequence to a person's life that can occur. However, what may be considered routine clinical recovery to experienced clinicians may be an unpleasant surprise to individual patients and using these principles, in particular allowing a person to express their own experience, concerns and feelings, can guide challenges in the postoperative period and improve Person-Centeredness of care. Patient navigators or patient care coordinators are also available in some settings to facilitate healthy conversations about the patient experience, and not just if there's a complication or untoward event.

35.5 Illustrative Cultural Perspectives on Person-Centered Surgery

Person-Centered medicine has become an important part of our journey to build a culture of health and wellness or whole person care. Moreover, it is a part of the right of every person to health in a world striving to achieve the universal health coverage as an important step to achieve health for all, everywhere and anywhere. The main goal of a person/patient-centered care model is to improve individual outcomes and satisfaction —when patients are more involved in their own care, they often recover more quickly and are more satisfied with the care they receive [18].

Person-Centered Surgery, as we know, is a critical part of Person-Centered Medicine that aims to extend the focus of medicine from disease/infirmity to patient/client person by integrating professionalism and humanism. So that we can promote our professional health care with mutual partnership with our clients in order to meet more and more of their health expectation to achieve their life's fulfilment. So, the practice of Person-Centered Surgery depends on the understanding and implementation of Person-Centered Medicine in general.

Reviewing Health and well-being profile of the Eastern Mediterranean Region [19], there are clearly diverse health care systems [20]. Many of them struggle to provide adequate care and treatment to their citizens due to a lack of financing and human resources especially in low-income countries as well as in countries of armed conflicts. Most countries in the Middle East have state-funded healthcare systems, but they all have varying degrees of stipulations to qualify for coverage and there are huge differences in quality of service [21]. The private sector as well as non-profit organizations are working to fill the growing lack of disparities in health care services [22]. Moreover, surgeons as well as other health care professionals have been educated in different languages such as Arabic, English, French and others [23].

In general, the population in the Middle East are deeply impacted by religious beliefs and religious leaders, spiritual individual and group practice, traditions, government health sector and policies as well as their families and their local community leaders as well as others. These factors as well others must be taken into consideration in order to practice efficient Person-Centered Surgery. To the list of features identified by ACS should be added

- Conflict and ethical and religious issues such as organ donations, transplantation and fertilizations as well as others.
- Other diverse issues.

These aspects as well as the person's motivations are impacted by cultural, social, education, religious and other individual and community factors. So, it is crucial for the surgeon as a professional and human being to fully understand and respect these issues during all the journey with the person who needs a surgery.

In the pre-operative phase, the surgeon has to tell the patients clearly the nature of his/her condition, the nature of the medical diagnostic/therapeutic procedure, focusing and reflecting on their individual situation, the risks related to the proposed procedure, the available therapeutic alternatives and the associated risks. Moreover, the possible risks of not performing the intervention as well as others. This information as well as others must be also included in the patient consent to medical diagnostic/therapeutic procedure. Health-care practitioners also need to be aware of particular items in the consent form (such as medical terminology) that may be problematic and to ask potential subjects direct easy questions about their understanding of those items [24].

In the operative phase, the surgeon must take the interest of the patient first and keep all commitment in the pre-operative phase in order to meet the expectation of the patients. Partnership with the anesthesia team and nurses including sharing information and plans is necessary in all stages of action. This is also required in some cases with other health professionals and specialties depending on the need of the patient.

In the post-operative phase and follow up, the surgeon in partnership with the patient have to work together to complete the therapeutic procedure as planned. The surgeon has to share all information related to the surgery with the patient as well as the follow up plan, in partnership with other patient care givers. Moreover, sharing together any assessment in the follow up phase. In some cases, involvement of the family or caregivers of the patient as well religious and/or spiritual persons is crucial to achieve the goal of the surgery. Religion and spirituality have received much interest in health care services, since they have been used to reduce stress and promote understanding and coping in strategies to improve health in all stages of intervention on diseases [25].

Post-operative phase and follow up, require active communication and in some cases requires special meeting to assess development and plans forward.

Introducing, implementing and promoting Person-Centered Surgery as well as Person-Centered Medicine in the middle east countries require important steps in order to create enabling environment to meet the needs and requirements of all stakeholders including people, health professionals including surgeons, health policy makers, professional societies, educational institutions, social and family societies as well as others. These steps and fields include:

- Production of basic necessary materials as well as publications on Person-Centered Surgery as well as Person-Centered Medicine in local languages such as Arabic, covering the basic concept and aspects.
- Approaching health care providers and policy makers in order to facilitate partnerships at diverse levels.
- Involvement of as many stakeholders as possible in the activities.
- Sharing lessons learned with other regions and international organizations.
- Supporting the development of client/patient groups on these issues.
- Supporting research on the impact and challenges of the practice of Person-Centered Surgery as well as Person-Centered Medicine.
- Introducing the concept and the practice of Person-Centered Surgery as well as Person-Centered Medicine in mainstream of medical education for students as well as Continuing Professional Development programs for health and social professionals.
- Others.

All these steps and activities as well as others should be tailored on the need and profile of each country and health system in the middle east in participatory involvement of health societies, academic institutions, and related public/community organizations (cultural, social and religious) for support and collaboration in building a Person-Centered Medicine dedicated to the promotion of health as a state of physical, mental, social and spiritual wellbeing and not only the absence of disease or infirmity.

Introducing and practicing Person-Centered Surgery as well as Person-Centered Medicine in the Middle East as well as in other parts of the world should be an integral part of our journey not only to build the culture of health in the region but also an essential part to the right to health of persons everywhere and anywhere.

35.6 Practical Implications for Person Centered Care in Surgery

If the practice of medicine requires a consideration of not only the pathophysiology, but they also of the patient and the context, this has many practical implications for the provision of person centered care in surgery and anaesthesiology.

35.6.1 To What Extent is Surgery and Anaesthesia Currently Person-Centered?

The ACS Statement of Principles emphasizes that surgeons must respect autonomy, and act with beneficence and justice. Heideggerian philosophy allows a better understanding of Beneficence, Autonomy (as its manifestation) and Justice not only as principles but as parts inherent in the relationship. From this, one sees how they become relationships [26]. Clearly, the act of 'care/concern' (in the context of Heidegger, Dasein exists to care about or be concerned with something) for the physician/surgeon is described and interpreted as beneficence, which in turn is described as the phenomenological entity of the relationship itself. Further analysis on 'communication, 'understanding' etc. allows a better description and elaboration of beneficence in the surgeon-patient relationship.

35.6.2 Obstacles to implementation of Person-Centered Surgery and Anesthesiology

Changes in the technology and infrastructure of health care in recent decades has affected how surgeons and their patients relate to each other. The role of surgery in treatment option has radically expanded due to advances in technology and in the support available to care for older, sicker patients. These advances have driven up health costs requiring the placement of constraints on resource allocation, surgery has been the target of employer and government attempts to limit expanding medical costs to a greater degree than other medical specialties [2]. The linkage between the financing and provision of services is seen to be creating tension between the surgeon's financial interest and the patient's health interest, straining the relationship between surgeons and their patients as never before.

35.6.3 The Changes that Are Needed to Make Surgery and Anaesthesia More Person-Centered

According to Axelrod and Goold [2] "within this milieu, it behooves surgeons to reflect on the moral underpinnings of the surgeon-patient relationship". This means defining the moral obligations and responsibilities surgeons have to their patients.

At this point, we will refer to selected arguments from the German philosopher Martin Heidegger which have been proposed as being useful for providing a moral basis of the physician-patient relationship [27]. While Heidegger's philosophy has been criticized as being inaccessible to clinicians, [28] with its complex language and neologisms, nevertheless we suggest here that examining the doctor-patient relationship through the phenomenological lens of his pivotal work, *Being and Time*, [29] can lead to greater Person-Centeredness in surgery and anesthesiology, even in the face of the challenges of surgical practice in the new millennium.

One important implication of taking a phenomenological perspective is that the best understanding of a person's behavior is obtained through his or her internal frame of reference: how the patient sees the situation. *Subjective* experience is thus the key to understanding because these are the fundamental causal agents of behavior. Every situational participant not only experiences but also *interprets* the medical encounter in relation with his or her own biography [30]. The physician needs a model on which to visualize going about this phenomenological approach. To do this, he must understand the possible positions with which he or she can view the patient, and the possible positions his or her role takes during interaction with the patient. A possible visual pattern is suggested here which explains these roles. Thus, there are objective and subjective roles of the doctor and of the patient as well. They come to interact with one another thus determining the ontological possibilities of how one relates to the other.

35.7 Conclusions

A Person-Centered approach to surgical care at present will intentionally elicit the patient agenda so that clinicians orient the priorities of a clinical encounter toward specific aspects that matter to each patient [31]. Traditional paternalistic surgical decision making will be transformed into a shared decision-making approach, a partnership will emerge between the surgeon, patient and/or surrogate decision maker, and key members of the interdisciplinary treatment team. The US Institute of Medicine [32] defines patient-centered care as respectful of, and responsive to, individual patient preferences, needs, and values, ensuring that patient values guide all clinical decisions. Perceived barriers to patient-centered care in surgery are surgical culture, time constraints, limited education and training focused on advanced communication skills, and burnout.

Eliciting the patient agenda inclusive of their concerns and listening carefully to them will require additional graduate medical education and continuing medical education designed to help surgeons in training and practice develop and master interpersonal and communication competencies. The Surgical Council on Resident Education (SCORE) curriculum for general surgery has acknowledged the importance of non-technical skills for surgeons (NOTSS) and Surgical Professionalism and Interpersonal Communication Education (SPICE) (curriculumoutline2019-2020.pdf (surgicalcore.org), accessed 9/28/21) Advanced communication skills will help fulfill qualifications of the responsible surgeon as specified by the American College of Surgeons competencies; interpersonal and communication skills that result in effective information exchange and effective interaction with patients, their families, and other collaborating health care professionals. Providing education and support so that patients can participate and make decisions in their own care is the hallmark of honoring patient autonomy, supports one's personhood (including that of the health professional and family members) and forms the basis of Person-Centered care.

Person-Centeredness is considered an important dimension of patient satisfaction and health care quality. Therefore, the future portends identifying the primary goals of care from the person's perspectives and addressing how the surgeon's care can achieve the person's objectives [33].

Acknowledgements and Disclosures The preparation of this chapter, as many others in this book, has involved the collaboration of scholars, surgeons and an anesthesiologist from various countries and world regions. The central organization and presentation of Person-Centered surgery and anesthesiology was prepared by Rebecca Martin from Australia, following initial outlines from Pringl Miller from the United States. Historical, philosophical and ethical perspectives were originally formulated by Gheorghe Borcean from Romania. The discussion of person-cantered medicine principles applied to surgery was originally written by Oscar Cluzet from Uruguay. The relevance of cultural diversity was illustrated by Ghassan Sharour from the Middle East.

Major editing was performed by book co-editor Paul Glare, complemented by lead editor Juan Mezzich.

The authors do not report conflicts of interest in the preparation of this manuscript.

References

1. American College of Surgeons Statements on Principles, in This version was published in print, September 2016 in the Bulletin of the American College of Surgeons. 2016, American College of Surgeons Chicago IL.
2. Axelrod DA, Goold SD. Maintaining trust in the surgeon-patient relationship: challenges for the new millennium. Arch Surg. 2000;135(1):55–61.
3. Beauchamp TL, Childress JF. The Principles of Biomedical Ethics. 5th. ed. Oxford: Oxford University Press; 2001. p. 454.
4. Christen M, Ineichen C, Tanner C. How "moral" are the principles of biomedical ethics?--a cross-domain evaluation of the common morality hypothesis. BMC Med Ethics. 2014;15:47.
5. Page K. The four principles: can they be measured and do they predict ethical decision making? BMC Med Ethics. 2012;13:10.
6. Westra AE, Willems DL, Smit BJ. Communicating with Muslim parents: "the four principles" are not as culturally neutral as suggested. Eur J Pediatr. 2009;168(11):1383–7.
7. Torjuul K, Nordam A, Sorlie V. Ethical challenges in surgery as narrated by practicing surgeons. BMC Med Ethics. 2005;6:E2.
8. Mezzich JE, Kirisci L, et al. Systematic conceptualization of person centered medicine and development and validation of a person-centered care. Int J Person Center Med. 2016;6(4):219–47.
9. Callahan D. The goals of medicine: Setting new priorities. Hast Cent Rep. 1996;26(6 (Nov-Dec)):S1–S27.

10. Mezzich JE, et al. Person-centered approaches in medicine: clinical tasks, psychological paradigms, and the postnonclassical perspective. Psychology in Russia: State of the Art. 2013;6(1):95–109.
11. Pacheco Ojeda L. La cirugía centrada en la persona. Revista De La Facultad De Ciencias Médicas (Quito). 2018;43(8):7–10.
12. Mezzich JE, Caracci G, Fabrega H Jr, Kirmayer LJ. Cultural formulation guidelines. Transcult Psychiatry. 2009;46:383–405.
13. Ortega y Gasset J. Meditaciones del Quijote. Madrid, Spain: Editorial Cátedra; 2005.
14. Glare P. Shared decision making. Int J Person Cent Med. 2018;8(4)
15. Australia. High Court. Rogers v. Whitaker. Aust Law J. 1993;67(1):47–55.
16. Warren AM, Jones AL, Shafi S, Roden-Foreman K, Bennett MM, Foreman ML. Does caring for trauma patients lead to psychological stress in surgeons? J Trauma Acute Care Surg. 2013;75:179–84.
17. Taenzer P, Melzack R, Jeans ME. Influence of psychological factors on postoperative pain, mood and analgesic requirements. Pain. 1986;24:331–42.
18. Guideway Care (2020). What Is Person Centered Care, and How Can it Improve Healthcare?, January 24, 2020, Accessed on Nov 30, 2021. https://guidewaycare.com/what-is-person-centered-care-and-how-can-it-improve-healthcare/
19. WHO EMRO (2019). Health and well-being profile of the Eastern Mediterranean Region: an overview of the health situation in the Region and its countries in 2019/World Health Organization. Regional Office for the Eastern Mediterranean, Accessed on Nov 30, 2021. https://applications.emro.who.int/docs/9789290223399-eng.pdf?ua=1
20. WHO EMRO (2021). Country health profiles. World Health Organization Eastern Mediterranean Region, Accessed on Nov 30, 2021. http://www.emro.who.int/entity/statistics/country-health-profiles.html
21. WHO EMRO (2012) Delivery of health services in Arab countries2012. Eastern Mediterranean Health Journal|Past issues|Volume 18, 2012|Volume 18, issue 12|, Accessed on Nov 30, 2021. http://www.emro.who.int/emhj-volume-18-2012/issue-12/08.html.
22. Fahimi F (2006), Gender and Equity in Access to Health Care Services in the Middle East and North Africa, Population Reference Bureau, Accessed on Nov 30,2021 at: URL: https://www.prb.org/resources/gender-and-equity-in-access-to-health-care-services-in-the-middle-east-and-north-africa/
23. Abdalla M, Suliman R. Overview of medical schools in the Eastern Mediterranean Region of the World Health Organization. East Mediterr Health J. 2013;19(12):2013, Page 6/1025
24. WHO EMRO (2014). Factors affecting the process of obtaining informed consent to surgery among patients and relatives in a developing country, Eastern Mediterranean Health Journal|Past issues|Volume 20, 2014. Accessed on Nov 30, 2021. http://www.emro.who.int/emhj-vol-20-2014/volume-20-9/factors-affecting-the-process-of-obtaining-informed-consent-to-surgery-among-patients-and-relatives-in-a-developing-country-results-from-pakistan.html.
25. Chirico F. Spiritual well-being in the 21st century: It is time to review the current WHO's health definition. J Health Soc Sci. 2016;1:11–6, Accessed on Nov 30,2021 at: https://journal-hss.com/wp-content/uploads/JHHS1111-16.pdf
26. Pellegrino ED. The four principles and the doctor-patient relationship: the need for a better understanding. In: Gillon R, editor. Principles of Health Care Ethics. Chichester, England: John Wiley & Sons; 1994. p. 353–66.
27. Svenaeus F. Illness as unhomelike being-in-the-world: Heidegger and the phenomenology of medicine. Med Health Care Philos. 2011;14(3):333–43.
28. Holm S. The hermeneutics of medicine and the phenomenology of health – steps towards a philosophy of medical practice. Med Humanit. 2000;26:61–2.
29. Heidegger M. Being and time. New York: Harper Collins; 2008. p. 608.
30. Zaner RM. Experience and moral life: A phenomenological approach to bioethics. In: DuBose ER, Hamel RP, O'Connell LJ, editors. A matter of principles? Ferment in US Bioethics. Valley Forge, PA: Trinity Press International; 1994. p. 224–30.

31. Singh Ospina N, et al. Eliciting the patient's agenda-secondary analysis of recorded clinical encounters. J Gen Intern Med. 2019;34(1):36–40.
32. US Institute of Medicine (2001). Committee on Quality of Health Care in America: Crossing the Quality Chasm: A New Health System for the 21st Century. 2001, Washington DC.
33. American College of Surgeons. Task Force on Surgical Palliative Care and the Committee on Ethics. Bulletin of, American College of Surgeons: Statement of principles of palliative care; 2005.

Chapter 36
Person-Centered Pain Medicine

Chris Hayes and Hema Rajappa

36.1 Introduction

Person centered pain medicine is holistic. It goes beyond biomedicine to include the psychological, social, environmental, cultural and spiritual context in which the individual lives and functions. Biomedicine can at times be more about the preferences and beliefs of the healthcare professional which are subject to both subtle and obvious biases including the influence of pharmaceutical companies. Person centered pain medicine is not just about patient satisfaction or knowledge provision. It has the loftier aim of empowering the individual to identify contributors to their pain experience and participate actively in treatment and recovery.

The experience of pain is universal. Everyone knows the urgent call of pain related to tissue injury. Such short lived or acute pain guides our path from infancy and throughout life. It is deeply personal. It differentiates threat from safety and is a strong protective response. It conveys a clear meaning; we move away from what is threatening and toward what is safe.

Yet for many people, pain is not experienced only as an isolated acute episode that resolves as bodily tissues heal. For them pain may recur intermittently, as in migraine for example, or persist and become chronic.

Pain can be classified according to duration, pattern and underlying condition. *Acute pain* is defined as lasting for 3 months or less. *Intermittent or recurrent pain* comes and goes. Pain that persists for more than 3 months is classified as chronic [1]. This is pain that persists beyond the usual time of tissue healing and is often related to nervous system sensitization. *Chronic non-cancer pain* (CNCP) is differentiated from *cancer pain* which, like acute pain, is typically more closely

---

C. Hayes (✉) · H. Rajappa
Hunter New England Local Health District, University of Newcastle,
Newcastle, NSW, Australia
e-mail: Chris.Hayes@health.nsw.gov.au; Hema.Rajappa@health.nsw.gov.au

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_36

associated with the extent of tissue injury or disease. The International Classification of Diseases 11 has recently sought to differentiate secondary pain, for example, related to a pathology such as osteoarthritis; from primary pain which relates to nervous system dysfunction [1, 2]. The challenge here is the lack of any clear diagnostic test to facilitate this distinction.

Regardless of the type of pain, a person centered approach can be beneficial. However it is in the setting of CNCP that the benefits have been most comprehensively researched. Epidemiological studies across the world show a population prevalence of CNCP approximating 20%. Prevalence rises as the population ages. This large cohort represents on one hand, an attractive target for commercial interests and biomedical reductionism, or on the other, an opportunity par excellence for person centered holistic medicine.

Some authorities see CNCP as lacking meaning or purpose because of its poor correlation with tissue injury or bodily structural pathology. However if the scope of enquiry is broadened to include psychosocial, environmental and spiritual aspects a sense of meaning often emerges and with it therapeutic direction. In contrast, if the person experiencing pain believes that their pain has no meaning they may see themselves as a victim of circumstances over which they have no control. They may become demoralised and vulnerable to offers of biomedical reductionist treatments that are more in keeping with the needs and beliefs of the healthcare provider and less likely to bring tangible health benefit to the recipient. Thus to disconnect the person from the meaning of their pain renders them a profound disservice.

The task of a person centered health professional is to help connect the person to the underlying meaning of their pain. This opens the way to requisite lifestyle changes, engagement with active self-management, more evidence based treatment and improved outcomes.

36.2 Objectives

This chapter will focus primarily on management of CNCP. Consequences to the individual and health system of using approaches that have an excessive biomedical focus will be considered. Exploration will follow of person centered models of pain care and the benefits that might arise from more widespread adoption of such practices. The challenges of implementation and outcome measurement will be discussed along with the personal perspectives of the authors.

36.3 Approach to Fulfilling the Objectives

- Narrative review of the literature
- Practical implications
- Personal perspectives of delivering chronic pain services in government funded hospitals in urban and regional Australia

36.4 The Knowledge Base of Person-Centred Pain Medicine

36.4.1 An Integrated Systems Approach to Health

The experience of pain, like the experience of personhood is multidimensional. A non-linear, systems approach is needed to map these dimensions and explore implications for diagnostic formulation and holistic management. Person centered care provides a suitable framework.

To achieve optimal organization or integration in any complex system both differentiation and linkage are required [3]. Differentiation means that key distinctive elements are recognized and celebrated. Linkage brings the differentiated parts together to function for the benefit of the whole. An orchestral performance demonstrates integration with the whole producing an experience which is greater than the sum of its individual parts. Likewise, an integrated or person centered approach to health requires recognition and linkage of key component parts. For example, in analysing an individual's experience of pain it is important to recognize the multiple elements that contribute and to consider the interactions between each element as a treatment plan is developed. This breadth of vision facilitates truly person centered pain medicine.

Another useful lens through which to envision person centered practice is the Behaviour Change Wheel [4]. Three concentric circles are described with the patient factors of capability, opportunity and motivation at the center. The next circle represents clinician input with the potential, for example, to implement therapeutic boundaries. The outer circle represents the policy aspect and broader societal influences. System integration occurs when the inputs from each circle are optimized.

Person centered practice has particular salience in the context of chronic disease multimorbidity. Many chronic conditions share common lifestyle based contributors. Person centered care highlights common prevention and treatment approaches which may benefit multiple conditions [5]. Conversely, a clinician centered approach tends to focus in a siloed way on the specific biomedical treatments of each chronic condition with an inherent power imbalance between the authoritative role of the clinician and the patient's role as a passive recipient of care. Person centered practice aims to place the person firmly in the driver's seat on their life journey to improved wellbeing with the clinician acting as a guide. It respects individual preferences and empowers the person to take active ownership of their health trajectory.

When health care is holistic and an effective systems approach is used, the importance of biomedicine diminishes, the patient becomes empowered, treatment options expand and outcomes improve. The practice of medicine falters when critical contributory elements of the person's illness, such as psychosocial, environmental or spiritual factors, are not recognized and not sufficiently valued in diagnostic formulation and treatment.

36.4.2 System Integration in the Pain Context

Historically the biopsychosocial model [6] has provided a useful framework for management of pain, as it has for multiple chronic conditions. However there have been and continue to be challenges in implementation. In medically dominated treatment settings there is a risk of paying lip service to the psychosocial and continuing to over-emphasise the biomedical. In some ways this may be less desirable than an explicit biomedical approach because of the lack of transparency involved. The referrer and perhaps patient may start with the expectation of a broader approach that does not materialize. The biomedical approach may have a certain honesty in not professing to be anything more than it is.

These challenges have led to a call to invert the biopsychosocial approach to pain training and practice [7, 8]. The call is made for a sociopsychobiomedical framework that prioritizes sociological and psychological aspects over biomedical.

Another outworking of the biopsychosocial model in the pain context is the whole person approach illustrated in Fig. 36.1 [9]. This seeks to use patient friendly, literacy appropriate language and consists of 5 component parts. The hand model provides a convenient way to represent the concept to patients and to address the multidimensional evidence informing person centered pain management. The usual transition in the CNCP context is away from passively received biomedical treatments and towards the active self-management approaches of mindbody, connection, activity and nutrition.

36.4.3 Biomedical

In acute and cancer pain, medications and procedural interventions can be highly effective. In contrast in CNCP biomedical monotherapies are generally ineffective. There are exceptions, hip arthroplasty surgery for example for the right person at the

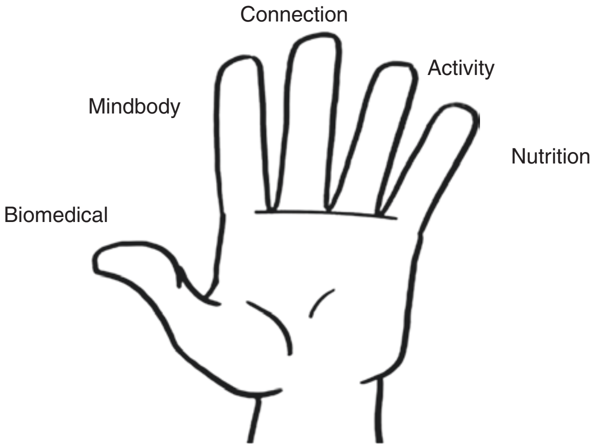


Fig. 36.1 Whole person approach

right time. Yet for most people, medications and interventional procedures are likely to produce more harm than benefit. The ‘whole person’ framing of biomedicine as one fifth part of overall treatment provides a suitable starting context. The utilization of biomedical treatments in CNCP runs the risk of distracting both patient and doctor from the potential advantages of active self-management strategies [10–12] which have generally been found to be more cost effective [13]. Therefore, strategy in CNCP often involves weaning off biomedical treatments and increasing engagement with the other component parts as supported by scientific evidence. Specific biomedical treatments are discussed in greater detail later in the chapter.

36.4.4 Mindbody

It is self-evident that what happens in the body effects the mind. Sensations of threat arising in the body challenge our sense of safety and resultant thought patterns. Reflecting on these thoughts, analysing whether or not they are helpful and their impact on function is part and parcel of the cognitive behavioural approach which has consistently shown benefit for pain and disability [14–16].

It is also true that what happens in our mind impacts our body. The power of focal attention provides a good example. ‘Where attention goes, neural firing flows and neural connection grows’ [17]. We can use our directed attention to lay down new, or strengthen existing, neural pathways.

The neurobiology of threat can be reinforced by our mind’s attention to, or rumination on, negative thought patterns. With this comes activation of the sympathetic nervous system and hypothalamic-pituitary-adrenal (HPA) axis and widespread consequences throughout the body. Alternatively a focus on calm can be used to activate the parasympathetic nervous system, damp down the HPA axis and harness the relaxation response. An example of this is the mindful practice of breath awareness.

Emerging therapeutic approaches which show promise in the mindbody area focus on awareness of bodily sensations and emotions rather than cognitions [18, 19].

36.4.5 Connection

There is an association between the experience of chronic pain and difficulty in social and workplace environments [20]. It has been proposed that social rejection and pain share overlapping neural pathways [21, 22]. As in mindbody interactions the relationship is bidirectional [23]. Chronic pain can on one hand lead to workplace and family problems. On the other hand, aversive social interactions or isolation can worsen pain. People who are isolated from a supportive community feel under threat. Those who are well connected are likely to feel safe. A context of threat can amplify the experience of pain via nervous system sensitization while building a context of safety can be a key part of pain recovery [21].

36.4.6 Activity

Physical activity is important in the prevention and treatment of chronic pain due in part to its impact on nervous system function. Regular planned physical activity results in long term neural adaptations leading to pain reduction via activation of opioid, serotonin and other mechanisms [24].

Pain may be seen as a barrier to participation in physical activity and it is well documented that a single bout of exercise may increase pain intensity [25, 26]. However, in the situation of chronic pain waiting for pain to diminish before increasing activity is counterproductive. Regular ongoing activity is recommended, starting with a small amount that is achievable 'even on a bad day'. Volume can then be increased on a time contingent basis. This avoids the instinctual 'boom and bust' and 'let pain be your guide' approaches and instead aims to reduce avoidance and gradually increase function [27].

No one modality of physical activity has proven superior for chronic pain [28]. Walking is easily accessible and should arguably be the default [29]. However, strength training and other forms of exercise also have a place. Guidelines recommend a combination of aerobic (150–300 min of moderate physical activity per week) and strength based (at least twice a week) exercise [30].

36.4.7 Nutrition

There is a bidirectional relationship between pain and nutrition. Pain can lead to comfort eating and difficulty in accessing good quality food. Poor nutrition can also be a contributor to pain. In part this can be due to the development of multimorbidity or excess body weight overloading tissues [5]. There are also the metabolic consequences of poor diet with the development of a state of low grade systemic inflammation or 'metaflammation' which in turn can sensitize the nervous system and amplify the experience of pain [31]. The impact of diet on the gut microbiome and in turn nervous and immune system function and pain is currently a topic of considerable scientific interest [32, 33].

Nutritional strategies for the treatment of chronic pain overlap with approaches to other chronic conditions and focus on eating vegetables, fruits, legumes, nuts/seeds, low glycaemic index foods, high fibre, antioxidants and high quality fats [34]. It is also important to reduce consumption of energy dense, nutrient poor foods (e.g., processed snacks and take-away foods).

A recent systematic review investigated nutritional interventions for chronic pain [35]. This incorporated meta-analysis of 23 studies which showed that nutritional interventions which altered overall diet composition or those that altered a single macronutrient were more likely than those that tested a supplement or involved fasting to result in significant reduction in pain intensity.

36.4.8 Group Pain Management Programs

Holistic self-management can be supported by interdisciplinary health professionals in either group or individual settings. The group format has resource efficiencies, allows participants to learn from each other and has been the predominant mode of delivery reported in the scientific literature.

The evidence for group programs has been well established over time [36, 37] and across diverse cultural settings [38]. The addition of cognitive strategies to ‘first wave’ behavioural programs brought improved outcomes and in recent decades group programs have been predominantly based on cognitive behavioural principles [39]. However, the magnitude of treatment gains has been called into question with effect sizes ranging from small to medium [16, 40]. Concern has also been raised about duration of treatment effect [41]. Hence there is a need to analyse the component parts of group programs with a view to efficient delivery and maximising cost benefit. The cognitive behavioural model which has provided the theoretical underpinning of a majority of pain management programs reported in the literature has not emphasised for example, emotional awareness and expression or nutrition. It may be that such components of therapy may add value and improve patient outcomes.

Education is a key component of self-management and lends itself to application via the group format [42–44]. Contemporary education addresses the role of the nervous system in pain and the therapeutic hope inherent in neural plasticity [43, 45].

Additional innovations include adoption of standardised group pathways as default to reduce wait times [46, 47] and improve patient flow through group self-assessment and group self-management [48, 49].

36.4.9 Telehealth

Thus far the use of telehealth has been a double-edged sword with benefits of improved healthcare access and challenges of suboptimal patient engagement and equity of care delivery. The onslaught of the COVID-19 pandemic has triggered rapid and exponential adoption of telehealth in most healthcare settings, translating mainstream pain assessment and treatment to telehealth modalities and contexts. There is emerging data on the use of telehealth in pain management with promising results of non-inferior outcomes compared to in-person interactions [50]. It is likely that even after the worst of the pandemic has passed, telehealth will continue to be a viable and preferred option for specific groups of patients.

36.4.10 Primary Care Application

It is recognized that only a small minority of people experiencing CNCP can access specialist pain services and that any increase in pain specific service infrastructure cannot keep up with demand. The majority are hence treated in the primary care setting. The broad approach to pain treatment with lifestyle management can be undertaken in primary care. However, the challenge for primary care physicians is to deliver person centred, multimodal pain treatment via brief, focused appointments over extended time periods to the majority of patients while referring a select minority to specialist services [51].

36.4.11 Cultural and Spiritual Perspectives

Detailed exploration of cultural and spiritual perspectives is beyond the scope of this chapter, nevertheless brief comment may be useful. Person centred pain medicine acknowledges the cultural and spiritual traditions of the person experiencing pain. A study of culture is necessary to inform an understanding of the person within it. Western culture predominantly enshrines the rights and the independence of the individual, Eastern culture responsibility to the collective. In either setting, the person may feel under stress or devalued for being less able to achieve the success of other individuals or less able to contribute to the community. Under such pressure the expression of pain and associated emotions and bodily sensations can be discouraged and leave the person feeling stigmatized [52] and vulnerable.

The major spiritual wisdom traditions have much to say about pain and this can interweave with the influence of culture. Buddhism's noble truths recognize that pain and suffering are a central part of life and that these can be overcome by letting go of personal desire. The Judeo-Christian tradition sees amplified pain as a consequence of Adam and Eve's quest for knowledge, arguable part of the evolution of human consciousness and also as redemptive and transformative. Hinduism promotes stoic acceptance of pain and suffering as a just consequence of previous misdeeds. Islamic tradition notes that where there is suffering there is a way through. Spiritual practices such as group and individual prayer, reading religious texts, chanting, meditation and participation in group philosophical discussions all aid the search for meaning in pain and building connections rather than numbing of pain, thought and consciousness by overuse of medications [53].

Exploration of pain beliefs and pain expressions may be even more challenging in disadvantaged and vulnerable populations. A recent systematic review [54] demonstrated considerable diversity in published literature regarding pain and its management in Indigenous Australians. Beliefs around violation of taboos as cause for pain, cultural preference for bravery, and a sense of shame around expression of some pains, especially in males in leadership roles was noted. It is of significant concern that clinician misconceptions and cultural misunderstandings in culturally unsafe clinical environments can further cause iatrogenic harm. This can result in demoralisation and disempowerment of people weighed down by the burden of multigenerational trauma, displacement and loss.

36.5 The Consequences of an Over-Emphasis on Biomedicine in Chronic Pain Management

In the context of chronic pain there are many negative consequences of an over-emphasis on biomedicine [55]. With regard to assessment the scope of enquiry is diminished and potentially important aspects of the 'whole-person' may be neglected. Less attention is paid to psychological, social, cultural and spiritual aspects. Medical investigations may be over-used. The results of spinal imaging, for example, may be over-interpreted. Formulation consequently runs the risk of excessive focus on potential biological contributors to the pain experience. A bulging lumbar spinal disc may be labelled as the critical diagnostic feature, failing to recognize that many people with a similar abnormality on imaging do not experience pain [56].

The diagnostic focus on bodily structure leads to a parallel biomedical treatment focus which preferences surgery, other procedural interventions or pharmacotherapy. It is not surprising that these medical treatments often achieve poor outcomes and low value care when the diagnostic workup has lacked sufficient breadth in terms of non-biomedical contributors [13].

36.6 Why Pain Management is not more Person-Centered Currently

Multiple factors contribute to an over-emphasis on biomedicine and the potential for therapeutics to move away from scientific evidence. These include health system funding models that provide greater financial return for doctors providing shorter rather than longer consultations and interventional rather than non-interventional treatments, the desire of the doctor to provide a biomedical solution, the influence of pharmaceutical and device company marketing and community expectations of passively received solutions for pain.

Specific issues related to opioids, cannabinoids and procedural interventions are explored below.

36.6.1 Opioids

The effectiveness or otherwise of opioid therapy depends on clinical context. Despite the challenges of trial design [57] opioids have shown consistent benefit in randomized controlled trials in acute pain [58]. Evidence from systematic reviews shows greater variability but overall support for opioid prescription in cancer pain [59, 60] and palliative care [61]. In CNCP the picture is very different. Evidence suggests that there may be modest initial pain reduction when a person with CNCP is commenced on opioids, however this does not lead to significant improvement in function and adverse effects are problematic [62]. Over time the benefits reduce as tolerance [63] and perhaps opioid induced hyperalgesia [64] develop. The longer the period of opioid prescription the greater the likelihood that harms will to outweigh any marginal benefits. Despite lack of efficacy, prescription of opioids for CNCP has increased dramatically in high income countries including the USA [65] and Australia [66]. An increasing opioid associated death rate has paralleled the increase in opioid prescribing [67, 68].

Most opioid trials in CNCP have been of limited duration (typically up to 12 weeks) making extrapolation to long term use questionable. The lack of well-designed long term opioid trials was addressed in 2018 with publication of a 12 month pragmatic randomized controlled trial that compared opioid to non-opioid medication for chronic back, hip or knee pain [69]. The opioid group reported greater pain intensity and more adverse effects throughout the study period. Another pivotal 2018 study found that after discontinuation of long term opioids pain intensity either did not change or improved slightly, even without the application of active self-management strategies [70]. The general rule therefore, according to current evidence, is not to initiate opioids for CNCP and to consider deprescribing in those already on opioid treatment. Depending on the degree of opioid harm the patient may be given a greater or lesser voice in the discussion about deprescribing. If deprescribing is ‘forced’, that is occurring completely against the patient’s wishes, there may be an increased risk of harms including transition to illicit opioids and suicidality [71]. Nevertheless, in routine practice within specialist multidisciplinary pain services, opioid deprescribing plans are commonly negotiated between patients, general practitioners and the specialist team. In this setting patients who achieve opioid cessation report greater pain reduction and improvement in function than those who reduce to a lesser extent or maintain or increase opioid dose [72].

Some chronic pain patients have comorbid opioid dependency (substance use disorder). If this is the dominant problem then maintenance opioid therapy via an addiction medicine pathway can be considered along with psychosocial interventions [73].

36.6.2 Cannabinoids

The current situation with ‘medicinal’ cannabis is similar to that of prescription opioids in the late 1980’s and 1990’s. In many countries legislation has been passed to make cannabis available for treatment of pain. This has occurred despite a body of scientific evidence suggesting that cannabinoids are only minimally effective or not effective at all, and carry significant risk of adverse effects [74]. In a detailed systematic review Stockings and colleagues found the number needed to treat was 24 (95% confidence interval 15–61) for 30% reduction in pain. The pooled change in pain intensity (standardised mean difference: −0.14, 95% CI −0.20 to −0.08) was equivalent to a 3 mm reduction on a 100 mm visual analogue scale greater than placebo. In contrast the number needed to harm was 6 (95% CI 5–8). There were no significant improvements in physical or emotional functioning with cannabinoid treatment. It is possible that future research may define subgroups of people with CNCP that derive greater efficacy and less harm from cannabinoid treatment. However, if we are prepared to learn from the history of opioid mismanagement, cannabinoids should not be used for treatment of CNCP outside a registered clinical trial or research setting at the present time [75].

36.6.3 Procedural Interventions

Procedural interventions, like opioids, have a predictable and evidence based benefit in acute pain and perioperative settings [58]. There is also reasonable evidence of effectiveness in the cancer setting, for example with a neurolytic coeliac plexus block [76]. However, the picture becomes much less clear in CNCP. A major obstacle, as with any form of biomedical treatment, is the potential to distract the recipient and provider from consideration of active self-management strategies. Although in theory the recipient may use the pain reduction of a procedure to increase engagement with self-management, this is difficult to achieve in practice. For example, Molloy and colleagues found that when an implanted intrathecal pump system was used in combination with an intensive cognitive behavioural therapy (CBT) program the outcomes were worse than CBT used in isolation [77]. This raised the possibility that the implant interfered with patient motivation and engagement with self-management.

Another obstacle is the limited duration of potential benefit derived from procedures. Local anaesthetic blocks last several hours, the addition of steroid may increase duration to several weeks. Radiofrequency thermal neurotomy can last months. The difficulty is that unless the person is able to make substantial life changes they are no better once the block wears off. The therapeutic ritual of the procedure may reinforce the passive behaviour of simply waiting for the next medical ‘fix’.

Procedural ‘neuromodulation’ provides an interesting example of biomedical treatment and associated marketing moving ahead of scientific evidence, with spinal cord stimulation a particular case in point. When the term ‘neuromodulation’ is applied exclusively to procedural interventions it demonstrates a lack of recognition that all of life is in fact a neuromodulating experience. The shackling of the neuromodulation term to procedural intervention narrows the patient’s expectation of the benefits of achieving neuroplasticity by active self management.

In high income countries spinal cord stimulation has increasingly been used to treat radicular leg pain and more recently axial back pain. This expansion of indication has been fostered by enthusiastic procedural doctors, the marketing of device companies and the desire of recipients for a quick passive biomedical option. Very few high quality studies had been undertaken until the advent of high frequency stimulation (HFS) with the possibility of patient blinding. Two double blind randomized controlled trials have been undertaken comparing HFS to placebo. The first showed no difference between HFS and placebo [78]. The second trial compared 3 different high frequency patterns (1200 Hz, 3030 Hz and 5882 Hz) to placebo; Two patterns were no better than placebo and the third (5882 Hz) was modestly better than placebo in terms of pain reduction with no difference in disability [79]. Despite such modest results spinal cord stimulation is considered by proponents to be an established treatment. Clearly further research is required exploring both efficacy and cost effectiveness before such an expensive therapy can rightly be accepted into routine clinical practice.

The intention of the authors is not to dismiss the role of pharmacotherapies or procedural interventions in the treatment of pain. However current evidence suggests that if treatment outcomes are to improve, the role of biomedicine must decrease and that of person centered self-management must grow.

36.7 Practical Implications for the Implementation of Person-Centered Care

36.7.1 Benefits of Greater Person Centeredness

The attempt to treat a person’s body in isolation from their mind and socioenvironmental context is an act of violence to their humanity. To treat them as a whole person is an act of restoration. To work in this way is not only helpful to the patient but also to the clinicians who treat them. Outcomes improve, patient-clinician collaboration is encouraged and the undue focus of the health system on biomedicine is returned to a point of balance.

36.7.2 Challenges to more Widespread Implementation of Person Centered Pain Medicine

Many challenges stand in the way of widespread implementation of person centered pain medicine. The Western societal belief in a dualism of mind and body is a major obstacle, which prioritizes treatment of the body over that of the mind. In reality mind and body are inseparable. Thus to promote mindbody treatment is part of the solution as it begins to dismantle the dividing wall of dualism.

Another challenge is that it takes courage to put aside, for a time, the distraction of the outer and quietly reflect upon our inner world. To the extent that clinicians are avoidant of their own inner journey they are restricted in their capacity to offer this to their patients. Recipients of health care may have their own resistance to looking within. This may influence them in the direction of external biomedical treatments rather than a more internally focused line of psychotherapy.

Mind and body interweave in interesting ways. The process of energy and information flow that constitutes mind is both embodied and relational [3]. Emotions arise out of the sensations of the body and in turn influence our behaviour. In the pain context, many of the pharmacotherapies blunt awareness of bodily sensations and emotions. They can be used to shield the resistant person from discomforting sensations and emotions. Thus the use of such medications can become an obstacle to the deepening awareness required to bring behavioural change and restoration of health and wellbeing.

Undoubtedly the structure and functioning of health systems is an obstacle to person centered pain medicine. Doctors are financially rewarded predominantly for providing biomedical treatments. The pharmaceutical and device companies reinforce this approach. In many countries and health systems mindbody and other more holistic therapies are not prioritized.

36.7.3 Measuring Outcomes of Implementation

Measuring the outcomes of person centered pain medicine needs to be multidimensional. Measures chosen should tap into the multiple dimensions of the person's experience within their family, society and environment. Pain intensity is a critical outcome measure. However for this to be meaningful it must be combined with measures of physical and psychological functioning. The overly enthusiastic attempt to abolish a person's chronic pain with medications that diminish cognitive and physical function results in a poor overall outcome.

In Australia [80] and the USA [81] large multidimensional data sets are now in use to compare outcome measures across pain services. Such big data analysis of 'real world' practice, as opposed to the somewhat 'artificial' world of randomized controlled trials, will play an increasingly important part in guiding practice improvement in the new era of better value health care.

Any meaningful contemporary analysis of health care interventions also needs to examine financial, social and environmental outcomes [82, 83]. For example, with high tech medical devices the carbon footprint of production and maintenance needs to be considered. Hypothetically, if a 50% reduction in pain intensity is achievable either with a carbon neutral self-management program or via a spinal cord stimulator with its substantial carbon footprint then the former is to be preferred. Recent evidence shows that health care accounts for 10% of the total carbon footprint of the USA compared to only 4% for the UK and 7% for Australia [84]. Pharmaceuticals account for 19% of total health care carbon emissions in Australia [84]. Hence deprescribing medication and other health system efficiencies may bring environmental benefit.

36.7.4 Future Challenges

A major future challenge is to continue to build an environment more conducive to person centered pain medicine. A strategic approach that targets multiple facets is required. The behaviour change wheel [4] provides a useful framework for such change and highlights the patient, clinician and policy opportunities for change. Helpful policy changes might include aligning regulation and funding to evidence informed care, promotion of team based models of care and support of community education, perhaps beginning at school.

36.8 Conclusions

In many countries there is an emphasis on biomedicine in the treatment of CNCP. Specialist multidisciplinary pain services may offer a different and more person centered approach to patients who are able to gain access. The challenge of enhancing outcomes for people experiencing CNCP involves continuing to improve access to, and performance of, specialist sector practice while also addressing practice in the primary care setting where the majority of people are treated.

Acknowledgements and Disclosures One author (CH) works at Hunter Integrated Pain Service, at John Hunter Hospital, a tertiary referral facility, in Newcastle, New South Wales, Australia. The whole person approach described above is the basis of treatment. The standard patient pathway is group based and participants can complete the program without any individual appointments [48]. People can be specifically triaged to individual assessment and/or treatment as the need arises. The overall approach encourages people to consider the multiple contributors to their experience of pain and then collaborate with the team to develop a management plan with personalized goals. There is an emphasis on first developing the connection between health professional and participant before potentially redirecting the person into more evidence informed treatment. This typically involves gradual weaning of medical treatments and supported transition to self-management. The

person centered approach recognizes the right of the participant to engage or not with such recommendations. Some choose discharge from the pain service because of a preference to continue with a predominant focus on medical treatments.

Pain service discharge involves a return to general practitioner led treatment. A discharge letter outlines recommendations from the pain service which again emphasize the whole person approach and its potential application in primary care [51].

The other author (HR) works at both Hunter Integrated Pain Service and at the Tamworth Integrated Pain Service, a tertiary multidisciplinary hospital-based service in Tamworth, in regional New South Wales, Australia. She is a woman of Indian heritage who brings her cultural perspective and knowledge of living and working amongst people of various religions in India and Singapore. She has a strong focus on developing sustainable models of care in rural and regional Australia with an insider/outsider lens on Aboriginal health, given India's colonial past. The pain service at Tamworth also has a multidisciplinary and broad approach to chronic pain management, using innovative telehealth based models of care and incorporating Aboriginal cultural safety in every clinical interaction. Patient story and context is respected and the patient journey through the service is strongly guided by patient choice. Patients are encouraged to develop meaningful practical goals and take ownership of their self-management.

References

1. Treede RD, Rief W, Barke A, Aziz Q, Bennett MI, et al. Chronic pain as a symptom or a disease: the IASP Classification of Chronic Pain for the International Classification of Diseases (ICD-11). Pain. 2019;160(1):19–27. https://doi.org/10.1097/j.pain.0000000000001384.
2. Nicholas M, JWS V, Rief W, Barke A, Aziz Q, et al. The IASP taskforce for the classification of chronic pain the IASP classification of chronic pain for ICD-11: chronic primary pain. PAIN. 2019;160(1):28–37. https://doi.org/10.1097/j.pain.0000000000001390.
3. Siegel DJ. Mind: A journey to the heart of being human. New York, London: Norton; 2017.
4. Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. Implement Sci. 2011;6:42. https://doi.org/10.1186/1748-5908-6-42.
5. Bruggink L, Hayes C, Lawrence G, Brain K, Holliday S. Chronic pain: overlap and specificity in multimorbidity management. AJGP. 2019;48(10):689–92.
6. Engel GL. The need for a new medical model: a challenge for biomedicine. Science. 1977;196(4286):129–36.
7. Carr DB, Bradshaw YS. Time to flip the pain curriculum? Anesthesiology. 2014;120(1):12–4. https://doi.org/10.1097/ALN.0000000000000054.
8. FPM ANZCA Curriculum (2015). http://fpm.anzca.edu.au/training/2015-training-program. Accessed 27 October 2019.
9. White R, Hayes C, White S, Hodson FJ. Using social media to challenge unwarranted clinical variation in the treatment of chronic non-cancer pain: the 'Brainman' story. J Pain Res. 2016;9:701–9.
10. Bair MJ, Matthias MS, Nyland KA, Huffman MA, Stubbs DL, Kroenke K, Damush TM. Barriers and facilitators to chronic pain self-management: a qualitative study of primary care patients with comorbid musculoskeletal pain and depression. Pain Med. 2009;10(7):1280–90. https://doi.org/10.1111/j.1526-4637.2009.00707.x.
11. Blyth F, March LM, Nicholas MK, Cousins MJ. Self-management of chronic pain: A population-based study. Pain. 2005;113(3):285–92. https://doi.org/10.1016/j.pain.2004.12.004.

12. Kim S, Slaven JE, Ang DC. Sustained benefits of exercise-based motivational interviewing but only among non-users of opioids in patients with fibromyalgia. J Rheumatol. 2017;44(4):505–11. https://doi.org/10.3899/jrheum.161003.
13. Turk D. Clinical effectiveness and cost-effectiveness of treatment for patients with chronic pain. Clin J Pain. 2002;18(6):355–65.
14. Richmond H, Hall AM, Copsey B, Hansen Z, Williamson E, Hoxey-Thomas N, Cooper ZL, SE. The effectiveness of cognitive behavioural treatment for non-specific low back pain: a systematic review and meta-analysis. PLoS One. 2015;10(8):e0134192. Published online 2015 Aug 5. https://doi.org/10.1371/journal.pone.0134192.
15. Skelly AC, Chou R, Dettori JR, Turner JA, Friedly JL, Rundell SD, Fu R, Brodt ED, Wasson N, Winter C, Ferguson AJR. Noninvasive nonpharmacological treatment for chronic pain: a systematic review [Internet]. Rockville (MD): Agency for Healthcare Research and Quality (US); 2018, Report No.: 18-EHC013-EF. AHRQ Comparative Effectiveness Reviews
16. Williams AC, Eccleston C, Morley S. Psychological therapies for the management of chronic pain (excluding headache) in adults. Cochrane Database Syst Rev. 2012;11:CD007407. https://doi.org/10.1002/14651858.CD007407.pub3.
17. Siegel DJ. Aware: the science and practice of meditation. London: Scribe; 2018.
18. Fogel A. Body sense: The science and practice of embodied self-awareness. New York: Norton; 2009.
19. Lumley MA, Schubiner H, Lockhart NA, et al. Emotional awareness and expression therapy, cognitive behavioral therapy, and education for fibromyalgia: A cluster-randomized controlled trial. Pain. 2017;158(12):2354–63. https://doi.org/10.1097/j.pain.0000000000001036.
20. Dueñas M, Ojeda B, Salazar A, Mico JA, Failde I. A review of chronic pain impact on patients, their social environment and the health care system. J Pain Res. 2016;9:457–67. https://doi.org/10.2147/JPR.S105892.
21. Eisenberger NI. The neural bases of social pain: evidence for shared representations with physical pain. Psychosom Med. 2012;74(2):126–35. https://doi.org/10.1097/PSY.0b013e3182464dd1. Epub 2012 Jan 27
22. Kross E, Berman MG, Mischel W, Smith EE, Wager TD. Social rejection shares somatosensory representations with physical pain. Proc Natl Acad Sci U S A. 2011;108(15):6270–5. https://doi.org/10.1073/pnas.1102693108.
23. Edwards RR, Dworkin RH, Sullivan MD, Turk DC, Wasan AD. The role of psychosocial processes in the development and maintenance of chronic pain. J Pain. 2016;17(9):T70–92.
24. Sluka KA, Frey-Law L, Bement MB. Exercise induced pain and analgesia? Underlying mechanisms and clinical translation. Pain. 2018;159(9):S91–7.
25. Dailey DL, Keffala VJ, Sluka KA. Cognitive and physical fatigue tasks enhance pain, cognitive fatigue and physical fatigue in people with fibromyalgia. Arthritis Care Res (Hoboken). 2015;67:288–96.
26. Smith BE, Hendrick P, Smith TO, et al. Should exercises be painful in the management of chronic musculoskeletal pain? A systematic review and meta-analysis. Br J Sports Med. 2017;51:1679–87. https://doi.org/10.1136/bjsports-2016-097383.
27. Racine M, Jensen MP, Harth M, Morley-Forster P, Nielson WR. Operant learning versus energy conservation activity pacing treatments in a sample of patients with fibromyalgia syndrome: a pilot randomised controlled trial. J Pain. 2019;20(4):420–39.
28. Booth J, Moseley GL, Schiltenwolf M, Cashin A, Davies M, Hubscher M. Exercise for chronic musculoskeletal pain: A biopsychosocial approach. Musculoskeletal Care. 2017;15(4):413–21.
29. O'Connor SR, Tully MA, Ryan B, Bleakley CM, Baxter GD, Bradley JM, McDonough SM. Walking exercise for chronic musculoskeletal pain: systematic review and meta-analysis. Arch Phys Med Rehabil. 2015;96(4):724–734.e3.
30. Brown, WJ., Bauman, AE., Bull, FC., Burton, NW. (2012). Development of evidence-based physical activity recommendations for adults (18-64 years). Report prepared for the Australian Government Department of Health. https://www1.health.gov.au/internet/main/publishing.nsf/content/F01F92328EDADA5BCA257BF0001E720D/$File/DEB-PAR-Adults-18-64years.pdf

31. Hayes C, Naylor R, Egger G. Understanding chronic pain in a lifestyle context: the emergence of a whole person approach. Am J Lifestyle Med. 2012;6(5):421–9.
32. Boer CG, Radjabzadeh D, Medina-Gomez C, Garmaeva S, Schiphof D, et al. Intestinal microbiome composition and its relation to joint pain and inflammation. Nat Commun. 2019;10(1):4881. https://doi.org/10.1038/s41467-019-12873-4.
33. Minerbi A, Gonzalez E, Brereton NJB, Anjarkouchian A, Dewar K, Fitzcharles MA, Chevalier S, Shir Y. Altered microbiome composition in individuals with fibromyalgia. Pain. 2019;160(11):2589–602.
34. Australian Government. Australian guide to healthy eating. Canberra: National Health and Medical Research Council and Department of Health and Ageing, 2017. eatforhealth.gov.au. Accessed 10 September 2019.
35. Brain K, Burrows TL, Rollo ME, Chai LK, Clarke ED, Hayes C, Hodson FJ, Collins CE. A systematic review and meta-analysis of nutrition interventions for chronic noncancer pain. J Hum Nutr Diet. 2019;32:198–225. https://doi.org/10.1111/jhn.12601.
36. Flor H, Fydrich T, Turk DC. Efficacy of multidisciplinary pain treatment centres: a meta-analytic review. Pain. 1992;49:221–30. https://doi.org/10.1016/0304-3959(92)90145-2.
37. Gatchel RJ, Okifuji A. Evidence-based scientific data documenting the treatment and cost-effectiveness of comprehensive pain programs for chronic non-malignant pain. J Pain. 2006;7:779–93. https://doi.org/10.1016/j.jpain.2006.08.005.
38. Cardosa M, Osman ZJ, Nicholas M, Tonkin L, Williams A, Abd Aziz K, Ali RM, Dahari NM. Self-management of chronic pain in Malaysian patients: effectiveness trial with 1-year follow-up. Transl Behav Med. 2012;2(1):30–7. https://doi.org/10.1007/s13142-011-0095-2.
39. Morley S, Eccleston C, Williams A. Systematic review and meta-analysis of randomized controlled trials of cognitive behaviour therapy and behaviour therapy for chronic pain in adults, excluding headache. Pain. 1999;80:1–13.
40. Kamper SJ, Apeldoorn AT, Chiarotto A, Smeets RJ, Ostelo RW, Guzman J, van Tulder MW. Multidisciplinary biopsychosocial rehabilitation for chronic low back pain. Cochrane Database Syst Rev. 2014;2(9):CD000963. https://doi.org/10.1002/14651858.CD000963.pub3.
41. Chipchase LS, Sheffield D, Hill PA. The long-term effectiveness of pain management programs: a systematic review and meta-analysis. J Pain Manag. 2012;5(3):215–30.
42. Joypaul S, Kelly F, McMillan SS, King MA. Multi-disciplinary interventions for chronic pain involving education: A systematic review. PLoS One. 2019;14(10):e0223306. https://doi.org/10.1371/journal.pone.0223306.
43. Moseley GL, Butler DS. Fifteen years of explaining pain: the past, present, and future. J Pain. 2015;16(9):807–13. https://doi.org/10.1016/j.jpain.2015.05.005.
44. Tegner H, Frederiksen P, Esbensen BA, Juhl C. Neurophysiological pain education for patients with chronic low back pain: a systematic review and meta-analysis. Clin J Pain. 2018;34(8):778–86. https://doi.org/10.1097/AJP.0000000000000594.
45. Malfiet A, Kregel J, Meeus M, Danneels L, Cagnie B, Roussel N. Patients with chronic spinal pain benefit from pain neuroscience education regardless of the self-reported signs of central sensitization. Phys Med Rehabil. 2018;10:1330–43.
46. Davies S, Quintner J, Parsons R, Parkitny L, Knight P, Forrester E, Roberts M, Graham C, Visser E, Antill T, Packer T, Schug SA. Preclinic group education sessions reduce waiting times and costs at public pain medicine units. Pain Med. 2011;12(1):59–71. https://doi.org/10.1111/j.1526-4637.2010.01001.x.
47. Hayes C, Hodson FA. A whole person approach to persistent pain: from conceptual framework to practical application. Pain Med. 2011;12(12):1738–49.
48. Rajappa H, Wilson M, White R, Blanchard M, Tardif H, Hayes C. Prioritizing a sequence of short-duration groups as the standardized pathway for chronic noncancer pain at an Australian tertiary multidisciplinary pain service: preliminary outcomes. Pain Rep. 2019;4(5):e780. https://doi.org/10.1097/PR9.0000000000000780.
49. Smith N, Jordan M, White R, Bowman J, Hayes C. Assessment of adults experiencing chronic non-cancer pain: A randomized trial of group versus individual format at an Australian tertiary pain service. Pain Med. 2016;17(2):278–94.

50. Eccleston C, Blyth FM, Dear BF, Fisher EA, Keefe FJ, Lynch ME, Palermo TM, Reid MC, Williams A. Managing patients with chronic pain during the COVID-19 outbreak: considerations for the rapid introduction of remotely supported (eHealth) pain management services. Pain. 2020;161(5):889–93. https://doi.org/10.1097/j.pain.0000000000001885.
51. Holliday S, Hayes C, Jones L, Gordon J, Harris N, Nicholas M. Prescribing wellness: comprehensive pain management outside specialist services. Aust Prescr. 2018;41(3):86–91.
52. Cohen M, Quintner J, Buchanan D, Nielsen M, Guy L. Stigmatization of patients with chronic pain: the extinction of empathy. Pain Med. 2011;12(11):1637–43. https://doi.org/10.1111/j.1526-4637.2011.01264.x.
53. Rajappa H, Hayes C. People, medicine, and society: An overview of chronic pain management. Arch Med Health Sci. 2020;8:68–74.
54. Arthur L, Rolan P. A systematic review of western medicine's understanding of pain experience, expression, assessment, and management for Australian aboriginal and torres strait islander peoples. Pain Rep. 2019;4(6):e764. https://doi.org/10.1097/PR9.0000000000000764.
55. Crowley-Matoka M, Saha S, Dobscha S, Burgess D. Problems of quality and equity in pain management: exploring the role of biomedical culture. Pain Med. 2009;10(7):1312–24.
56. Brinjikji W, Luetmer PH, Comstock B, Bresnahan BW, Chen LE, Deyo RA, Halabi S, Turner JA, Avins AL, James K, Wald JT, Kallmes DF, Jarvik JG. Systematic literature review of imaging features of spinal degeneration in asymptomatic populations. Am J Neuroradiol. 2015;36(4):811–6.
57. Gilron I, Carr DB, Desjardins PJ, Kehlet H. Current methods and challenges for acute pain clinical trials. J Pain Rep. 2019;4(3):e647.
58. Schug SA, Palmer GM, Scott DA, Halliwell R, Trinca J. APM:SE Working Group of the Australian and New Zealand College of Anaesthetists and Faculty of Pain Medicine, Acute Pain Management: Scientific Evidence. 4th ed. Melbourne: ANZCA & FPM; 2015. p. 194–220.
59. Koyyalagunta D, Bruera E, Solanki DR, Nouri KH, Burton AW, Toro MP, Bruel BM, Manchikanti L. A systematic review of randomized trials on the effectiveness of opioids for cancer pain. Pain Physician. 2012;15:ES39–58.
60. Wiffen PJ, Wee B, Derry S, Bell RF, Moore RA. Opioids for cancer pain—an overview of Cochrane reviews. Cochrane Database Syst Rev. 2017;6(7):CD012592. https://doi.org/10.1002/14651858.CD012592.pub2.
61. Jansen K, Haugen DF, Pont L, Ruths S. Safety and effectiveness of palliative drug treatment in the last days of life—a systematic literature review. J Pain Symptom Manag. 2018;55(2):508–521.e3.
62. Busse JW, Wang L, Kamaleldin M, Craigie S, Riva JJ, Montoya L, Mulla SM, Lopes LC, Vogel N, Chen E, Kirmayr K, De Oliveira K, Olivieri L, Kaushal A, Chaparro LE, Oyberman I, Agarwal A, Couban R, Tsoi L, Lam T, Vandvik PO, Hsu S, Bala MM, Schandelmaier S, Scheidecker A, Ebrahim S, Ashoorion V, Rehman Y, Hong P, Ross S, Johnston BC, Kunz R, Sun X, Buckley N, Sessler D, Guyatt GH. Opioids for chronic noncancer pain: a systematic review and meta-analysis. JAMA. 2018;320(23):2448–60. https://doi.org/10.1001/jama.2018.18472.
63. Ballantyne JC, Shin NS. Efficacy of opioids for chronic pain: a review of the evidence. Clin J Pain. 2008;24(6):469–78. https://doi.org/10.1097/AJP.0b013e31816b2f26.
64. Higgins C, Smith BH, Matthews K. Evidence of opioid-induced hyperalgesia in clinical populations after chronic opioid exposure: a systematic review and meta-analysis. Br J Anaesth. 2019;122(6):e114–26. https://doi.org/10.1016/j.bja.2018.09.019. Epub 2018 Oct 25
65. Boudreau D, Von Korff M, Rutter CM, Saunders K, Ray GT, Sullivan MD, Campbell CI, Merrill JO, Silverberg MJ, Banta-Green C, Weisner C. Trends in long-term opioid therapy for chronic non-cancer pain. Pharmacoepidemiol Drug Saf. 2009;18(12):1166–75. https://doi.org/10.1002/pds.1833.
66. Karanges EA, Blanch B, Buckley NA, Pearson SA. Twenty-five years of prescription opioid use in Australia: a whole-of-population analysis using pharmaceutical claims. Br J Clin Pharmacol. 2016;82:255–67.

67. Centers for Disease Control and Prevention 2017. https://www.cdc.gov/drugoverdose/data/statedeaths/drug-overdose-death-rate-increase-2013-2017.html
68. Penington Institute. Australia's annual overdose report. Melbourne: Penington Institute; 2019.
69. Krebs EE, Gravely A, Nugent S, Jensen AC, DeRonne B, Goldsmith ES, et al. Effect of opioid vs. nonopioid medications on pain-related function in patients with chronic back pain or hip or knee osteoarthritis pain: The SPACE randomized clinical trial. JAMA. 2018;319:872–82.
70. McPherson S, Lederhos Smith C, Dobscha SK, Morasco BJ, Demidenko MI, Meath THA, et al. Changes in pain intensity after discontinuation of long-term opioid therapy for chronic noncancer pain. Pain 2018;159:2097–104.
71. Glare P, Ashton-James C, Han E, Nicholas M. Deprescribing long-term opioid therapy in patients with chronic pain. Intern Med J. 2020;50(10):1185–91. https://doi.org/10.1111/imj.15023.
72. Tardif H, Hayes C, Allingham S. Opioid cessation is associated with reduced pain and improved function in people attending specialist chronic pain services. Med J Aust. 2021;214(9):430–2. https://doi.org/10.5694/mja2.51031.
73. Hruschak V, Cochran G, Wasan AD. Psychosocial interventions for chronic pain and comorbid prescription opioid use disorders: A narrative review of the literature. J Opioid Manag. 2018;14(5):345–58. https://doi.org/10.5055/jom.2018.0467.
74. Stockings E, Campbell G, Hall WD, Nielsen S, Zagic D, Rahman R, Murnion B, Farrell M, Weier M, Degenhardt L. Cannabis and cannabinoids for the treatment of people with chronic non-cancer pain conditions: a systematic review and meta-analysis of controlled and observational studies. Pain. 2018;159(10):1932–54. https://doi.org/10.1097/j.pain.0000000000001293.
75. FPM ANZCA PM10. (2019). Statement on "Medicinal Cannabis" with particular reference to its use in the management of patients with chronic non-cancer pain. http://fpm.anzca.edu.au/documents/pm10-2018.pdf. Accessed 3 May 2021.
76. Eisenberg E, Carr DB, Chalmers TC. Neurolytic celiac plexus block for treatment of cancer pain: a meta-analysis. Anesth Analg. 1995;80(2):290–5.
77. Molloy AR, Nicholas MK, Asghari A, Beeston LR, Dehghani M, Cousins MJ, Brooker C, Tonkin L. Does a combination of intensive cognitive-behavioral pain management and a spinal implantable device confer any advantage? A preliminary examination. Pain Pract. 2006;6(2):96–103.
78. Perruchoud C, Eldabe S, Batterham AM, Madzinga G, Brookes M, Durrer A, Rosato M, Bovet N, West S, Bovy M, Rutschmann B, Gulve A, Garner F, Buchser E. Analgesic efficacy of high-frequency spinal cord stimulation. Neuromodulation. 2013;16:363–9. https://doi.org/10.1111/ner.12027.
79. Al-Kaisy A, Palmisani S, Pang D, Sanderson K, Wesley S, Tan Y, McCammon S, Trescott A. Prospective, randomized, sham-control, double blind, crossover trial of subthreshold spinal cord stimulation at various kilohertz frequencies in subjects suffering from failed back surgery syndrome (SCS Frequency Study). Neuromodulation. 2018;21(5):457–65. https://doi.org/10.1111/ner.12771.
80. Tardif H, Arnold C, Hayes C, Eagar K. Establishment of the Australasian electronic persistent pain outcomes collaboration. Pain Med. 2017;18(6):1007–18. https://doi.org/10.1093/pm/pnw201.
81. Dressler AM, Gillman AG, Wasan AD. A narrative review of data collection and analysis guidelines for comparative effectiveness research in chronic pain using patient-reported outcomes and electronic health records. J Pain Res. 2019;12:491–500. https://doi.org/10.2147/JPR.S184023.
82. Australian Medical Association. (2019). Environmental Sustainability in Health Care – 2019. https://ama.com.au/position-statement/environmental-sustainability-health-care-2019
83. Sustainable Development Unit. Reducing the use of natural resources in health and social care. London: NHS England, Public Health England; 2018. Available from: https://www.sduhealth.org.uk/policy-strategy/reporting/natural-resource-footprint-2018.aspx
84. Malik A, Lenzen M, McAlister S, McGain F. The carbon footprint of Australian health care. Lancet Planet Health. 2018;2018(2):e27–35.

Chapter 37
Person-Centered Palliative Care

Odette Spruijt, Dante E. Manyari, Rachel Halpin-Evans, and Paul Glare

37.1 Introduction

The care of patients with incurable, progressive disease who are approaching the end of life has challenged physicians and the health care system from the outset [1]. Even as there were striking advances of medical care in the twentieth century, many inadequacies of end-of-life care continued to be evident. In response to this situation, the modern hospice movement was established in the 1960's. As it evolved over the next 60 years, it led to the development of palliative care and the speciality of palliative medicine.

Unlike the other medical specialities discussed in this section of the textbook, hospice/palliative care arose outside the practice of mainstream medicine. As will be discussed, this enabled the pioneers of hospice/palliative care to take a very person-centered approach that would not have been possible within the existing healthcare model. Despite the effectiveness of hospice/palliative care in relieving

---

O. Spruijt (✉)
University of Melbourne, Melbourne, VIC, Australia
e-mail: Odette.Spruijt@petermac.org

D. E. Manyari
Department of Cardiology, University of British Columbia, Vancouver, BC, Canada

Cardiology Department, Surrey Memorial Hospital, Surrey, BC, Canada

R. Halpin-Evans
Sydney Children's Hospital, Westmead, NSW, Australia
e-mail: rachel.halpinevans@health.nsw.gov.au

P. Glare
Northern Clinical School, Faculty of Medicine and Health, University of Sydney,
Sydney, NSW, Australia

Memorial Sloan-Kettering Cancer Center and Weill Cornell Medical College,
New York, NY, USA
e-mail: paul.glare@sydney.edu.au

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_37

suffering associated with serious illness [2], it continues to be a challenge to establish this approach into mainstream medicine, healthcare education and globally, into healthcare systems. There continues to be marked global disparity and unmet need for palliative care for adults and children with advanced illness [3].

37.2 What is Palliative Care?

In 2020, a new consensus definition of palliative care was published, building upon the previously accepted World Health Organisation (WHO) definition. The new definition states that palliative care is “the active holistic care of individuals across all ages with serious health-related suffering (SHS) due to severe illness and especially of those near the end-of-life. It includes the prevention, early identification, comprehensive assessment and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress and social needs” [4]. In this definition, the emphasis is on need arising from unrelieved suffering, moving away from a focus on end-of-life care alone. It emphasises the focus on the relief of health-related suffering associated with any illness and for any age group and aims to accommodate the earlier integration of palliative care in the course of illness. It also seeks to increase the scope of palliative care practice in response to both patient needs and health care system capacity. For example, in India, palliative care services provide care for patients with paraplegia, stroke, old age and debility, psychiatric illness and many other chronic illnesses, when other community-based health care is not available [5, 6]. This revised definition has a strong evidence base and is supported by major national and international organizations [7]. However, the field of palliative care continues to debate the definition, scope and focus of this speciality [8], perhaps not surprising given the diversity of needs, resources, services available, patterns of development and associated funding models observed internationally. Continued dialogue and a willingness to encompass diversity within the specialty, while adhering to the core principles of person-centredness that underpin this speciality, will help to sustain the differences many of which arise from local needs and particularities.

The earlier integration of palliative care into the care of patients with oncological and other advanced illnesses has been supported by leading healthcare organisations and research for over 20 years [9–11]. However, despite this, it has proven difficult to convince patients, the public, and even healthcare providers, of this upstream migration of palliative care, with many continuing to associate palliative care exclusively with end-of-life care [8].

37.3 The Origins of Modern Palliative Care-a Brief History

The origins of palliative care lie in the British hospice movement of the mid-twentieth century. The hospice movement, founded by Dame Cicely Saunders, arose out of a concept of hospitality, of welcome of the ‘other’, who is suffering and dying [12]. She wrote of her commitment to openness to all who would come, and to intellectual rigour coupled with a 'friendship of the heart, the vulnerability of one person before another' and that "We need our personal meetings with dying people if we are to remain human and true to (*these*) original commitments' [13]. Australian palliative care pioneer, Norelle Lickiss, echoes this insight, noting that 'Interpersonal solidarity remains the lynch pin' [14] for the relief of that suffering which involves loss of personal coherence or integrity. Saunders's focus on the person with illness and the uniqueness of their physical, social, spiritual, emotional and psychological suffering, contrasted with the increasingly disease-focus of the practice of medicine of the mid-twentieth century [15]. She coined the term 'total pain' in 1964 to describe the suffering arising from the multidimensional impact of illness upon a person, described to her by a patient as 'all of me is wrong' [16]. She wrote about the many layers contributing to the experience of pain which need to be explored in the terminally ill, as in all patients and emphasised that an exploration of the meaning which they give to their pain is an important key to relieving that pain.

> 'A cry just to be rid of pain is not worthy of man … Man by his very nature finds that he has to question the pain he endures and seek meaning in it.' [17].

Without finding a sustaining meaning in their experience, chronic cancer pain becomes 'timeless, endless, bringing a sense of isolation and despair' [17].

By the mid-1980s 'total pain' had become firmly established as a central concept within the emerging palliative care specialty [18, 19]. It has proved a useful concept in clinical work, in teaching and research, succinctly articulating the 'assembling of heterogeneous phenomena within the domains of pain' [19], namely the physical, psychological, social, spiritual domains which contribute to the experience of pain, without hierarchy; they are interactive and responsive to each other, and to interventions directed toward each component.

Drawing on this understanding of pain, clinicians are challenged to widen their gaze beyond the biomedical and strive to understand and respond to the complexity of person with illness. Indeed, the concept of total pain may well be judged as one of the most innovative concepts yet to emerge from the field of palliative care.

This origin story characterises palliative care and constitutes its roots and place in medical practice. Australian author and social commentator, Richard Flanagan [20] writes that a country needs a depth story, such as those of the Aboriginal dreaming and creation stories, to sustain, unite and direct it forwards. Our depth story in palliative care is about hospitality, the welcome of the 'other', recognising in this 'stranger' the common condition of human suffering, and responding with all the means at one's disposal, including the person and presence of the palliative care practitioner. It will be important to retain connection to this origin story, as the speciality diversifies and responds to modern day challenges.

From this early work of Saunders, the field of palliative medicine and hospice care has established itself internationally [21]. For example, in the early 1970's, Balfour Mount, a urologic cancer surgeon, was inspired by a presentation on Kubler-Ross's book "On Death & Dying". This prompted him to survey the standard of terminal care at his hospital, the prestigious Royal Victoria Hospital (RVH) in Montreal. He described the results of the survey as "catastrophic". In response, he visited Saunders at her south London-based hospice, St Christopher's, and observed what could be achieved in relieving suffering. On returning to Montreal, he elected to establish a hospice-style ward within RVH rather than trying to create the independent, free-standing type of unit he had seen in St Christopher's. Furthermore, being in Montreal, he couldn't call use the term "hospice" because this means "nursing home" in French. So he coined the term "palliative care", derived from the Latin, "pallium" meaning cloak, symbolising symptom control as providing a cover over the problem, when the underlying cause is irreversible. This symbol suggests a nurturing element of wrapping the sufferer with care and embrace and echoes the hospitality or welcome of the other of Saunders' original insight. The launch of this ward marked the entry of "palliative care" into its modern English usage. The World Health Organization's Technical Reports on Cancer Pain Relief and Palliative Care [22, 23] also provided an important authoritative basis for the development of this specialty.

Nowadays, consultative services, community-based practice and inpatient palliative care units constitute the contemporary specialist palliative care triad. In addition, day hospices, outpatient clinics, and public health programs have emerged [7]. In 2014, the World Health Assembly (WHA) resolved that palliative care be part of mainstream health care systems throughout the life course ([24] Resolution 67.19). While the WHA included palliative care in the WHO global action plan for the prevention and control of non-communicable diseases 2013–2020, as previously noted, there remains a global lack of access to palliative care and a pressing need to establish palliative care and pain management as part of the WHO strategic planning toward universal health coverage [3].

Differentiating between the generic palliative care principles and skills needed by all clinicians of all disciplines, involved in the relief of suffering, and those required by specialist palliative care providers, has encouraged the spread of knowledge and skills beyond the specialist field. Palliative care providers have been leading proponents of education in pain and other symptom management, communication skills and advance care planning, end-of-life care and ethical decision-making. In recognition of the complexity of person, and multitude of needs present at the end-of-life, competent interdisciplinary teams, involving doctors, nurses, physiotherapists, pharmacists, social workers, pastoral carers, occupational therapists and volunteers, are ideal for the delivery of palliative care [7]. However, where resources are limited, practitioners attempt to be attuned to the person and at the very least, recognise, acknowledge, bear witness to, and validate the suffering of their patients. This witnessing is, in itself, is a healing human act [25]. Importantly, palliative care has been focused on quality of life through to death, rather than on death itself. As Saunders so eloquently and movingly stated, "You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die." [26].

37.4 The Concept of Person-Centredness in Palliative Care

Conceptual thinking about personhood has occupied philosophers, historians, developmental psychologists, sociologists, and theologians [14] but has been lacking in medicine. Physicians have intimate professional involvement with persons but may lack an articulate concept of what person is [14]. There is need for such a conceptualisation which resonates with physicians' experience and frame of reference, and which may enrich understanding in the face of the current widespread thrust, more marked in 21C, for 'person- centred medicine'. Person-centered medicine attempts to address this gap in understanding by giving expression to the professional experiences of clinicians of varied expertise, of their lived experience with the suffering and distress of patients, to articulate the elements of medical care that entail healing and humanistic care [27]. The understanding of person-centredness which guides this textbook is "of the person, for the person, by the person and with the person". If palliative medicine is to achieve its fundamental aim of the relief of suffering, this conceptualization of personhood rightly occupies a particular claim on our attention.

Despite the lack of conceptual clarity about what constitutes 'person' in medicine, the terminology of person-centered care is now widely used in the medical literature, and often used interchangeably with patient-centeredness. However, it is proposed that person-centeredness differs from patient-centeredness on several grounds. For example, a 'person' exists before a 'patient' and encompasses many dimensions beyond patient-ness. In particular, the notion of 'person' is highly relational, including relationships with health care professionals but extending far beyond [28].

The physician and bioethicist Eric Cassell wrote about the concept of person in medicine over 40 years ago, and recognised that 'suffering is experienced by persons' [29], not bodies. Therefore, it is necessary to look at the concept of person carefully and comprehensively. He offered a typology of person which presents the multifaceted nature of person in the health context. Persons have a body, regular behaviours and are able to do things. They have personality and character, a past, life experiences and memories, family and/or other important relationships, spiritual or existential dimension, hopes, a perceived future, roles, culture, and is a social and political being. In addition, persons have a secret life, fantasies, and dreams [29, 30]. Any and all of these dimensions may be affected by health-related suffering and provide an avenue for healing engagement. Cassell [29] also identified that in addition to relieving patient suffering, medicine may also contribute to suffering, largely through a decreased capacity to address the subjective experience of the person with illness and an unwillingness to operate without certainty, leading to excessive intervention and investigation.

Lickiss developed an ecological relational understanding of person, which stresses that "person is a relational reality, a web as it were, of relationships in a dynamic whole" [14]. In this model, relationships are constitutive of personhood; we are constantly in flux, in an intersubjective, reciprocally interacting world of experience [31]. Understanding this intersubjective framework is important in clinical practice, as we as health care practitioners, are components of the intersubjective world of the patient. We also bring our own subjectivities to the encounter [32]. When a dialogical encounter takes place, something not of either alone but arising in the "realm of the 'between'", [33] may emerge,through meeting [34], and offer possibilities of healing change.

Vafiadis' [35] model of bidirectional care refocuses attention on the person of the doctor in palliative care, in which the humanity of the doctor meets with the humanity of the patient. He suggests that such bidirectional care is more evident in end-of-life care, as the distance between the professional (with expertise) and the patient (in need) is less than that which is seen in other domains of specialist medical care and where the capacity that patients have to share of themselves, in interhuman connection, may be given more expression.

37.5 Practical Implications for Person-Centered Palliative Care

37.5.1 Key Factors to Assess the Implementation of Person-Centered Palliative Care

With the renewed focus on the relief of suffering in recent years, palliative care has restated its commitment to person-centered care. The importance of relational care was emphasised in a narrative study in which palliative care doctors in Australia and India stressed the importance of forming connection with their patients, of listening to them and being present in that moment with them. Despite the cultural differences and the different resources available across the two countries of practice, all participants emphasised their focus on the person with illness, their understanding of the multidimensional nature of suffering and therefore, the need for multidimensional responses. Abhit described the need to 'be that person's friend enough so that he is able to bring out what is most important to that person' [36].

Palliative care, to remain true to its origins and genius of honouring the dialogical nature of care, needs to retain its focus on the person with illness, and on the relational delivery of care and to do so while also striving to increase access and availability of palliative care for all who need this care.

Organizations such as The Joint Commission have described the necessary components of an accreditable palliative care program (https://www.jointcommission.org/accreditation-and-certification/certification/certifications-by-setting/hospital-certifications/palliative-care-certification/). Outcomes such as symptom control, time on hospice, health care utilization and place of death have been measured and been shown to improve with palliative care [2]. The need for a single measure of "palliative net benefit" has also been called for [37]. But demonstrating that the delivery of care of such care is truly relational is not easy.

37.5.2 The Extent to Which Current Palliative Care is Actually Person-Centered

In the public health response to COVID-19, the relational understanding of person was subsumed in the wide-ranging restrictions on visiting family members in hospitals, nursing homes and hospices in most countries struggling with controlling the spread of the virus. The devastating impact of this loss of relationship at times of medical crises and life-threatening illness, was experienced by patients, families and caregivers, and also by healthcare professionals [38, 39]. The depth of distress calls for a new understanding of person in relation to others, which can be sustained in tangible ways despite public health crises such as pandemics. Relational being is not an optional extra, but a core dimension of being a human person.

Expanding this understanding of person-centered care to explicitly include relationship-centred care offers insights to sustain practitioners and systems as well as improve the quality of patient care. There are tensions to be held, rather than solved, in attending to multiple relationships and demands of modern interdisciplinary, team-based healthcare. Organisational theorists have developed programs to help foster change through non-hierarchical engagement of all levels within the organisation, with focus on the social, interpersonal and behavioural factors of healthcare [40]. Compassionate, cooperative leadership, attentive to the wellbeing of team members, where there is a shared vision, and an acceptance of death and dying, has been suggested as contributing to the observed lower incidence of burnout among palliative care providers [41].

Advocacy to governments to make palliative care an essential component of universal health coverage is achieving a broader understanding of relieving health-related suffering through a person-centered approach [42]. This essential package of palliative care includes not only medications and equipment, but also paid staff to administer and monitor medications and support patients and their caregivers [43]. In addition, ongoing advocacy to ensure access to essential medicines, including opioids, is essential [44–46]. The COVID-19 pandemic has brought new focus on the need to incorporate palliative care into pandemic and humanitarian crisis responses [47].

There is marked global inequity in the relief of serious health-related suffering (SHS) [3, 48]. ASCO developed resource-stratified guidelines for the implementation of palliative care [49]. Enabling palliative care providers from high income areas to become advocates and partners with colleagues in low-and-middle-income countries through official training programs, offered in partnership between institutions from both settings, may provide an important avenue for global improvement [50]. Resources and guidelines assist new providers to integrate palliative care into existing health care [7, 49]. Other examples of international models of collaboration can be found in the Lien Foundation-sponsored, ‘Train the Trainer’ program; the Palliative Care-Promoting Access and International Cancer Experience (PC-PAICE) quality improvement project, led by the Stanford University Palliative Care department, in collaboration with the Stanford Clinical Excellence Leadership

Training (CELT) program [51]; in the International Association of Hospice and Palliative Care advocacy action; and in mentoring projects such as Project Hamrahi, a collaboration between Pallium India and Australasian Palliative Link International which aims to foster the development and sustainability of new services in India [52].

Increasing the palliative care workforce includes the non-specialist health care provider. Key competencies in palliative care include symptom control, communication expertise especially in delivering difficult news and coping with emotional distress and developing ethical awareness and understanding. In India, while there is no incorporation of discrete palliative care training into the undergraduate curriculum, key competencies have been embedded across all years of training in the Attitudes, Ethics and Communication (AETCOM) program established in 2019 [53]. Integrating palliative care into primary health care is another important strategy for reducing global inequities in health care [54].

Opportunities to improve access to person-centered palliative care also arise from technological advances which support educational initiatives, not only nationally but internationally. With the COVID-19 pandemic impacting on the capacity to hold in-person education, there has been an upsurge in the adoption of videoconferencing for education and virtual conferences in 2020. This has democratized knowledge access and may result in ongoing changes beyond the pandemic era. One program, Project ECHO (Extension for Community Healthcare Outcomes) predated the pandemic and was well placed to provide a platform for many more institutions and organisations. From origins in University of New Mexico, USA, in 2003, Project ECHO has gained international prominence and utilisation, with hundreds of programs in over 40 countries [55]. Project ECHO has been adopted by many specialist palliative care providers, for clinical care and teaching purposes. The project facilitates peer-to-peer learning, through shared case discussion and decision making, as well as learning opportunities, creating a knowledge network and community of practice [56]. For example, Hospice UK has used Project ECHO to build relationships with other health care services, to help increase their confidence and capacity to deliver end-of-life care in any setting [57].

37.5.3 Specific Barriers that Interfere with the Implementation of Person-Centered Palliative Care

There are many barriers to providing person-centered palliative care. The understanding of palliative care remains limited as is knowledge of symptom management and other core skills [58].

Organisational modern medicine continues to favour the focus on the physical dimension of person in neglect of the non-physical [15]. This is apparent in multidisciplinary team meetings MDMs in general and specialist medicine in which the diagnostic and interventional aspects of care are discussed but little is discussed about the person with illness. While the physical is the specialist zone of medicine, this dualistic separation hampers healthcare's ability to advance. The reasons for this separation in practice are many. There are tensions in meeting workload demands, which therefore limit the time available for discussion. Much of medical practice is active doing, fixing, solving problems. Recognising the more subjective aspects of patient care requires a different lens, often more experiential and reflective. Most MDMs function on the assumption that cure or life prolongation is the self-evident goal of patients, family and staff. The patient's priorities are seldom identified or discussed; they do not feature as guiding principles of clinical decision-making. If identified the focus of the discussion and the leadership of the MDM discussion might vary accordingly for each patient. If it is cure of an early cancer diagnosis, staging and diagnostic discussion is likely to be consistent with the person's priorities. If it is symptom management, a different discussion is needed. If it is spiritual distress, again a different discussion. If it is home-based management, community nursing might be invited to lead discussion.

Other barriers include resource constraints for health care providers and for family members, stigma attached to palliative care, death and dying, socioeconomic deprivation and lack of education, and the impact of distance on the accessibility of professional care. Time constraints are also a major barrier to person-centered care, especially in low-and-middle-income countries, where a doctor may be seeing 70 patients an outpatient clinic [59].

37.5.4 What Would Have to Change in Health Systems and Actual Practice to Enable or Facilitate more Person-Centered Palliative Care

There is the ongoing challenge of embedding palliative care into health care, at both the public health level and institutional health care level. This is not just in lower resourced countries, but also within high income countries, in their more remote communities, in vulnerable communities such as prisoners, homeless, people affected by humanitarian crises and by drug addiction, and in paediatric care (National Palliative Care Strategy 2018). Palliative care remains a more Westernised concept in health care, with poor understanding in some cultural groups. For example, in New Zealand, where palliative care is well-integrated and established in general, the Pacific populations have limited access to, and low understanding of, palliative care [60]. Adapting services to meet the needs of people of all cultures within multicultural societies calls for greater cultural competence and engagement and may challenge notions of autonomy, truth telling and shared decision making [61, 62]. More exploration into the needs of marginalised or disadvantaged populations is required, but presents practical and ethical complexities, resulting in systematic neglect in both research and care provision.

Particular challenges arose in 2020 in response to the COVID-19 pandemic, which brought into focus the lack of access to palliative care and equitable universal health care in many countries, including in the USA, one of the countries most severely affected by the pandemic. The need for comprehensive public health systems into which palliative care services are well integrated, was highlighted.

It remains a tension to balance the risks of opioids with the imperative to ensure access to essential opioids for pain relief. While inadequate access is more critical in low-and-middle-income countries, barriers are again not confined to these regions [63]. Increasing regulation leading to overly cautious opioid prescribing is impacting on the availability of essential opioids in palliative care, even in high income countries, and is described as a "pernicious reverse problem" to overprescribing [44].

It is challenging to retain the focus on person within organisational systems of care. Current trends (e.g., towards brokering of care, outsourcing of tasks to other services and increasing referrals without adequate service-capacity growth) are challenging the development of a meaningful relationship with patients. Health care services are largely organised around delivery of services and provision of interventions. Greater efficiency is recognised as an important aspect of quality of practice. Protocolised care details the pathways and processes for health care providers. Reducing delays and waiting times, facilitating timely reviews and discharges, coordinating investigations and appointments, careful and correct provision of medications for appropriate time periods, anticipating likely eventualities and planning for these, are all aspects of efficiency which are person-centered and enhance the patient experience. However, all processes and protocols need humanising to be truly effective in meeting the needs of persons. For example, many palliative care community services in Australia prefer to have injectable medications prescribed and available in the home, in case of emergency. However, not all patients want these medications in their homes and for those who are referred earlier in their disease trajectory, the presence of injectables, syringes, and locked containers with opioid medications, can be confronting. Services are challenged to recognise the impact and messaging which these medications communicate to patients and carers, while also responsibly anticipating possible complications and emergency needs in the future care of that person. Similar sensitivity is required on admission to a palliative care service. Many services discuss resuscitation plans on admission. However, when also advocating for earlier integration of palliative care and concurrent care with life-prolonging measures, automatic exclusion of resuscitation including blood transfusion, antibiotics and palliative chemotherapy on admission to palliative care services, while it may be practical, may also be at odds with person-centered care.

37.6 Palliative Care for Diagnoses Other than Cancer

The specialty of palliative care largely grew out of a response to the needs of patients with cancer, and little was known about the needs of patients dying from causes other than cancer. Few patients with illnesses other than cancer, received hospice in-patient, home care or day care even though many hospices stated that their services were available to patients with any diagnosis [64]. The needs and experiences of patients dying from conditions such as stroke, heart disease or dementia and the importance of palliative care for such patients became increasingly recognized by the beginning of the twenty-first century. Policy makers recommended that palliative care should be accessible to all patients who need such care, and that integration of palliative care into patient care improves outcomes but recognised that this raises a number of important questions regarding service provision. Here we discuss specific issues related to the integration of palliative care into cardiac disease management.

Decades of medical advances in cardiology have significantly improved the life expectancy in patients with cardiac disease. As disease burden progresses despite optimal medication regimens, patients may be candidates for interventions such as implantable cardiac defibrillators (ICD) and/or bi-ventricular pacing (BVP). Selected patients may be candidates for ventricular assist devices, cardiac transplantation, transcatheter aortic valve implantation, or mitral valve repair. These advances have improved the prognosis of some cardiovascular disorders even further. However, increased longevity is often associated with more complex life-sustaining measures in patients with increasing disabilities. Thus, despite advances in therapy, there is a point when sustaining life may be associated with little subjective gain for the patient with poor and diminishing quality of life. With this increasing burden of disease and its management primary attention should be focused on diminishing suffering rather than life-prolongation. Over the last decade or two, it has become increasingly evident that palliative care in cardiology is akin to palliative care for patients with advanced, incurable cancer [65, 66]. Some guidelines suggest that palliative care should sometimes be introduced early rather than later in the disease process [67], so called parallel treatment, as is also advocated in the care of patients with advanced cancer [68].

As in oncological palliative care, the role of the palliative care team in cardiology spans several domains, from symptom control, psychological wellbeing, improved communication between health care teams, help with advance care planning, optimization of community supports, provision of respite and caregiver relief, and end-of-life care. It can be provided in various settings, including hospital, hospice, and the patient's own home [66]. Palliative care acknowledges that patients can live a long time while receiving both curative/therapeutic/symptomatic treatments as well as supportive care. There is a common misconception that palliative care is synonymous with hospice care and dying, and some physicians perceive a transition to palliative care as a defeat. As a result, palliative care referrals are commonly initiated after life-prolonging measures have been exhausted, care has become too burdensome and death is imminent, thereby limiting the benefits patients can receive through receiving earlier palliative measures. Therefore, there are calls for education on palliative care during the cardiology fellowship training [65].

The cardiac palliative health care team should include specialists in palliative care, cardiology, a social worker, pharmacist, nurses, a psychologist, and a spiritual advisor. Protocols should be in place for patient intake and follow-up visits as needed. Although a systematic approach may be helpful to the health care organization, patients will be best served by individualized care. Each patient may be affected by the same clinical condition differently, not only in physical and functional terms, but also emotional and socially. Each has unique ways to respond to the same challenge. Therefore, care should be individualized especially if we consider that each individual has his/her own set of values, beliefs and priorities. By definition, a person-centred approach is best suited to fulfill the needs of the patient and family, following the principles that have been outlined [69].

Thus, the main message of this section is to practice true person-centred care when managing patients with chronic heart disease by considering early referral to the palliative care team, not in order to transfer care but to work alongside the cardiac team, and to incorporate the palliative care perspective in treatment planning discussions with the patient and their carers.

37.7 Key Issues in Cardiology Palliative Care

1. **Palliative Cardiac Care in Persons with Advanced Heart Disease (AHD):** Among patients with obvious need for palliative cardiology care are those with class IV heart failure who are not candidates for cardiac transplantation, those with destination left ventricular assist devices, symptomatic patients with advanced coronary artery disease who are not candidates for revascularization, and patients with valvular heart disease who are not candidates for valve intervention. These patients benefit from person-centred care aimed at palliating symptoms, and providing mental and spiritual comfort. In addition, the palliative health care team must use available local resources in accordance with the wishes and objectives of each individual patient and family.
2. **End-of-Life (EOL) in a Person with Heart Failure:** One can arrange for a home-care nurse team to provide *intermittent IV positive inotropic agents* at home or in hospital to a patient with end-stage heart failure to prevent multiple re-hospitalizations. Only a person-centered approach is practical to achieve this shared decision after appropriate discussions with the patient, family and other members of the health care team. Often at the EOL, patients want to spend their last few days in the comfort and intimacy of their homes, with their family, friends, pets around them, rather than dying in a hospital setting. The cardiologist who is able to facilitate this personal mode of dying, and honour the patient's wishes in this way, is offering their patients a great service. This does however require considerable care coordination and advance planning to ensure that community services, medications, and timely death certification will be available to the patient and their family at the end of life.
3. **End-of Life in a Person with an Implantable Cardioverter Defibrillator (ICD):** In patients with an ICD, it is critical to have EOL conversations because of the complications this device can cause if the patient dies. This may be difficult because in practice approximately 40% of patients would prefer to not have an EOL discussion about deactivation of the ICD [70]. Recipients of ICDs rarely

have directions regarding ICD deactivation in their advanced directives or living wills [71]. The physician wishing to provide the best person-centred care therefore, has to be able to introduce the topic of deactivation of the ICD with empathy and understanding, and proceed carefully as guided by the patient. This task should be the responsibility of the most trusted person on the team in the patient's eyes, usually the senior physician involved in their care. It may also be wise at the time of ICD insertion to include a general discussion of the aims and limitations of this treatment and that it may need to be deactivated if the patient reaches a more advanced stage of their heart disease or other medical complications. In the context of EOL discussions, the topic of *if and when to deactivate the ICD* should be included. Indeed, guidelines advise providers to have discussions about EOL scenarios with all patients with an ICD, but despite these recommendations, it is not often done [70] It is up to the cardiology community wishing to provide good quality person-centred care to address this omission, by enhancing their capacity to better educate and counsel patients with ICDs about the limitations of this intervention, well in advance of their imminent dying and certainly to avoid inappropriate activation of the ICD in the dying patient [72]. Factors to be included in the discussion before making a shared-decision regarding deactivation of the ICD include most importantly the patient's prognosis, severity of symptoms, alternative treatments, recurrence of appropriate shocks, and own wishes. Other factors that may influence the shared decision are family and religious concerns and beliefs. The health care team should be an active participant in the shared-decision making by providing timely and pertinent information, communicating clearly with other health care team members, being available to answer the questions of patient and family, and being supportive of their decisions without biases or pressure. A third set of important factors to consider is the clinical scenario and the role that the ICD plays in the health of the particular patient. In some, the ICD is therapeutic and the patient may be brought to life every time a shock is delivered. With a few exceptions, the time of the next shock can't be predicted. In other scenarios, the ICD may deliver shocks that are not appropriate, due to malfunction or because of electrical artefacts. Another scenario is pump failure and circulatory shock, with death not being the result of an electrical problem, but the ICD will deliver electrical shocks that are "appropriate' by design but inappropriate for the clinical circumstance. Knowledge of these potential scenarios and how they apply to the patient's own clinical situation are crucial information the patient must receive from the cardiology team to make a well informed shared-decision.

Patients with an ICD who are doing well with their cardiac illness but have an unrelated life-limiting condition, such as disseminated cancer, represent a unique clinical scenario. In this circumstance, the question of the continuing benefit of ICD therapy should be raised as defibrillation can cause physical discomfort and emotional distress to the patient, and also distress to their families [73]. Professionals have a duty of care to consider withdrawal of non-helpful therapies and the distress caused by resuscitation measures in those near the EOL with an irreversible health decline. The goals of care can change if clinically appropriate, and it is ethically acceptable to withdraw such therapy if that is consistent with the patient's preferences. Initial discussions regarding ICD deactivation should start when the patient is felt to be approaching the end-of-life and should be incorporated in the local Do Not Attempt Resuscitation (DNAR) policies. In general, maintaining an ICD in active defibrillation mode is inconsistent with a DNAR order. There are guidelines with suggestions and recommendations to follow as to when to deactivate ICDs [74] but in our opinion, each patient has a unique clinical scenario and we need to consider not only the affecting illness but the physical, mental, sociocultural, and spiritual aspects of the person. In summary, discussions on when to deactivate an ICD should involve the patient, the family, and all members of the health teams. The final shared-decision should be consistent with the patient's wishes and preferences. The role of the health care teams is informative and supportive of the patient's decisions.

4. **Palliative Cardiology Care on Hospice**: When the prognosis is poor and the likelihood of survival is days or weeks, a decision needs to be made about optimum place of care for the comfort and well-being of the patient and family. Options may be home with home-care assistance, hospice or may take place in hospital. One reason to consider hospice care is the relief and support it can provide family members. The hospice-based palliative care team then takes charge of all decisions, with the assistance of the cardiology team.

37.8 Pediatric Palliative Care

37.8.1 How is Paediatric Palliative Care Person-Centred?

Paediatricians recognised the need for children to have access to palliative care clinical expertise and services by the late 1970s [75]. The origins of paediatric palliative care as a speciality discipline is rather more complex than those of its adult parent. Helen House, the world's first children's hospice opened its doors in late 1982. Located in East Oxfordshire, England, Helen House was founded by Sister Frances Dominica, a nurse and Anglican Nun. The hospice was born through a friendship that Sister Frances developed with a family whose two-year-old daughter, Helen, had suffered a profound neurological injury following surgery to remove a brain tumour, and who required around-the-clock care (source: www.icpcn.org/a--global-history-of-childrens-palliative-care/, accessed June 23 2020). A few years later (1986), Dr. Ann Goldman, the first ever Consultant in Paediatric Palliative Care (PPC) established the Symptom Care Team at Great Ormond Street Hospital for Children, London, England. This was the first multi-disciplinary specialist paediatric palliative care team and has since grown to become the largest specialist PPC team in Europe.

Over the past three decades, PPC has established itself as a specialist field of medical expertise, and much like any new speciality, has faced challenges as it has done so [75, 76]. Many of the core skills required are similar to its adult counterpart, yet there is considerable heterogeneity among the practitioners of PPC, drawing many from the fields of oncology, neurodisability and rehabilitation, community paediatrics, intensive care and acute pain. While this has been of significant benefit in developing clinical services and expertise to care for children with diverse symptomatology, it has represented challenges in establishing consistent standards in clinical expertise, education and research [75]. Paediatric Palliative Medicine has continued to grow across the world throughout the twenty-first Century and was recognised formally as a sub-speciality in the USA in 2006 and in the UK in 2009.

In 2018, the World Health Organisation stated that under 20-year-olds made up 35% of the global population, and up to 40% of the population of the world's least-developed nations [77]. They estimated that the number of children (neonates, infants, children and adolescents up to 19 years of age) needing paediatric palliative care each year could be as high as 21 million. There can be no doubt, therefore, that there is growing need for PPC services to ensure the prevention and relief of suffering in children with life-limiting and life-threatening illness.

Pediatric palliative care is fundamentally "patient centred and family engaged" [76]. The WHO states that palliative care is integral to people-centred health care services. Further, that "nothing is more people-centred than relieving their suffering, be it physical, psychological, social or emotional" [78]. At its core, paediatric palliative care's purpose is to advocate for the best possible quality of life and care for children with life-limiting or life-threatening illness and for their families. Key to this is ensuring patient and family choice; choice in terms of place of end-of-life care and place of death, and choice in spiritual, emotional and bereavement support.

Together for Short Lives is the umbrella organisation for PPC in the UK. It defines palliative care for children and young people as "an active and total approach to care, from the point of diagnosis, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family". It goes on to mention that palliative care for children and young people (CAYP) "includes the management of distressing symptoms, provision of respite breaks, care at the end-of-life and bereavement support" (www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/introduction-childrens-palliative-care/ accessed June 23 2020).

Practitioners working in either adult palliative care or PPC would identify similarities in the fundamentals of their practice; namely, an approach to individual patient care aimed at augmenting and maintaining quality of life, while at the same time promoting dignity and comfort [79]. There are, however, significant differences in the needs of their respective patient populations and therefore in practice.

While the majority of adult patients with palliative care needs traditionally have cancer, more than two-thirds of children and young people with life-limiting and life-threatening illness have non-malignant conditions. Unlike the adult population, the disease trajectory for children living with life-limiting conditions often spans many years and is frequently punctuated by acute, life-threatening events. One such example is acute apnoea, secondary to mucus plugging of the airways and is often seen in children with swallow insufficiency, such as those with cerebral palsy.

Through an intimate understanding of the individual patient, and how he or she is affected by their condition, the paediatric palliative care clinician is able to anticipate that such emergencies may arise and ensure that children and families have access to medications and equipment (such as oropharyngeal suction machines), across home, hospice and school.

Key to patients maintaining good quality of life, is impeccable symptom management. Thus, the cornerstone of paediatric palliative care in practice is providing patients and their families with individualised symptom management plans (SMPs). SMPs are integrated into the practice of PPC in many parts of the world fortunate to have well established services. Typically, authors are clinicians with an expert understanding of the particular life-limiting or life-threatening condition, and intimate knowledge of how said condition affects the individual patient, for whom the plan is being written. The SMP document will summarise the clinical context of the individual child and provide a list of anticipated, or potential symptoms that may arise during the course of their illness, or end-of-life. Each symptom is then listed in turn, with a detailed plan of current treatment, as well as options for treatment escalation, should the child's condition change or deteriorate [79].

Authors must take into consideration the child's individual context as well as their family circumstance, language comprehension, their school provision and access to healthcare. The SMP must cater for lay parents and caregivers, and health professionals alike. It is then shared with the patient's family, their GP, local hospital and ambulance service.

The general unpalatability for needles and injections among the paediatric and adolescent population requires practitioners caring for such patients to become adept at using novel routes for medication administration (such as buccally), rarely utilised by adult practitioners [79].

Another key difference between adult palliative care and PPC is that commonly, active, disease-directed therapy continues alongside the input and support of the palliative care team [79]. As mentioned above, many children with life-limiting illness experience long disease trajectories, punctuated by episodic—sometimes life-threatening—deterioration, from which they often recover. The benefits of timely referral to a palliative care service are many, but not least the crucial ability to foster strong therapeutic alliance between patients and their families over time.

In the parts of the world with access to PPC teams, care can over time (often years) be provided to children with life-limiting or life-threatening illness at home, at hospice and at hospital. This is certainly the case in the U.K, Australia and the U.S.A, although there are some differences with the model of care in the U.S.A in that "hospice care" is a separate entity to palliative care, and specifically relates to care in the last six months of life. Commonly, PPC teams will visit children across all three of these settings. Consequently, its practitioners will often be uniquely positioned to have detailed knowledge of the child's condition when 'well', adding valued and trusted opinion to discussions with paediatric intensive care teams and retrieval teams upon whom there is increasing bed pressure. An essential part of the role of PPC clinicians is, when appropriate, to advocate for patients with life-limiting illness who may benefit from an admission to PICU for treatment of a potentially reversible cause for acute deterioration. Equally important, is the role that PPC clinicians play in supporting the often-tricky discussions with families at times when children are not responding to life-saving or prolonging therapies.

In the U.K. for example, in such circumstances where the consensus decision is that on-going intensive care for a child is futile and therefore its burden heavily outweighs any benefit to the child, families are, where possible, offered choice as to the place in which intensive care should be removed, be that in hospital, at the child's home or in a hospice.

One of the benefits of early palliative care referral is, much like a personalised SMP, the child and family have opportunity to discuss and document their wishes both in terms of treatment escalation in the setting of acute deterioration, as well as their choices for end-of-life care, in a supported and informed manner. This document is often called an 'Emergency Care Plan' (or Advance Care Plan).

While some families may feel that formalising such decisions in document form is somewhat confrontational, advance care plans are not a legally binding document. The document represents the thoughts of the child, family and clinicians at the time that it was written and is a useful framework for other clinicians to work with at the time of an acute deterioration. It is best reviewed at least annually, in discussion with the child and their family or if the child's condition changes.

As mentioned earlier, another complexity faced by PPC teams is in caring for children and families who may be living with life-limiting illness for a number of years. In some instances, this can be from birth. While there is interaction with the child, the communication in terms of the disease process is with the family or caregivers. This can pose a challenge as children and young people get older. Those working in PPC must be able to navigate how information is imparted to the child as they become more mature and develop, enabling their understanding of their own condition, while also respecting the thoughts and wishes of their parents or caregivers.

The principles of PPC are applicable throughout the child's entire lifespan, yet the PPC practitioner must pay careful attention to the physical, developmental, socio-psycho, spiritual and ethical phenomena that are unique to children. The sharing of information is often particularly challenging. Many paediatric patients may have felt a sense of "Why don't the doctors talk to me?" quickly become "Why do they now ONLY talk to me?" after they have gone through the transition process [79]. This is another nuanced area of PPC and its practitioners are often skilled in supporting both medical practitioners, parents and young people in the developmentally appropriate dissemination of information.

37.9 Conclusions

Much has been done in the past half-century to address the suffering of the person with advanced, progressive and life-limiting illness. Person-centeredness drove the approach taken by Saunders and the hospice movement while it operated in a relatively small number of charity-funded hospices, located outside the mainstream and predominantly caring for British adults with end-stage cancer. Maintaining this pre-eminence of person-centeredness becomes much more challenging when palliative care is part of the mainstream and is taken to scale around the world, across the lifespan, and independent of diagnosis and prognosis.

Acknowledgements and Disclosures The authors do not report conflicts of interest in the preparation of this manuscript.

References

1. Szabo J. Incurable and Intolerable: chronic disease and slow death in nineteenth-century france. New Brunswick NJ: Rutgers University Press; 2009.
2. Davis MP, Temel JS, Balboni T, Glare P. A review of the trials which examine early integration of outpatient and home palliative care for patients with serious illnesses. Ann Palliat Med. 2015;4:99–121.
3. Knaul, F. M., Farmer, P. E., Krakauer, E. L., De Lima, L., Bhadelia, A., Kwete, X. J., Arreola-Ornelas, H., Gómez-Dantés, O., Rodriguez, N. M., Alleyne, G. A. O., Connor, S. R., Hunter, D., , Lohman, D., Radbruch, L., Del Rocío Sáenz Madrigal, M., Atun, R., Foley, K. M., Frenk, J., Jamison, D. T., Rajagopal, M. R. & on behalf of the Lancet Commission on Palliative Care and Pain Relief Study Group. 2018. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report. Lancet, 391, 1391-1454.
4. Radbruch L, De Lima L, Knaul F, Wenk R, Ali Z, Bhatnaghar S, Blanchard C, Bruera E, Buitrago R, Burla C, Callaway M, Cege Munyoro EC, Centeno C, Cleary J, Connor S, Davaasuren O, Downing J, Foley K, Goh C, Gomez-Garcia W, Harding R, Khanh QT, Larkin P, Leng M, Luyirika E, Marston JSM, Osman H, Pettus K, Puchalski C, Rajagopal MR, Spence D, Spruijt O, Venkateswaran C, Wee B, Woodruff R, Yong J, Pastrana T. Redefining palliative care—a new consensus-based definition. J Pain Symptom Manag. 2020;60(4):754–64.
5. Paleri ANM. The evolution of palliative care programmes in North Kerala. Indian J Palliat Care. 2005;11:15–8.
6. Singh T, Harding R. Palliative care in South Asia: a systematic review of the evidence for care models, interventions, and outcomes. BMC Res Notes. 2015;8:172. https://doi.org/10.1186/s13104-015-1102-3.
7. Gómez-Batiste X, Connor S, editors. Building integrated palliative care programs and services. World Hospice and Palliative Care Alliance; 2017.
8. Ryan S, Wong J, Chow R, Zimmermann C. Evolving definitions of palliative care: upstream migration or confusion? Curr Treat Options Oncol. 2020;21(3):1–20. https://doi.org/10.1007/s11864-020-0716-4.
9. Institute of Medicine (US) and National Research Council (US) National Cancer Policy Board. Improving palliative care for cancer: summary and recommendations. In: Foley KM, Gelband H, editors. Washington, DC: National Academies Press (US); 2001.
10. Cherny N, Catane R, Schrijvers D, Kloke M, Strasser F. European Society for Medical Oncology (ESMO) Program for the integration of oncology and Palliative Care: a 5-year review of the Designated Centers' incentive program. Ann Oncol. 2010;21:362–9.
11. Smith TJ, Temin S, Alesi ER, Abernethy AP, Balboni TA, Basch EM, Ferrell BR, Loscalzo M, Meier DE, Paice JA, Peppercorn JM, Somerfield M, Stovall E, Von Roenn JH. American Society of clinical oncology provisional clinical opinion: the integration of palliative care into standard oncology care. J Clin Oncol. 2012;30:880–7.

12. Saunders C. A personal therapeutic journey. BMJ. 1996;313:1599–601.
13. Saunders C. The evolution of palliative care. Patient Educ Couns. 2000;41:7–13.
14. Lickiss JN. On facing human suffering. In: Malpas J, Lickiss JN, editors. Perspectives on human suffering. Springer Science+Business Media B.V.; 2012. p. 245–60, 256.
15. James N, Field D. The routinization of hospice: charisma and bureaucratization. Soc Sci Med. 1992;34:1363–75.
16. Saunders C. Care of patients suffering from terminal illness at St. Joseph's Hospice. Hackney, London: Nursing Mirror; 1964. p. vii–x.
17. Saunders C. The moment of truth: care of the dying person. In: Pearson L, editor. Death and dying: current issues in the treatment of the dying person. Cleveland: The Press of Case Western Reserve University; 1969. p. 49–78.
18. Clark D. `Total pain', disciplinary power and the body in the work of Cicely Saunders, 1958–1967. Soc Sci Med. 1999;49:727–36.
19. Gunaratnam Y. Learning to be affected: social suffering and total pain at life's borders. Sociol Rev. 2012;60:108–23.
20. Flanagan R. The world is being undone before us. If we do not reimagine Australia, we will be undone too. 2018. https://www.theguardian.com/australia-news/2018/aug/05/the-world-is-being-undone-before-us-if-we-do-notreimagine-australia-we-will-be-undone-too.
21. Lynch T, Connor SR, Clark D. Mapping levels of palliative care development: a global update. J Pain Symptom Manag. 2013;45:1094–106.
22. World Health Organization. Cancer pain relief and palliative care. Technical Report Series 804. Geneva: World Health Organisation; 1990.
23. World Health Organization. Cancer pain relief. Second edition. With a guide to opioid availability. Geneva: World Health Organisation; 1996.
24. World Health Assembly. Strengthening of palliative care as a component of integrated treatment throughout the life course. Geneva: WHO; 2014. A67/31
25. Scott JG, Scott RG, Miller WL, Stange KC, Crabtree BF. Healing relationships and the existential philosophy of Martin Buber. Philos Ethics Humanit Med. 2009;4:11.
26. Twycross RG. A tribute to Dame Cicely – Cicely Mary Strode Saunders 1918-2005 [Online]. 2005. https://www.stchristophers.org.uk/about/damecicelysaunders/tributes. Accessed 1 Jul 2020.
27. ICPCM Secretariat. 2009-2020. The international college of person centred medicine (ICPCM) [Online]. https://www.personcenteredmedicine.org/. Accessed 1 Jul 2020.
28. Van Staden W. Six differences between person-centred medicine and patient-centred medicine. ICPCM Newsletter; 2020.
29. Cassell EJ. The nature of suffering and the goals of medicine. N Engl J Med. 1982;306:639–45.
30. Cassell EJ. The nature of healing. New York: Oxford University Press; 2013.
31. Stolorow RD. Dynamic, dyadic, intersubjective systems: an evolving paradigm for psychoanalysis. Psychoanal Psychol. 1997;14:337–46.
32. Papadatou D. In the face of death: professionals who care for the dying and the bereaved. New York, New York: Springer; 2009.
33. Buber M. Between man and man. London: Kegan Paul, Trench, Trubner & Co.; 1947.
34. Buber M. Healing through meeting. Pointing the way. Collected essays. New York: Harper Torchbooks; 1963.
35. Vafiadis P. Mutual care in palliative medicine: a story of doctors and patients. Sydney: McGraw-Hill; 2001.
36. Spruijt O. The empty-handed doctor. Responding to the suffering of patients approaching the end of life. PhD, Lancaster University; 2020.
37. Currow DC, Abernethy AP, Bausewein C, Johnson M, Harding R, Higginson I. Measuring the net benefits of hospice and palliative care: a composite measure for multiple audiences-palliative net benefit. J Palliat Med. 2011;14:264–5.
38. Koh M. Palliative care in the time of COVID-19: reflections from the frontline. J Pain Sympt Manag. 2020;60:e3–4.

39. Wallace CL, Wladkowski SP, Gibson A, White P. Grief during the COVID-19 pandemic: considerations for palliative care providers. J Pain Symptom Manag. 2020;60:e70–6.
40. Steckler NA, Rawlins DB, Williamson PR, Suchman AL. Preparing to lead change: an innovative curriculum integrating theory, group skills and authentic presence. Healthcare. 2015;4:247–51.
41. Granek L, Buchman S. Improving physician well-being: lessons from palliative care. Can Med Assoc J. 2019;191:E380–1.
42. Centeno C, Arias-Casais N. Global palliative care: from need to action. Lancet Glob Health. 2019;7:e815–6.
43. Krakauer EL, Rajagopal MR. End-of-life care across the world: a global moral failing. Lancet. 2016;388:444–6.
44. Berterame S, Erthal J, Thomas J, Fellner S, Vosse B, Clare P, Hao W, Johnson DT, Mohar A, Pavadia J, Samak A, Sipp W, Sumyai V, Suryawati S, Toufi J, Yans R, Mattick RP. Use of and barriers to access to opioid analgesics: a worldwide, regional, and national study. Lancet. 2016;387:1644–56.
45. Cleary J, Hutson PR, Joranson DE. Access to therapeutic opioid medications in Europe by 2011? Fifty years on from the single convention on narcotic drugs. Palliat Med. 2010;24:109–10.
46. Vallath N, Tandon T, Pastrana T, Lohman D, Husain SA, Cleary J, Ramanath G, Rajagopal MR. Civil society-driven drug policy reform for health and human welfare—India. J Pain Symptom Manag. 2017;53:518–32.
47. Sphere Association. Sphere handbook. Humanitarian charter and minimum standards in humanitarian response. 4th ed; 2018.
48. Sleeman KE, De Brito M, Etkind S, Nkhoma K, Guo P, Higginson IJ, Gomes B, Harding R. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. Lancet Glob Health. 2019;7:e883–92.
49. Osman H, Shrestha S, Temin S, Ali ZV, Corvera RA, Ddungu HD, De Lima L, Del Pilar Estevez-Diz M, Ferris FD, Gafer N, Gupta HK, Horton S, Jacob G, Jia R, Lu FL, Mosoiu D, Puchalski C, Seigel C, Soyannwo O, Cleary JF. Palliative care in the global setting: ASCO resource-stratified practice guideline. J Global Oncol. 2018;4:1–24.
50. Rhee J, Foley K, Morrison R, Centeno C, Krakauer E. Training in global palliative care within palliative medicine specialist training programs: a moral imperative. J Pain Symptom Manag. 2018;55:E2–4.
51. Lorenz, K. 2020. The Palliative care - promoting assessment and improvement of the cancer experience (PC-PAICE) project: a multi-site international quality improvement collaborative. J Pain Sympt Manag 61(1):190-197.
52. Spruyt O. The status of palliative care in the Asia-Pacific Region. Asia Pac J Oncol Nurs. 2018;5:12–4.
53. Tom Mishael J, Vaz M, Timms O. Looking back– looking forward: ethics finds its place in the medical curriculum in India. Int J Ethics Educ. 2019;4(2):97–107.
54. Moine S, Murray SA, Boyd K, Engels Y, Mitchell G, European Association for Palliative Care Primary Care Reference Group. Palliative care and the endless cycle of serious health-related suffering. Lancet. 2018;392(10146):471–2.
55. Project ECHO. ECHO movement overview. 2020. https://echo.unm.edu/data/movement, www.echopalliative.com. Accessed 27 Aug 2020.
56. Arora S, Smith T, Snead J, Zalud-Cerrato S, Marr L, Watson M, Yennu S, Bruce A, Piromalli C, Kelley S, Vallath N, Píriz G, Sehabiaga G, Méndez A. Project ECHO: an effective means of increasing palliative care capacity. Am J Manag Care. 2017;23(7 Spec No.):SP267–71.
57. Hospice UK. Project ECHO. 2020. https://www.hospiceuk.org/what-we-offer/clinical-and-care-support/project-echo. Accessed 27 Aug 2020.
58. Agustini NLPIB, Nursalam N, Rismawan M, Faridah VN. Undergraduate nursing students' knowledge, attitude and practice toward palliative care in indonesia: a cross-sectional online survey. Int J Psychosoc Rehabilit. 2020;24
59. Giannitrapani K, Bhatnagar S, Satija A, Ganesh A, Spruijt O, Lorenz K. Barriers and facilitators of using quality improvement methods to foster locally initiated innovation in palliative care services in India. J Gen Intern Med. 2019;36(2):366–73.

60. Foliaki S, Pulu V, Denison H, et al. Pacific meets west in addressing palliative care for Pacific populations in Aotearoa/New Zealand: a qualitative study. BMC Palliat Care. 2020;19(1):100.
61. Candib LM. Truth telling and advance planning at the end of life: problems with autonomy in a multicultural world. Fam Syst Health. 2002;20:213–28.
62. Denier Y, Gastmans C. Realizing good care within a context of cross-cultural diversity: an ethical guideline for healthcare organizations in flanders. Belgium: Social Science & Medicine; 2013.
63. Vranken MJM, Lisman JA, Mantel-Teeuwisse AK, Jünger S, Scholten W, Radbruch L, Payne S, Schutjens M-HDB. Barriers to access to opioid medicines: a review of national legislation and regulations of 11 central and eastern European countries. The Lancet Oncology. 2016;17(1):e13–22.
64. Addington-Hall JM, Higginson I. Palliative care for non-cancer patients. New York: Oxford University Press; 2001.
65. Crousillat DR, Keeley BR, Buss MK, Zheng H, Polk DM, Schaefer KG. Palliative care education in cardiology. J Am Coll Cardiol. 2018;71:1391–4.
66. Slawnych M. New dimensions in palliative care cardiology. Can J Cardiol. 2018;34:914–24.
67. Braun LT, Grady KL, Kutner JS, Adler E, Berlinger N, Boss R, Butler J, Enguidanos S, Friebert S, Gardner TJ, Higgins P, Holloway R, Konig M, Meier D, Morrissey MB, Quest TE, Wiegand DL, Coombs-Lee B, Fitchett G, Gupta C, Roach WH Jr, American Heart Association Advocacy Coordinating Committee. Palliative care and cardiovascular disease and stroke: a policy statement from the American Heart Association/American Stroke Association. Circulation. 2016;134:e198–225.
68. Ferrell BR, Temel JS, Temin S, Alesi ER, Balboni TA, Basch EM, Firn JI, Paice JA, Peppercorn JM, Phillips T, Stovall EL, Zimmermann C, Smith TJ. Integration of palliative care into standard oncology care: American Society of Clinical Oncology clinical practice guideline update. J Clin Oncol. 2017;35:96–112.
69. Mezzich J, Snaedal J, Van Weel C, Heath I. Toward person-centered medicine: from disease to patient to person. Mt Sinai J Med. 2010;77:304–6.
70. Thompson JH, Thylen I, Moser DK. Shared decision-making about end-of-life care scenarios compared among implantable cardioverter defibrillator patients: a national cohort study. Circ Heart Fail. 2019;12:e005619.
71. Kramer DB, Matlock DD, Buxton AE, Goldstein NE, Goodwin C, Green AR, Kirkpatrick JN, Knoepke C, Lampert R, Mueller PS, Reynolds MR, Spertus JA, Stevenson LW, Mitchell SL. Implantable cardioverter-defibrillator use in older adults: proceedings of a hartford change agents symposium. Circ Cardiovasc Qual Outcomes. 2015;8:437–46.
72. Knoepke CE, Mandrola JM. Don't be afraid: using an icd means having difficult conversations. Circ Heart Fail. 2019;12:e006289.
73. Kirkpatrick JN, Gottlieb M, Sehgal P, Patel R, Verdino RJ. Deactivation of implantable cardioverter defibrillators in terminal illness and end of life care. Am J Cardiol. 2012;109:91–4.
74. Clark AM, Jaarsma T, Strachan P, Davidson PM, Jerke M, Beattie JM, Duncan AS, Ski CF, Thompson DR. Effective communication and ethical consent in decisions related to ICDs. Nat Rev Cardiol. 2011;8:694–705.
75. Hain R, Heckford E, Mcculloch R. Paediatric palliative medicine in the UK: past, present, future. Arch Dis Child. 2012;97:381–4.
76. Feudtner C, Womer J, Augustin R, Remke S, Wolfe J, Friebert S, Weissman D. Pediatric palliative care programs in children's hospitals: a cross-sectional national survey. Pediatrics. 2013;132:1063–70.
77. WHO. Integrating palliative care and symptom relief into paediatrics: a WHO guide for health care planners, implementers and managers. Geneva: World Health Organization; 2018.
78. Friedrichsdorf SJ, Postier A, Dreyfus J, Osenga K, Sencer S, Wolfe J. Improved quality of life at end of life related to home-based palliative care in children with cancer. J Palliat Med. 2015;18:143–50.
79. Spathis A, Harrop E, Robertshaw C, Elverson J, Lapwood S. Learning from paediatric palliative care: lessons for adult practice. Palliat Med. 2012;26:777–9.

Chapter 38
People-Centered Public Health

Fredy A. Canchihuaman, Christine C. Leyns, and Juan E. Mezzich

---

F. A. Canchihuaman (✉)
Public Health and Postgraduate Schools, Cayetano Heredia Peruvian University, Lima, Peru

Department of Epidemiology, University of Washington, Seattle, WA, USA

C. C. Leyns
Department of Public Health and Primary Care, Faculty of Medicine and Health Sciences, Ghent University, Ghent, Belgium

Fundación Vida Plena, Sacaba, Cochabamba, Bolivia

Faculty of Social Sciences, Universidad Mayor de San Simon, Cochabamba, Bolivia

Physician and Community Educator, Cochabamba, Bolivia
e-mail: christine.leyns@ugent.be

J. E. Mezzich
Presidency 2009–2013, International College of Person-Centered Medicine, New York, NY, USA

Presidency 2005–2008, World Psychiatric Association, Geneva, Switzerland

Division of Psychiatric Epidemiology and International Center for Mental Health, Icahn School of Medicine at Mount Sinai, New York, NY, USA

Hipolito Unanue Professor of Person Centered Medicine, San Fernando School of Medicine, San Marcos National University, Lima, Peru

Professor of Epidemiology, Graduate School of Public Health and Professor of Psychiatry, School of Medicine, University of Pittsburgh, Pennsylvania, PA, USA

Department of Psychiatry and Behavioral Sciences, Stanford University School of Medicine, Stanford, CA, USA

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_38

38.1 Introduction

38.1.1 *Public Health: A Dynamic Field*

38.1.1.1 What Is P.ublic Health?

Public health might be understood as a discipline, science, and art [1], in which the main study objects are people and communities and whose subsequent activities and functions are undertaken principally at the collective level. There are different definitions of public health. A novel definition of public health that remains valid until today was given by Charles Edward Winslow in 1920 as "the science and the art of preventing disease, prolonging life, and promoting physical health and efficiency through organized community efforts" [1]. A reviewed definition, based upon the challenges and opportunities for strengthening practice, organization, and impact of public health, was made by a committee established at the US National Research Council [2, p. 6]. There, public health was characterized by making a distinction between three elements, first the actors (that undertake public health actions and that exist beyond the governmental sector), second the mission (the public health aims), and third, the substance (the public health study matter) [2, p. 36]. The governmental responsibilities in public health, denominated as core functions of public health, were then divided in three areas: assessment, policy development and assurance [2, p. 43]. More recent definitions of public health were proposed by Richard Riegelman and Kirkwood [3, p. 5] as "The totally of all evidence-based public and private efforts through the life cycle that preserve and promote health and prevent disease, disability, and death" and by Detels et al. [4, p. 3] as "the process of mobilizing and engaging local, state, national, and international resources to assure the conditions in which people can be healthy". The latest definitions emphasize the multisectoral and multilevel nature of public health and the need to coordinate collective action for the health of all.

38.1.1.2 What Are the Functions of Public Health?

There are multiple tasks, services or activities that are undertaken in this broad field by individuals, communities, professionals, clinicians, public health practitioners, and sectorial and multisectoral organizations. These tasks are grouped operationally in public health functions. Many organizations and countries named them "essential public health functions", although they may vary to some extend between countries and organizations [5, 6, p. 3]. The Essential Public Health Functions were recently updated by the Pan American Health Organization [7] and the Essential Public Health Services were updated by the Public Health National Center for Innovations [8]. An essential transcendent goal of public health functions is equity, targeting both direct factors leading to inequitable service access and indirect factors like the social determinants of health. These functions might be understood as medical specialties (areas of action), comparable with clinical medicine fields, executed by accountable public health practitioners, public health organizations or others with public health mandates.

Public health is in constant motion and its shape has varied considerably. Today, in pandemic times, the world expects an effective encompassing response and in this sense the person- and people-centered medicine approach is a promising strategy.

38.2 Public Health Perspectives in Person Centered Medicine

The International College of Person Centered Medicine (ICPCM) has developed through research sponsored by the World Health Organization a profile of concepts and principles of person centered medicine . The elucidation of these principles led to the development of a Person-centered Care Index (PCI) [9]. International research with the PCI is evolving, particularly in Latin America. Illustratively, Perales et al. [10] have carried out a successful comparison of prototype hospitals in Lima in terms of person centered care on the bases of health professionals rating institutions with the PCI.

People or communities are not only groups of individuals [11, p. 7]; they form a living entity with a proper identity. This understanding produced the naissance of new public health fields such as public health ethics [12] and people-centered public health. Nevertheless, persons-centered medicine principles are generally applicable to both clinical care and public health, as both arenas are highlighted in the PCM set of principles.

In fact, Appleyard et al. [13] presented an articulation of *Patterns and Prospects for the Implementation of Person-Centered Primary Care and People-Centered Public Health* as the content of *the D*eclaration of London 2015 at the conclusion of the Fifth International Congress of Person Centered Medicine.

Furthermore, reflecting the recognized innovativeness of the Latin American Region concerning public health policies, the annual Latin American Conferences on Person Centered Medicine have been, particularly in recent years, yielding innovative fundamental strategies for integral health care, bringing to fruition the inspiration to the health field afforded by the Alma Ata (1978) and Astana (2018) Conferences. To note, the main theme of the Sixth Latin American Conference of PCM in Montevideo, December 2020, was *Person-centered Integral Health Care, Human Rights and Sustainable Development Goals* and that of the Seventh Latin American Conference in Lima, December 2021, was *Mutual and Integral Health Care Aimed at the Well-being of All Persons.* Their outcomes are displayed, respectively, in the 2020 Montevideo Declaration and the 2021 Lima Declaration [14, 15].

Figure 38.1 presents schematically and graphically a conceptual representation of the health field (clinical medicine and public health) within the programmatic perspective of Persons-Centered Medicine. It further allegorizes a prospective support of Persons-Centered Medicine to the previously outlined Essential Public Health Functions and Services.

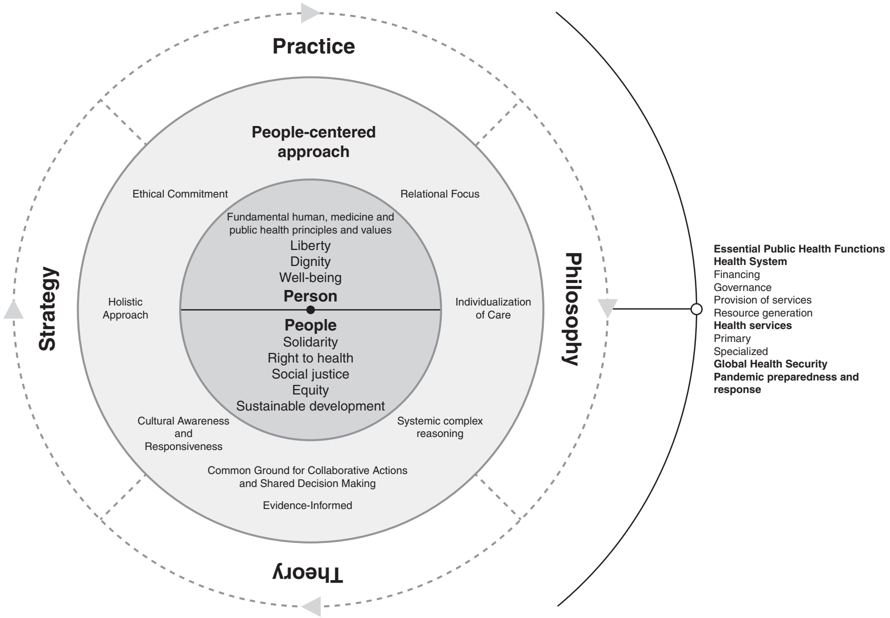


Fig. 38.1 Schematic representation of clinical medicine and public health within the programmatic perspectives of Persons-Centered Medicine, and its prospective support to the Essential Public Health Functions and Services

38.3 Additional Considerations for the Further Development of People-Centered Public Health

To strengthen the applicability of person-centered medicine to public health, a number of considerations have been listed by Canchihuamán et al. [16] and they are further elaborated in this section of the manuscript. Public health inspired by the person- and people-centered approach (Fig. 38.1) may result in an equity-focused ever-evolving contextualized scope of actions and functions guided by a more efficient organization, implementation, and evaluation.

The people-centered public health approach emphasizes the interconnectedness of persons, the importance of the community context and the need for collective participation and organization. This participation based on shared decision making, embedded in the values of equity and social justice, is based on cultural awareness and responsiveness. The goal is achieving universal health coverage and the right to health for all [17]. This is only possible through a holistic public health approach that understands the intersectoral nature of health as described by the sustainable development goals and the social determinants of health [17–19]. The WHO described the preconditions for this integrated people-centered health services approach in five strategic goals:

1. Empowering and engaging people.
2. Strengthening governance and accountability.
3. Reorienting the model of care.
4. Coordinating services.
5. Creating an enabling environment.

The Person-Centered Medicine principles that largely overlap with the five strategic goals of the WHO strategy on integrated people centered health services, can guide actions (behaviors or conducts) and function's in the public health field undertaken by individuals, communities, professionals, and organizations. This approach began with the person and people at the center interconnected with the fundamental principles and values of human, medicine, and public health [9, 13]. The person—the human being—is the origin of these principles and values and they are simultaneously the origin of the person-centered approach (the person as the origin and the person as the end). These bedrock principles are unfolded on more specific principles and values and together embedded on the person-centered approach, a form of practical application of them. The person-centered approach is a way of living as well as an operational approach. Approaches having these features were previously proposed for primary health care (philosophy and strategy) [20, p. 4] and human security (philosophy, concept, and guide) [21, p. 9]. These different aspects (such as philosophy, theory, strategy and practice) of the person-centered approach have the potential to influence, transform or reorient life and health; like a vinyl record transmitting sound waves of change (see Fig. 38.1). There are different elements that might be permeated, such as disciplines (medicine, public health, research, and education) and their practices. The person-centered approach is a promising strategy to translate theory into practice. The conceptual model might help to guide the analysis of the influence and impact of the approach on each discipline and their practices.

38.3.1 Person-Centered Public Health in Practice Including the Pandemics

To illustrate the potential influence and application of the person-centered medicine approach (concepts, values and principles) in the discipline and practice of public health we use the case of COVID-19 [9, 16]. The prevention and control of acute public health threats as pandemics is the second function of the Essential Public Health Functions [7] and Services [8] mentioned in Table 38.1.

We explore the impact of the people-centered perspective on health security, pandemic preparedness, and response models; then we describe how the principles and values of the person- and people-centered perspective can guide public health actions and practice.

The COVID-19 pandemic affects people's lives in every corner of the planet. We live an era that will leave a devastating trace in the history of humanity. An era characterized by multiple crises (health, economic, social, and political),

Table 38.1 Updated Essential Public Health Functions and Services

The Essential Public Health Functions [7]	The Essential Public Health Services [8]
Assessment 1. Monitoring and evaluation of health and well-being, equity, social determinants of health, and health system performance and impact 2. Public health surveillance; control and management of health risks and emergencies 3. Promotion and management of health research and knowledge **Policy development** 4. Development and implementation of health policies and promotion of legislation that protects the health of the population 5. Social participation and social mobilization, inclusion of strategic actors, and transparency **Resource allocation** 6. Development of human resources for health 7. Ensuring access to and rational use of quality, safe, and effective essential medicines and other health technologies 8. Efficient and equitable health financing **Access** 9. Equitable access to comprehensive, quality health services 10. Equitable access to interventions that seek to promote health, reduce risk factors, and promote healthy behaviors 11. Management and promotion of interventions on the social determinants of health	**Assessment** 1. Assess and monitor population health 2. Investigate, diagnose, and address health hazards and root causes **Policy development** 3. Communicate effectively to inform and educate 4. Strengthen, support, and mobilize communities and partnerships 5. Create, champion, and implement policies, plans, and laws 6. Utilize legal and regulatory actions **Assurance** 7. Enables equitable access 8. Build a diverse and skilled workforce 9. Improve and innovate through evaluation, research, and quality improvement 10. Build and maintain a strong organizational infrastructure for public health

disproportionately affecting vulnerable populations, and challenging the structures of existing health care models. Pandemics, however, are not the only threat to global public health; and it is likely that other threats will emerge in the future [22].

In response to the exponential increase in international travel and trade, and (re) emergence of international disease threats, 196 countries agreed to implement the International Health Regulations (2005) with the scope and purpose to prevent, protect against, control, and provide a public health response to the international spread of disease [23]. Recent outbreaks such as SARS and Ebola showed shortcomings in this international response leading to the development of global health security initiatives and instruments to support the implementation of this regulation [23], as well as to the identification of needs for capacity building. Based on these regulations and instruments to help in its implementation, countries achieved different levels of preparation toward public health hazards. However, COVID-19 has generated an unexpected, isolated, disarticulated, specialized and reductionist response in many countries, often neglecting the way partially paved by these regulations and tools. COVID-19 surpassed even the most prepared countries.

To effectively address COVID-19 and other future health threats, an integration and a refinement of approaches may be helpful. Such changes might involve a reexamination of the International Health Regulations and other similar developments. A response model influenced by a person-centered perspective should be developed based on the following key approaches, frameworks and tools linked to health security and pandemic preparedness:

- The International Health Regulations [24], the Global Health Security Index [25], the State Party self-assessment annual reporting tool [26], and the Joint external evaluation tool [27]. These documents describe core elements, areas of essential capabilities and indicators for responding to public health threats.
- The International Health Conceptual Model proposed by the Population Leadership Program [28], which makes emphasis on the multilevel dimensionality of health by delimiting the role of the international determinants of health.
- The Framework on Integrated, People-Centered Health Services [29] including an “enabling environment” and the “coordination of services within and across sectors”.
- The One Health Approach, which stressed the interconnectedness of the three elements, animal, human and environment [30].
- The Health Emergency and Disaster Risk Management Framework [31] and other models for controlling emergencies (the emergency management cycle and the phases of emergency management) [32, 33], which describe the system, stages, processes, and capacities and activities for managing emergency and disasters. Among the proposed phases of these models are “prevention and reduction disaster risk, improving preparedness and disaster response, and post-disaster recovery rehabilitation and reconstruction”, last named as “build back better”. Part of these phases constitute to the core elements of health security on the Joint External Evaluation (JEE) [27] and Global Health Security Index (GHSI) [25].
- The non-linear model for controlling pandemics reviews the emergency management cycle and claims that for a pandemic such as COVID-19 some phases (preparedness, response, and mitigation) are sequential but other phases are not (response and recovery). The explanation is that pandemics unlike natural disasters are a versatile phenomenon, have impacts occurring in cascade form and have unique and complex cyclical cycles (“waves”) [34].

Such a person- and people-centered model may guide the four pillars or critical axes of any emergency repose (continuous promotion, prevention, and preparation; early detection and report; rapid response and control; and increased or sustained recovery) and the steps needed to reach the desired outcome, having a safe and healthy world. Identification of gaps in capabilities, development of plans to strengthen capabilities or competencies and route maps and implementation strategies to translate them into concrete actions are needed [35]. All of these constitute the operational mechanisms for the implementation of the International Health Regulations.

The COVID-19 pandemic requires changes in paradigm and the articulation of different strategies for which the person-centered approach [9] might be the great articulator and integrator. Considering the person and people as the center of each public health action has special particularities that facilitate implementation from the roots, supported by the people for the people. The person and people are intuitive concepts. If each public health action, independent of existing norms and regulations, considers people as the focus of attention and as masters of their own reality, the transformation will occur from the bottom to the top, from the practice or reality to the norms and policies, making changes equitable, needs based, scalable, flexible, and sustainable over time.

38.3.1.1 Liberty, Autonomy, and Respect for Person

The COVID-19 pandemic brought liberty, autonomy, and respect to the social debate. In a time where public health interventions include individual and collective liberty restrictions, public health actions must balance individual human rights, the empowerment of people to take conscious actions to safeguard their health (freedom needs to be catalyzed by information and facts) and collective rights and health. This includes considering the perspectives of the people, their needs and priorities, promoting some degree of community autonomy, supported by tools and processes for informed consensus building [11, p. 24].

Preventive interventions for COVID-19 aimed to protect health and wellbeing at the individual and collective level can disarticulate individual and collective autonomy. A risk benefit and other factor analysis (as in the case of clinical or research field) at individual and collective level (social welfare) is needed to take optimal public health measures [11, p. 26] at any point of time during a health care crisis like this pandemic.

During the pandemic many countries were in the midst of social and political conflicts hindering trust in the government and in the interventions they imposed. In this context, a people centered health approach would have promoted a more adequate response, replacing the resistance-inducing top-down measures by a bottom-up approach supported through education by trusted primary health care providers and local leaders. Rarely a top-down approach in public health is effective in reaching minority or marginalized groups. The COVID-19 pandemic emphasized the importance of combining personalized with population strategies and primary health care with public health.

Paraphrasing perspectives in the clinical field [36], it may be said that public health of the people is developed for the people, by the people, with the people, and through the people, always putting at the center the needs of those involved, complemented with the knowledge and evidence delivered by trusted health care professionals and authorities.

38.3.1.2 Wellbeing and Solidarity

The word “solidarity” was present early in the worldwide discourse to address the COVID-19 pandemic. Solidarity might imply the extension of genuine concern about our own wellbeing and personal health to concern about our families, other persons, and the community, including especially those most vulnerable. Public health actions must be founded on solidarity. Solidarity must come from all people at all levels. Quarantines for example are likely to be more effective if complemented with strategies to remediate the needs of those most affected by these measures (the needs of the most vulnerable being considered a priority), but also related to vaccination, applied for individual protection but also to protect others. An important concept of solidarity is proportionate universalism or investing more in those with more needs recognizing that needs have a gradient. This means that if we only support the worst of, those that are just above will be the hardest hit, calling for a strategy that leaves no one behind [37].

38.3.1.3 Social Justice, Equity, Access and Right to Health and Dignity

The people centered approach puts the health and well-being of the people first, which means investing more in those more vulnerable centered approach. At the international level, this means that technology, resources, and knowledge must be shared for the common good of mankind. This is in contrast with the current reality around August 2021 when 31.4% of the world population has received at least one dose of a COVID-19 vaccine, while for people in low-income countries this is only 1.3%. (https://ourworldindata.org/covid-vaccinations; August 16, 2021). Debatable issues around COVID-19 vaccines are lack of cooperation, disputes on purchases, and unequitable access [38].

At the national level, this calls for a revision of the fragmentation and unequal distribution of health services, prevalent in many countries, lacking universal access to high quality health care. This unequal access and fragmentation lead to ineffectiveness, a huge administrative load and duplication of services.

The COVID-19 pandemic emphasized the importance of social justice, equity, access, right to health and dignity. These principles are inter-related and interconnected with each other. Dignity is the core of a human being. Currently, it is evident that to effectively fight pandemics as COVID-19, reduction of inequity (addressing all health determinants), reaching universal access to create the conditions to include everyone in reaching the “maximum potential of health”, and warrant the right to health (as a human rights) are critical and imperative. Public health actions must be oriented to achieve social justice. Barrett et al. [11, p. 9], based on Whitehead [39] and Powers and Faden [40], describe social justice as a duty of any collective society to make all necessary efforts to create the conditions to include everyone in reaching the “maximum potential of health”, and in consequence the duty of investing more in those with more needs ([11, p. 9]).

38.3.1.4 Sustainable Development and Ecological Protection

Many pandemics originate from originate from the disequilibrium the disequilibrium between animal, human and environmental health. In the case of the COVID-19 pandemic, a hypothesis is that a disruption of the ecosystem related to social development enabled the virus to migrate from wild animals to intermediate reservoirs and to the human host. To avoid future pandemics, humans need to respect ecosystems as part of sustainable development. Public health must take the growing interconnectedness between animal, human and environmental health into account as proposed in the One Health approach [30].

38.3.1.5 Systemic Complex Reasoning

The COVID-19 pandemic revealed the cracks in the fundaments of our health care system and services, calling for their transformation, demonstrating that the health of a person may depend on a functional health care system and services. A systemic approach considers the diversity of elements and factors that are part of a whole, as well as the complexity and intricate interrelation between them [41, p. 1].

Public health solutions and strategies for better individual or collective care may consider systemic complex reasoning. Interventions need to consider the characteristics and complexity of the health system (which include the global health system). The integrated people-centered service model can assist in this complex analysis to transform the health system and services. The essential elements of this systemic approach relate to the essential characteristics of primary health care, an intrinsic people centered care model [42, 43] with features applicable at the level of the health system (integral, integrated, continuing, longitudinal, multisectoral, innovative, sustained, social participative and person-centered). Experiencing the worldwide collapse of hospitals during this covid-19 pandemic ones again emphasized that strong health systems must be built on a strong primary health care fundament.

38.3.1.6 Evidence Informed and Supported by Technology

COVID-19 demonstrated that knowledge gaps might limit the decision-making process and the effectiveness of any public health intervention. The lack of evidence led to some erroneous public health interventions that were corrected later. The flood of fake information caused controversies on treatments, diagnostic tests and even on preventive measures in some countries. Science influenced by politics was another negative factor (“politicization of science”) [44]. In the context of a new disease and the need for a rapid response, science accelerated, and evidence grew exponentially, leading to unprecedented fast discoveries to control the pandemic, like in the case of vaccines. Unfortunately, science also proved that interventions which initially created great expectations showed to be ineffective.

Evidence is essential for public health as it is for clinical care. Thus, public health must be informed by the best up to date evidence at all levels (public health based on evidence). But if evidence is not yet available, common sense and clear collaborative communication must guide the decision process.

The discovery of the COVID-19 vaccine reminds us that science is crucial and critical to produce knowledge and technology to improve and protect health and wellbeing at both the individual and collective level, making such investment necessary. Although, new technology is often first available for the best off, leaving vulnerable groups behind. The people centered care model that emphasizes our interconnectedness, and even in the case of COVID-19, our interconnected vulnerability, lets us rethink the relation between economics and social justice. Patents are a way to guarantee the funds to advance technology, but must this cost be borne equally between societies with unequal resources? This is the difference between equity and equality, to invest the same in those with few and many needs. This discussion must be strengthened at the global public health agenda.

38.4 Integrating Person Centered Medicine, Social Determinants of Health, Sustainable Development Goals, and Essential Public Health Functions and Services (EPHF)

Person Centered Medicine (PCM)) [9], modern public health, especially its Essential Functions [7]) and Services [8], the Social Determinants of Health (SDH), and Sustainable Development Goals may be seen as coherently articulated and synergistic with each other.

As pointed out by Eugenio Villar [45], these concepts have emerged as comprehensive responses to the scientific, social and health conceptual challenges of our time characterized by deep and growing inequalities in all spheres. These challenges include an erosion of the foundational ethical-moral values of medical work and its role in society, the state, the market, and the private sector as a consequence of the globalization underway in recent decades. Based on the affirmation of integral and holistic health enshrined in the Constitution of the WHO, PCM in reference to persons and the EPHF, SDH, and SDG for communities refocus humanistic, ethical and equity values towards the articulation of science and humanism for the total health of persons and communities.

All of this is progressively and consistently being framed within the sustainable development approaches and in particular the Sustainable Development Goals (SDG)) that the concert of nations members of the UN, have developed globally as part of the 2030 Agenda. In effect, the SDG Health third goal, largely embodies Person Centered Medicine and Social Determinants of Health when it establishes as key objective “Ensuring healthy lives and promoting well-being for all at all ages.” Likewise, the renewal of the strategy of “Primary Health Care” in the Astana

Conference (2018) reiterates the validity of these strategies for the achievement of the SDGs. The aforementioned constitutes a formidable general challenge in the health field and for the training of future health workers [45].

38.5 Conclusions

Seeing public health through the lens of person- and people centered care will accelerate both the achievement of the Universal Development Goals as universal access to health, in terms of rights and responsibilities. Public health activities and actions (e.g., essential public health functions) will have to be implemented at the global, national, and local level. At this last level, it is strongly entangled with primary health care. The COVID-19 pandemic illustrates and magnifies the work ahead to strengthen public health. All public health functions were called upon in parallel during the covid-19 pandemic: monitoring of the pandemic evolution, supporting the development of evidence based public policy, preventing transmission, evaluating, and adapting health services, training human resources while evidence grew, and empowering communities. It is argued that limiting the first three functions to the global and national agenda has weakened the opportunity to empower communities. Although it is laborious to empower people and even more so in an equitable way, including reaching the hard to reach, it is worthwhile to work on this strategy, making people co-responsible as actors and not as populations acted upon. In a public health pandemic like the one lived with COVID-19, there will never be sufficient trained public health providers to successfully perform all essential public health functions, but people engaged as partners would be better prepared and able to face the next global crisis.

Evidence on the need to build health systems on strong primary health care was already present before the pandemic but became more visible during these last years. In many low-resource countries vaccination rates, identification and follow up of non-communicable diseases and timely identification of communicable diseases, like tuberculosis, went down; leaving these countries with a heavy additional health burden for the years to come. These challenges can be addressed effectively if strong primary health care is constructed for all with competent health professionals working hand in hand with communities. As stated before, there is no one size that fits all. It is the persons, with their unique individual and community identities, who must be part of this construction. Person- and people-centered medicine as a philosophy, theory, and strategy is emerging to be a powerful approach for awareness, understanding, action and practice.

Acknowledgements and Disclosures The authors do not report any conflicts of interest concerning the preparation of this paper.

References

1. Winslow CE. The untilled fields of public health. Science. 1920;51(1306):23–33.
2. Institute of Medicine (US). Committee for the Study of the Future of Public Health. The Future of Public Health [Internet]. Washington (DC): National Academies Press (US); 1988. Accessed July 28 2021. http://www.ncbi.nlm.nih.gov/books/NBK218218/.
3. Riegelman R, Kirkwood B. Public Health 101: improving community health. 3rd ed. Burlington, Massachusetts: Jones & Bartlett Learning; 2018. p. 436.
4. Detels R, McEwen J, Beaglehole R, Tanaka H, editores. Oxford Textbook of Public Health. 4th ed. Oxford; New York: Oxford University Press; 2002. p. 1956.
5. Rechel B, McKee M. Facets of public health in Europe: an introduction. In: Rechel B, McKee M, editors. Facets of Public Health in Europe, Maidenhead, Berkshire. England: McGraw Hill Education, Open University Press; 2014. p. 346. (European Observatory on Health Systems and Policies series).
6. World Health Organization. Essential public health functions, health systems and health security: developing conceptual clarity and a WHO roadmap for action. Geneva: World Health Organization; 2018. https://apps.who.int/iris/handle/10665/272597. Accessed 9 April 2019.
7. Pan American Health Organization. The Essential Public Health Functions in the Americas: A Renewal for the 21st Century. Conceptual Framework and Description. Washington, D.C.: Pan American Health Organization; 2020. https://iris.paho.org/handle/10665.2/53124
8. Public Health National Center for Innovations. Celebrating 25 years and launching the Revised 10 Essential Public Health Services. 2020. https://phnci.org/national-frameworks/10-ephs
9. Mezzich JE, Kirisci L, Salloum I, Trivedi J, Kar SK, Adams N, et al. Systematic Conceptualization of Person Centered Medicine and Development and Validation of a Person-centered Care Index. Int J Pers Center Med. 2016;6:219–47.
10. Perales A, Kirisci L, Mezzich JE, Sánchez E, Barahona L, Zavala S, Amorín E. Comparative study of prototype hospitals in lima with the person-centered care index rated by health professionals. Int J Person Center Med. 2018;8(1):47–61.
11. Barrett DH, Ortmann LW, Dawson A, Saenz C, Reis A, Bolan G. Public Health Ethics: Cases Spanning the Globe. Springer Cham; 2016. p. 329. Available at: http://link.springer.com/10.1007/978-3-319-23847-0 (Accessed 29 September 2019).
12. DeSalvo KB, O'Carroll PW, Koo D, Auerbach JM, Monroe JA. Public Health 3.0: Time for an Upgrade. Am J Public Health. 2016;106(4):621–2.
13. Appleyard J, Botbol M, Epperly T, Ghebrehiwet T, Grove J, Mezzich JE, et al. Patterns and prospects for the implementation of Person-Centered Primary Care and People-Centered Public Health. Int J Pers Centered Med. 2016;6(1):9–17.
14. Latin American Network of Person Centered Medicine (in press). Montevideo Declaration on Person-centered Integral Health Care, Human Rights and Sustainable Development Goals. International Journal of Person Centered Medicine; 2020. https://www.personcenteredmedicine.org/doc/2021-Montevideo-Declaration.pdf. Accessed 6 January 2022.
15. Latin American Network of Person Centered Medicine (in press). Lima declaration on mutual and integral health care aimed at the well-being of all persons. International Journal of Person Centered Medicine; 2021. https://www.personcenteredmedicine.org/doc/2021-Lima-Declaration.pdf. Accessed 6 January 2022.
16. Canchihuaman FA, Appleyard J, Mezzich J. Concepts and strategies of people-centered public health. Int J Pers Centered Med. 2018;8(2):43–57.
17. United Nations. Declaration of Human Rights. 1948. https://www.un.org/sites/un2.un.org/files/2021/03/udhr.pdf
18. Commission on Social Determinants of Health. Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health. Geneva: World Health Organization; 2008. https://apps.who.int/iris/bitstream/handle/10665/43943/9789241563703_eng.pdf?sequence=1

19. Leyns CC, De Maeseneer J, Willems S. Using concept mapping to identify policy options and interventions towards people-centred health care services: a multi stakeholders perspective. Int J Equity Health. 2018;17:177. https://doi.org/10.1186/s12939-018-0895-9.
20. Macinko JA, Montenegro Arriagada H, Nebot C. Pan American Health Organization. Renewing primary health care in the Americas: a position paper of the Pan American Health Organization/World Health Organization (PAHO/WHO). Washington, D.C: Pan American Health Organization; 2007.
21. Korc M, Hubbard S, Suzuki T, Jimba M, Nihon Kokusai Kōryū Sentā, et al. Health, resilience, and human security: moving toward health for all. Japan Center for International Exchange and Pan American Health Organization; 2016. http://iris.paho.org/xmlui/handle/123456789/28286. Accessed 24 September 2019.
22. Calistri P, Decaro N, Lorusso A. SARS-CoV-2 Pandemic: Not the First, Not the Last. Microorganisms. 2021;9(2):433.
23. Gozzer E, Canchihuamán F, Piazza M, Vásquez H, Hijar G, Velásquez A. Contribution of Peru in initiatives to promote global health security. Rev Peru Med Exp Salud Publica. 2016;33(3):574–9.
24. World Health Organization. International health regulations (2005). 3rd ed. Geneva, Switzerland: World Health Organization; 2016. p. 74.
25. Cameron EE, Nuzzo JB, Bell JA. Global Health Security Index: Building Collective Action and Accountability. [Internet]. 2019. Available at: https://www.ghsindex.org/
26. World Health Organization. International Health Regulations: State Party self-assessment annual reporting tool. Geneva: World Health Organization; 2018. https://www.who.int/publications-detail-redirect/WHO-WHE-CPI-2018-16. Accessed 29 July 2021.
27. World Health Organization. Joint external evaluation tool: International Health Regulations. 2nd ed. Geneva: World Health Organization; 2018. https://apps.who.int/iris/handle/10665/259961. Accessed 29 July 2021.
28. Organización Panamericana de la Salud. Abordaje de temas de salud para la perspectiva de salud internacional y la construcción de un modelo conceptual. Programa de Líderes en Salud Internacional "Edmundo Granda Ugalde". Washington, D.C.: Organización Panamericana de la Salud/Organización Mundial de la Salud; 2019.
29. World Health Organization. Framework on integrated, people-centred health services. Report by the Secretariat. 2016. http://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_39-en.pdf?ua=1
30. Mushi V. The holistic way of tackling the COVID-19 pandemic: the one health approach. Trop Med Health. 2020;48:69.
31. World Health Organization. Health emergency and disaster risk management framework. Geneva: World Health Organization; 2019. https://apps.who.int/iris/handle/10665/326106. Accessed 5 August 2021.
32. Rose DA, Murthy S, Brooks J, Bryant J. The Evolution of public health emergency management as a field of practice. Am J Public Health. 2017;107(Suppl 2):S126–33.
33. United Nations. Sendai Framework for Disaster Risk Reduction 2015–2030. 2015. https://digitallibrary.un.org/record/793460. Accessed 06 August 2021.
34. Fakhruddin B, Blanchard K, Ragupathy D. Are we there yet? The transition from response to recovery for the COVID-19 pandemic. Prog Disaster Sci. 2020;7:100102.
35. World Health Organization. International Health Regulations (2005): IHR monitoring and evaluation framework [Internet]. Geneva: World Health Organization; 2018. p.19. https://www.who.int/publications-detail-redirect/international-health-regulations-(-2005)-ihr-monitoring-and-evaluation-framework. Accessed 10 August 2021.
36. Mezzich J, Snaedal J, Van Weel C, Heath I. Toward person-centered medicine: from disease to patient to person. Mt Sinai J Med. 2010;77(3):304–6. https://doi.org/10.1002/msj.20187.
37. Marmot Review Team. Fair society, healthy lives: strategic review of health inequalities in England post-2010. London, Marmot Review; 2010. https://www.instituteofhealthequity.org. Accessed 15 September 2022.

38. Ghebreyesus TA. Director-General's opening remarks at the media briefing on COVID-19 – 9 April 2021. World Health Organization; 2021. [Internet]. https://www.who.int/director-general/speeches/detail/director-general-s-opening-remarks-at-the-media-briefing-on-covid-19-9-april-2021. Accessed 10 August 2021.
39. Whitehead M. The concepts and principles of equity and health. Int J Health Serv Plan Adm Eval. 1992;22(3):429–45.
40. Powers M, Faden R. Social justice: the moral foundations of public health and health policy. New York: Oxford; 2006. p. 248.
41. Kaplan G, Bo-Linn G, Carayon P, Pronovost P, Rouse W, Reid P, et al. Bringing a Systems Approach to Health. NAM Perspectives. Discussion Paper, National Academy of Medicine. Washington (DC): National Academy of Medicine; 2013. https://nam.edu/perspectives-2013-bringing-a-systems-approach-to-health/. Accessed 10 August 2021.
42. World Health Organization, UNICEF. International Conference on Primary Health Care: Alma-Ata U, Primary health care: report of the International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978. http://apps.who.int/iris/handle/10665/39228. Accessed 31 October 2019.
43. World Health Organization. Declaration on Primary Health Care. Astana; 2018. https://www.who.int/primary-health/conference-phc/declaration. Accessed 31 may 2019.
44. Abbasi K. Covid-19: politicisation, "corruption," and suppression of science. BMJ. 2020;371:m4425.
45. Villar E. Social Determinants of Health and Sustainable Development Goals: Experience and Training in People-Centered Public Health and Inter-Sectorality. Paper presented at the 7th Latin American Conference on Person Centered Medicine, December 16–18, 2021. https://www.personcenteredmedicine.org/. Accessed 6 January 2022.

Chapter 39
Person-Centered Nursing and Other Health Professions

Tesfamicael Ghebrehiwet and Julio Mendigure

39.1 Introduction

Today we hear a lot about person-centred approach in health care. But what does this mean to nurses and other health professionals? How does it differ from traditional medical model? Will adopting this model improve performance of health systems and improve health outcomes? Person-centred care is a term that is becoming increasingly popular within health care at a global level. It is being used to describe a standard of care that ensures that the patient is at the centre of care delivery. A similar development in medicine has been articulated by the International College of Person-Centred Medince, aimed at promoting medicine *of the person*, *for the person*, *by the person* and *with the person* [1].

In an era of increased consumer demand, shifting disease patterns with increasing chronic diseases, providing quality care calls for a more tailored and quality care. Nurses and other health professionals are, more than ever, challenged to discover better ways to deliver care that best meets the health needs of individuals, families and communities. Person-centred approach is one solution.

The aim of this chapter is to outline the key issues in person-centred care, differentiate person-centred care from the traditional medical model of care, and review the components, and the benefits of adopting person-centred care to health systems, patients, and health professionals.

T. Ghebrehiwet (✉)
International College of Person Centred Medicine, New York, NY, USA

Formerly, Consultant, Nursing and Health Policy, International Council of Nurses,
Geneva, Switzerland

J. Mendigure
Ministry of Health, Lima, Peru

Graduate School of the Universidad San Juan Bautista and Universidad Peruana Unión,
Lima, Peru

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_39

39.2 Current Paradigm of Health Care

Person-centred care reflects modern times and a shift from the traditional medical model of health care that focused on disease. It is in sharp contrast to the traditional medical model of health care delivery where patients are passive recipients of care and are not involved in their own care or how care should be tailored to meet their needs.

In the medical model, the physician takes total responsibility for decisions about patient care; and nurses and other health professionals have a passive and supportive role, providing services, information and advice when asked. The medical model lacks flexibility and understanding of the roles of others, and does not invite leadership or full participation from the other members of the health team.

The current paradigm of healthcare has its focus on responding to acute problems, urgent needs and pressing concerns of "patients" as passive recipients of care, with little or no involvement in their care. This means the current health care systems are inadequate for person- and-people-centred model of care and are not-fit-for-purpose.

In fact, there is concern that health professionals in general, and nurses in particular, tend to [2, 3]:

- Focus of disease and emphasis treatment of problems;
- Assume they 'know what is best' for clients;
- Not encourage patient participation in decision-making;
- Not involve family unless necessary; and then control that environment;
- Be individualistic in approach rather than multi-disciplinary;
- lack team skills and negotiation; and
- Fail to understand health and social policy and impact on patients and outcomes.

This points to the need for nurses and other health professionals to refocus to a new paradigm of health care that engages people as active participants in their care, and that puts them at the centre of care delivery. A better future perhaps lies in person-centred care that gives a human face to care and support services, based on the needs and voices of people, not on the needs of a health system.

39.3 Person-Centred Care

In recent years we have witnessed a growing movement towards involvement of people in their care, driven by the quest for quality and cost-effectiveness from within the health professions as well as growing societal demands and expectations. This trend toward person-centredness has as its driving forces the increased consumer demand, empowered patients who are interested in their health conditions, patient advocacy and the affirmation of "*nothing about me without me*" [4].

In order to understand the concept of person-centred care it is important to define the idea of what constitutes a 'person'. The concept of personhood was first applied to people with dementia by Kitwood (1997) [5]. According to Kitwood, "*personhood is 'a standing or status that is bestowed upon one human being, by others, it implies recognition, respect and trust'. Through this recognition, respect and trust, the personhood of an individual will be enhanced as well as their wellbeing* (p. 8). And the person is to be thought of in a contextualized manner, in the words of the philosopher Ortega y Gasset, *I am I and my circumstance* [6].

Based on literature review and using Kitwood's definition, McCormack [7] expanded the concept of 'person' to include four core concepts that are at the heart of person-centredness: being in relation, being in a social world, being in place, and being with self. McCormack further elaborates these concepts as follows:

- *Being in relation* highlights the importance of relationships and the interpersonal processes that have therapeutic benefits.
- *Being in a social* world considers persons as interconnected with their social world, creating and recreating meaning through their being in the world.
- *Being with self,* is closely linked to being in a social world *and* which emphasises the importance of persons 'knowing self' and the values they hold about their life and how they make sense of what is happening to them.
- *Being in place* encourages us to be cognizant of the 'place' and recognise the impact of the 'milieu of care' on the care experience.

Person-centredness has its origins in humanistic psychology exemplified through the work of Carl Rogers [8], who viewed those in therapy as 'clients', not 'patients', and as equal partners with the professionals. The biopsychosocial model of medicine where a patient was not just seen as a biological collection of symptoms, but as a whole person with psychosocial circumstances that impact their health has also influenced the move to person-centred care [9]. Similarly, the 'person' and 'people' are also at the centre of the WHO policy strategy in which the aim is a global movement for person-centredness [10].

From the nursing perspective, a focus on the patient as a whole person, not simply a health problem—has been at the centre of nursing care. Nurse leaders and theorists have promoted that the nurse strives to "get inside the skin" of the person by listening and establishing a dialogue with a view to creating a therapeutic relationship in which the person is a key partner [11]. Equally, *ICN's Basic Principles of Nursing Care* affirms that the nurse is only justified in deciding for, rather than with, what is good for the patient in highly dependent states, such as when a patient is in coma. At all other times the rights, values, needs and preferences of people are paramount and must be used to tailor care to meet patient's specific needs [11]. Furthermore, the ICN Code of Ethics for Nurses [12] affirms "*In providing care, the nurse promotes an environment in which the human rights, values, customs and spiritual beliefs of the individual, family and community are respected*" (p. 2).

The concept of person-centred care is an approach to care that places the person at the centre of their own care. Individuals are supported, facilitated and enabled to contribute to their care through shared decision making, communication and mutual respect. Therefore, person-centred care is an approach that is considered humanistic, dignified and morally ethical [13, 14]. The approach of person centred care applies to all people requiring any form of health care.

As described by McCormick and others, person-centred care is an "*an approach to practice established through the formation and fostering of therapeutic relationships between all care providers...patients and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding*" [15, p. 13]. Furthermore, McCormick identified three factors that enable person-centredness to operate in practice namely: the patient's values, the nurse's values and the context of the care environment [7].

Sepucha et al. [16] define person-centred care as a way of thinking and doing that views the people using health services as equal partners in planning, developing and monitoring care to make sure it meets their needs. This means putting people and their families at the centre of decisions and seeing them as experts, working alongside professionals to get the best outcome. This approach considers people's desires, values, family situations, social circumstances and lifestyles; seeing the person as an individual, and working together to develop appropriate solutions.

The promotion of 'person-centredness' is consistent with health-care policy direction globally. In its *global strategy on people-centred and integrated health services*, WHO [10] argues that people-centred health services is an approach to care that consciously adopts the perspectives of individuals, families and communities, and sees them as participants as well as beneficiaries of health systems that respond to their needs and preferences in humane and holistic ways.

Some challenges to the focus on person-centredness in nursing and health care are presented in a recent book on person-centred nursing and health care practice, edited by McCormack and McCance [17]. Some authors are of the view that other approaches such as "relationship-centred care", "compassionate care" and even "dignified care" are more appropriate frameworks than person-centred care. However, McCormack and McCance argue that these concepts are components of person-centred nursing and health care that explain different dimensions of person-centredness and not alternatives to the concept of person-centred care.

Despite the seemingly clear definition of person-centred care, a plethora of terms are often used interchangeably to describe the same concept. These include: personhood, person-centred, patient-centred, people-centred, client-centred, woman-centred, and relationship-centred care. These terms are often used interchangeably to express the concept of being person-centred care [18].

This terminological jungle means that health administrators and health care provides assume they understand each other when they may be referring to different concepts of person-centred approaches, resulting in lack of clarity, confusion and miscommunication. This has led some to argue that the use of this term is an example of tokenism by those using it; because some even claim that they are practicing person-centred care without any real understanding of what the term actually means [7].

39.4 Components of Person-Centred Care

Person-centred care is not a single dimensional concept and constitutes a number of components for its implementation. WHO [19] presents a range of issues to be addressed in order to make health-care systems more people-centred. These components include:

- Identifying and respecting the person's preferences, values, and differences and expressed needs.
- Coordinating continuously and timely care.
- Alleviating pain and suffering.
- Listening and communicating.
- Providing education and information.
- Sharing decision-making and management with patients and families.

Similarly, the Picker Institute (www.pickerinstitute.org) outlines a number of different aspects of person-centred care, including:

- Respecting people's values and putting people at the centre of care
- Taking into account people's preferences and expressed needs
- Coordinating and integrating care
- Working together to ensure good communication, information and education
- Making sure people are physically comfortable and safe
- Emotional support and alleviation of fear and anxiety
- Involving family and friends
- Making sure there is continuity between and within services

In today's health care, person-centred care is becoming a high priority. Making sure that people are involved in their care is now recognized as key element of quality health care.

39.5 Outcome of Person-Centred Care

The research evidence [20, 21], has shown that person-centred care can have a big impact on the quality of care. It can:

- Improve the people's experience of their care, their satisfaction with care, and encourage them to lead a healthier lifestyle.
- Encourage people to be more involved in decisions about their care so they get services and support that are appropriate for their needs.
- Impact on people's health outcomes, such as their blood pressure.
- Reduce the frequency of use of health services by populations; in turn resulting in reduced overall cost of care.
- Improve the feeling of confidence and satisfaction of health professionals about the quality of care provided.

Furthermore, the evidence suggests that person-centered approach improves care outcomes including client satisfaction with care, adherence to therapeutic regimens, reduced morbidity and improved quality of life [22].

While it is not the focus of health care, person-centred care can also improve outcomes for professionals. A review of seven studies about professionals delivering person-centred care in nursing homes found that this approach improved job satisfaction, reduced emotional exhaustion, and increased the sense of accomplishment amongst professionals [23].

39.6 How Person-Centered Is Currently by Nursing and Allied Professions?

In the current complex landscape of health care systems with rapid growth in knowledge and information that is required to solve problems, presence of multiple diseases or co-morbidity, person-centered care needs to combine the efforts of physicians, nurses, pharmacists, social workers and other health care professionals, as no single health professional can have all the knowledge or skills to provide the continuum of services needed. That is why there is a need for collaborative practice between different health professions so their competencies are integrated to provide holistic and person-centred care [24]. This means there must be interprofessional collaboration and communication.

39.7 What Are the Current Barriers for Nursing and Allied Health to Be More Person-Centred?

Despite their clinical expertise, health professionals are often hampered to provide quality care due to lack collaboration and communication. As the Institute of Medicine [25] reported, lack of interprofessional collaboration was one of the most often cited reasons for medical errors. In contrast effective interprofessional collaboration is linked with better patient care outcomes [26].

Poor Interprofessional collaboration and communication can put patient safety at risk. As Mezzich and his colleagues affirm impaired and weak communication between health professionals and patients constrains understanding and collaboration and undermines the effective coordination of health care [27].

In fact failures in collaboration and communication are cited as the leading root causes for medication errors, delayed treatment, misdiagnosis, and patient injury or death [28, 29].

Research evidence indicates that there are strong positive relationships between a healthcare team member's communication skills and a patient's capacity to follow medical recommendations, self-management of chronic medical condition, and adopt preventive health behaviours [30]. Effective communication is a cornerstone of patient safety and quality of healthcare. On the other hand ineffective health team communication is the root cause for nearly 66% of all medical errors [30].

Most of the collaboration and communication failures can be overcome with an open attitude, mutual respect and trust. IPE offers an upstream solution to reduce the failures.

A related concept of interprofessional education (IPE) is key for Interprofessional collaboration and communication and provides a promising solution to work in smart and efficient way to deliver person-centered care.

39.8 Going Forward, What Would Need to Change to Make Nursing and Allied Health More Person-Centered?

39.8.1 Interprofessional Collaboration and Communication for Person-Centred Care (IPCC)

According to WHO [31] collaborative practice occurs when different health professionals provide comprehensive services by working with patients, families, caregivers and communities to deliver quality care. The shift from the traditional biomedical view of the human body to a biopsychosocial approach requires interprofessional collaboration of health professionals with varied skills and knowledge working in interdisciplinary teams [32]. In the current landscape of global shortage of human and financial resources and fragmented health systems, interprofessional collaboration offers a promising solution to strengthening health systems to meet complex health needs, and improve health outcomes [33].

Interprofesssional Collaboration is essential for improving access to patient-centered care. The ICN Code of Ethics for nurses urges nurses *to "sustains a collaborative and respectful relationship with co-workers in nursing and other fields*" [12, p. 4].

In collaborative practice health professionals:

- Cooperate and assume complementary roles.
- Share responsibility for problem-solving and decision-making to formulate and implement patient care plans [34].
- Increase awareness of team members' knowledge and skills, leading to continued improvement in decision-making [35].

Collaborative practice comprises three basic elements:

- *Multiple providers: no single profession can meet all patient's needs*
- *Service coordination/collaboration*
- *Communication: in order to provide comprehensive, efficient and patient-centred care*

At the core of the interdisciplinary team approach is the person who has health problems and who should be an active partner and at the center of care. Collaboration between physicians, nurses, and other health care professionals increases awareness of each other's knowledge and skills, leading to respect and involvement in decision-making [35]. Interprofessional collaboration may help in preventing fragmentation of care due to specialization, as patients who receive care from a team can benefit from the inputs of different professionals with diverse knowledge and skills [36].

A key tenet of interprofessional collaboration is communication between the different professionals on continuous basis. Effective communication facilitates information-sharing and decision-making, mutual respect, trust, and active participation by all team members, resulting in stronger team identity, reduction in hierarchy, increased responsiveness to job demands, higher job satisfaction and better staff retention [37]. Similarly, a workplace environment that fosters consistent and effective communication between health professionals leads to low staff turnover, better clinical outcomes, shorter hospital stay, and higher quality of care [38].

39.8.2 Learning Together to Work Together

Interprofessional education (IPE) defined as, the process by which a group of profession-specific students from different health-related occupations learn together at some point of their education, in order to work together [31]. Interprofessional education aims to ensure that all members of the health team understand each other's roles, core competencies, basic language and mind-sets, and that they develop attitudes and behaviours that facilitate collaboration.

Initial research studies reveal that IPE increases confidence in health professionals' identity and appreciation of the roles of other professions, and improves communication and team-working skills [39].

Some authors have noted that the education of health professionals in silos does not prepare them for interprofessional collaboration and communication [31, 39]. However, there is a positive movement towards developing core competencies for interprofessional collaborative practice that aims to build on each profession's specific competencies, and engage students of different professions learn together [29]. Thus, in order to implement IPCC health profession curriculum needs to be transformed to include IPE with collaboration and communication as core competencies [31, 39].

39.9 Conclusions

The growing interest on person-centred care is a timely move; however we need to move beyond rhetoric to redesign health systems that are fit for purpose, and invest in training of health professionals who are 'collaborative practice ready', as no single health professional can have all the knowledge and skills to meet health care needs. Making sure that people are fully involved in their care is now recognized as key element of care. In our approach for a holistic perspective, we should locate person centred-care within the larger context of family and community in a dynamic and interactive state. This will mean that person-centred care will require a new set of competencies of nurses and other health professionals. In order to put patients at the centre of care, we need health professionals with competencies in communication and assessment, counselling and behaviour change strategies, supporting self management of illness and wellness, and coordination of care across time and with other health professionals [19].

Health care organizations need to offer a safe and supportive practice environment with programmes that foster interprofessional collaboration and communication that embrace person-centred care and improve patient outcomes.

Acknowledgements and Disclosures The authors do not report any conflicts of interest in the preparation of this manuscript.

References

1. Mezzich JE, Snaedel J, van Weel C, Health I. The international network for person-centred medicine: background and first steps. World Med J. 2009;55:104–7.
2. International Council of Nurses. Developments and Innovations in the Nursing Care of Older People: an international review. Geneva: ICN; 1999.
3. Institute of Medicine. The future of nursing, leading change, advancing health. 2010. www.iom.edu/nursing
4. Billingham V, Gerteis M, Edgman-Levitan S, Jennifer Daley J, et al. Through the patient's eyes: understanding patient-centered care. San Francisco: Jossey-Bass, Inc.; 1993.
5. Kitwood T. Dementia reconsidered: The person comes first. Berkshire, UK: Open University Press. 1997.
6. Mezzich JE. Psychiatry for the Person: articulating medicine's science and humanism. World Psychiatry. 2007;6(2):65–7.
7. McCormack B. A Conceptual Framework for Person-Centred Practice with Older People. International Journal of Nursing Practice. 2003;9(3):202–9.
8. Rogers C. On becoming a person. A therapist's view of psychotherapy. Boston MA: Houghton Mifflin; 1961.
9. Engel GL. The need for a new medical model: a challenge for biomedicine. Science. 1977;196:129–36.
10. World Health Organization. WHO global strategy on people-centred and integrated health services. Interim report. Geneva: WHO; 2015.
11. Henderson V. ICN's basic principles of nursing care. Geneva: ICN; 2004.
12. ICN Code of Ethics for Nurses. Geneva: International Council of Nurses; 2012.
13. Perez-Merino R. Strategies for enhancing the delivery of person-centred care. Nurs Standard. 2014;28(39):37–41.
14. Steenbergen E, van der Steen R, Smith S, Bright C, Kaaijk M. Perspectives of person-centred care. Nurs Standard. 2013;27(48):35–41.
15. McCormack B, Dewing J, Breslin L, Tobin C, Manning M, Coyne-Nevin A, Kennedy K, Peelo-Kilroe L. The implementation of a model of person-centred practice in older person set-

tings. Final report, Office of the Nursing Services Director, Health Services Executive, Dublin, Ireland. 2010.
16. Sepucha K, Uzogarra B, O'Connor M. Developing instruments to measure the quality of decisions: early results for a set of symptom-driven decisions. Patient Educ Counsel. 2008;73(3):504–10.
17. McCormack B, McCance T, editors. Person-centred practice in nursing and health care: theory and practice. 2nd ed. John Wiley & Sons, Ltd.; 2016.
18. Leplege A, Gzil F, Cammelli M, Lefeve C, Pachoud B, Ville I. Person-centredness: conceptual and historical perspectives. Disabil Rehabil. 2007;29(20–21):1555–65.
19. WHO. Preparing a health care workforce for the twenty-first century. The challenge of chronic conditions. Geneva: WHO; 2005.
20. Mead N, Bower P. Patient-centred consultations and outcomes in primary care: a review of the literature. Patient Educ Couns. 2002;48(1):51–61.
21. McMillan SS, Kendall E, Sav A, King MA, Whitty JA, Kelly F, Wheeler AJ. Patient-centered approaches to health care: a systematic review of randomized controlled trials. Med Care Res Rev. 2013;70(6):567–96.
22. Mead N, Bower P. Patient centeredness: a conceptual framework and review of the empirical literature. Soc Sci Med. 2000;51:1087–110.
23. van den Pol-Grevelink A, Jukema JS, Smits CH. Person-centred care and job satisfaction of caregivers in nursing homes: a systematic review of the impact of different forms of person-centred care on various dimensions of job satisfaction. Int J Geriatr Psychiatry. 2012;27(3):219–29.
24. Bower P, Campbell S, Bojke C, Sibbald B. Team structure, team climate and the quality of care in primary care: an observational study. Qual Saf Health Care. 2003;12(4):273–9.
25. Institute of Medicine. Health professions education: a bridge to quality. Washington, DC: National Aacademy Press; 2003.
26. Wheelan SA, Burchill CN, Tilin F. The link between teamwork and patients' outcomes in intensive care units. Am J Crit Care. 2003;12:527–34.
27. Mezzich JE, Snaedal J, van Weel C, Heath I. Toward Person-centered medicine: from disease to patient to person. Mount Sinai J Med. 2010;77:304–6.
28. Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards, September 2012. Sydney. ACSQHC. https://www.safetyandquality.gov.au/
29. Interprofessional Education Collaborative. Core competencies for interprofessional collaborative practice: 2016 update. Washington, DC: Interprofessional Education Collaborative; 2016.
30. Institute for Healthcare Communication. Impact of communication in healthcare. 2011. https://healthcarecomm.org/about-us/impact-of-communication-in-healthcare/ Accessed 18 Mar 2020.
31. World Health Organization. Framework for action on interprofessional education & collaborative practice. Geneva: WHO; 2010. http://whqlibdoc.who.int/hq/2010/WHO_HRH_HPN_10.3_eng.pdf?ua=1
32. Boon HS, Mior SA, Barnsley J, Ashbury FD, Haig R. The difference between integration and collaboration in patient care: results from key informant interview working in multiprofessional health care team. J Manip Physiol Ther. 2009;32(9):715–22.
33. Mickan S, Hoffman SJ, Nasmith L. Collaborative practice in a global health context: Common themes from developed and developing countries. World Health Organization, Study Group on Interprofessional Education and Collaborative Practice. J Interprof Care. 2010;24(5):492–502.
34. Fagin CM. Collaboration between nurses and physicians: no longer a choice. Nurs Health Care. 1992;13(7):354–62.
35. Christensen C, Larson JR. Collaborative medical decision making. Med Decis Mak. 1993;13:339–46.
36. Wagner EH. The role of patient care teams in chronic disease management. Br Med J. 2000;320:569–72.

37. Weiss D, Tilin F, Morgan M. The interprofessional health care team: leadership and development. Burlington, MA: Jones & Bartlett Learning; 2014.
38. Suchman A, Sluyter D, Williamson P. Leading change in healthcare: transofrming organisations using complexity, positive psychology and relationship-centred care. London: Radcliffe Publishing; 2011.
39. WHO. Transforming and scaling up health professionals' education and training. Geneva: WHO; 2013. http://apps.who.int/iris/bitstream/10665/93635/1/9789241506502_eng.pdf
40. Frenk J, Chen L, Bhutta ZA, Cohen J, Crisp N, Evans T, et al. Health professionals for a new century: transforming education to strengthen health systems in an interdependent world. The Lancet. 2010;376:1923–58.

Chapter 40
Person-Centered Traditional Medicine

Thomas Heise, Martha Villar-Lopez, and Oswaldo Salaverry

40.1 Introduction

The apparent complexity of traditional medical systems is due, in large part, to the fact that they correspond to a matrix of thought that is not exclusively rational or reductionist, based only on what is materially demonstrable, as occurs in Western thought. For this reason, in order to find the relationship between the practices, rituals and content of the different traditional medical systems and person-centered medicine, we have followed a scheme by which, first of all, we characterize the traditional medical system and his way of understanding health and disease; then we identify those practices, knowledge and other evidence that clearly show us this orientation towards the person, and finally we propose how an adequate approach to traditional medical systems will allow us not only a better understanding of the millions of users of contemporary traditional medicine, but to identify possible incorporations to western medicine that will enrich Person-Centered Medicine.

Traditional medicine thinking does not separate the body from its environment, nor does it separate the body from its spirit. But even more importantly, it does not separate the patient from the healer, since both are considered components of the same process. Traditional medical systems integrate the body as a whole, not separating it into systems and organs independent of each other, but considering

---

T. Heise (✉)
Medical University of Hannover, Hannover, Germany

Institute for Holistic Health Counselling, Feuerthalen, Switzerland
e-mail: thohei@gmx.de

M. Villar-Lopez
Department of Preventive Medicine and Public Health, Faculty of Medicine, San Marcos National University, Lima, Peru

O. Salaverry
Faculty of Medicine, San Marcos National University, Lima, Peru
e-mail: osalaverryg@unmsm.edu.pe

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_40

corporality as a complex system of internal relationships that in turn is also linked to another complex system of relationships in its cosmic environment and spiritual world.

In its origins, Western medicine was based on rationalized traditional practices, including its holistic vision. But as it developed, it abandoned the idea of the relationship of the body with its psychic component, then also abandoned the relationship of the body with its cosmic environment, and finally introduced an approach by systems and organs independent from each other that gave meaning to their clinical reasoning. Traditional medical systems never abandoned that initial unit. That is the reason why specialties are not observed in traditional medicine. It is the Western perspective that when interpreting the practices studying these traditional systems tries to delimit the functions within a scheme of Western specialties.

40.1.1 Cultural Space and Time

People constantly interact with the space where they live, coming to understand it and adapt to it, making a series of adjustments in their beings in order to achieve a harmonious balance between themselves, the community and the space-time where they live. It is built through history, and through the practice of a series of values and specific objectives that form knowledge, beliefs and customs until they become a cultural pattern, originating a worldview that is nothing more than a philosophy of life [1, 2].

A traditional approach in medicine is in most cultures understood as the specific cultural way to the concerned system of healing in a person-centered manner. But this was not always meant in a very individualistic way, being linked to the own responsibility for health and for the entire cosmos as well, as will be shown.

The great cultures have contributed with their traditional health systems. Among them is traditional Chinese medicine, Ayurvedic medicine, Unani medicine, naturopathic medicine, Americas' indigenous medicine, where traditional Andean medicine is located, and many others. Virtually all of them are alive today and are based on the understanding of the complexity of life and the human being. They have a holistic and transcendent vision of life, although each one preserves its own particularities [3].

When one thinks of China, most people identify this with acupuncture, herbs and qigong, forming the therapies of a rather consistent and ever since monolithic system of the well known traditional Chinese medicine (TCM). It will be shown that it is much more complicated than that. Modern scientifical research will shed a new light on its understanding. Some spotlights placed on traditional medicines in other areas and continents will give us further insight into how traditional medicines are looked at today and what it can mean to us.

40.1.2 Objectives, Approaches and Knowledge Base

The idea how traditional medical systems are constructed and how they pursue a person-centered approach is presented, using mostly China as an example. Besides his training in medicine, psychiatry and psychotherapy, with a specialization in transcultural issues [4–6] the author fulfilled also other PhD studies. These included archeology, prehistory and Chinese studies, ending in a 2 years bigovernmental scholarship to study Traditional Chinese Medicine in the P.R. of China 1984–1986. Results from this, researching in Chinese, English and German literature and journals, as well as further investigations, especially on history, theory and clinical practice of qigong in China [7] and in Germany [8], have been published in two thesis. Besides various longer visits, he worked in Shanghai in his private holistic dayclinic from 2010 to2013. All this is used as a knowledge base to fulfill the objectives. In addition, extensive travelling to many parts of the world and studying various cultures and their histories, including the medical ones, led to my becoming an officer in the German anthropological society (AGEM, Arbeitsgemeinschaft Ethnomedizin) for many years. Another result was the book “Kulturen der Menschheit: Woher und wohin?” (in German; “Cultures of Mankind. Whence and Whither?”) [9].

40.2 The Example of China

40.2.1 Historical Development

In the book of Lieh-Tzu (also: Liezi), which in parts is dating back to about 400 B.C., it is written about a case of loss of memory of Hua-Tzu [10]. To treat him well, the relatives asked at first a fortune teller, but he couldn’t find a prophecy. Then magicians did their enchantations to ban the evil spirits, but with no result. Only then they looked for the doctors to come, as they probabely were more expensive than the others. As they had no success the case was handed over to a scholar from the state of Lu, who said, he could help. The relatives offered half of their fortune, if he would cure him.—So here we can see a broader variety of very individual and person-centered approaches, as all their means were just meant to fit in this very case. And all of these healing approaches could be found in China at least widely spread until the communist party took over and tried to ban all “superstitious” beliefs and practices. But still a lot of these survived in the underground, or are accepted officially now as a part of buddhist or daoist rituals. So for example there exists a great amount of literature on the book of Yijing, which is used for fortune telling widely, showing the most probable future, if one does not intervene strongly. And also there are abundant works and workshops on fengshui, as the energetical components of the environment play also an important role, as this contributes to the personal health. This is seen partly as well by social psychiatry, when talking of the sociomedical factors.

Besides of course, as China is a country with 56 minority cultures, which originally covered 60% of the Country's surface, we do not only find the well known Han-Chinese, Tibetan, Mongolian and Hui traditional medicine.

During the course of history, many different schools of traditional medicine of the Han Chinese developped. There didn't exist the idea of a standardization, especially as many recepies have been transmitted to the next generation only as a family secret. It took Mao Zidong a big effort, to convince the traditional healers to write down these and to collect them in herbal pharmacopedias or in books on acupuncture and manual therapy as well as qigong. The later happened only after his death, as he accepted only taiji quan for his wife and the population. And this was so despite the fact that all the governmental members went regularly to the big qigong rehabilitation center and hospital in Beidaihe, which even during the "Cultural Revolution" wasn't closed. Years later, with the rise of narcissistic tendencies as a result of the "one child family policy", suddenly everyone was a specialist with a singular and marvelous medical discovery. This gave the possiblity to earn fame and money.

All these different schools gave often diverging emphasis on parts of the theoretical body of TCM, as this has been put together later in the beginning of the PR of China. Mao who first believed only in Western medicine, found out after the war that nearly no Western trained doctor was left over in his country. He had to accept and propagate TCM and a kind of westernization of TCM started and research was enhanced.

40.2.2 The Person-Centered Ideas of TCM and Obstacles for Implementation

A person-centered approach makes a change in the formal aspects of responsibility taken for health as well. In West Germany one can answer with the following generalization: the patient of tomorrow is paying his health insurance today and in the case of "damage" he presents himself to the doctor whose duty it is to make him fully functionable as quickly and as well as possible in order to be able to survive the stress of an overcivilized world. That is to say that often the few patients who would be open-minded enough to other i.e. lengthy and patient activating therapeutic approaches are not able to do this because of their professional situation "time is money." They cannot or will not afford an extended rest to leave their accustomed habits like "too much eating, too much drinking, too much smoking, too little sport, too little pauses for quiet reflection." Thus one only "cures" the symptoms when they occur, while the known sources of disease are not really addressed; the path from health to minor functional and psychosomatic disorders and eventually to the manifestation of disease which one can no longer overlook as gradually intensifying warning signal is often not only not correctly interpreted but is ridiculed. Too many still think that diseases occur suddenly. That the patient was still healthy the day before and thus nobody can be blamed for his falling ill. Schools where the possibility would exist to create a class like health education to be taught by e.g.

unemployed or retired doctors are not spared from the growing specialization of our society. Even the biology class teaches genetics on an already university-like level, while no one gives sufficient and reliable instruction in common diseases, preventive medicine and botany with medical herbs etc. Therefore most youth must rely on magazines or pharmaceutical advertisements for their general medical education. Also hard to understand is the fact that the state is prevented from a wholehearted interest in the wellbeing of its citizans. It benefits from the tobacco- and alcohol tax, thus preventing the struggle against addiction and the related social misery, sometimes causing a symptom called "people who die earlier don't need a pension." Many other "solutions" in the health policy are also shortsighted, not including the knowledge of the different experienced specialists and general practitioners. Health policy tends to be more determined by administration employees and officials who generally know more about short time economies and financial profit than about medicine and healthy living in a clean nature where even our grandchildren could live without problems. Unfortunately we succeeded in exporting this way of thinking into too many countries leading to the fact, that we are now controlled widely by Big Pharma and Big Tech.

In contrast, the meaning of "medicine" in the original TCM is already fundamentally different from the meaning of "medicine" in the West. The old pictogram for medicine shows a dancing shaman. Preventive measures and rehabilitation are, in the former instance, already fully integrated in a distinctive way. Let us begin with a traditional farming family in the PR of China or an urban family that still bears the traits of the culture. The father of a family is returning home in the evening from work and feels he is coming down with the flu. Already on his way home he will beginn with "Anmo" (massage) of the "Hegu"-points, and in the case of a cold he will use the "Yinxiang"-points as well (this kind of massage is often called acupressure). He knows that in the evening his wife who has some knowledge in "Shiliao"(dietetic) will, unsolicited, serve him a soup with ginger and a medicinal tea. He will eventually practice "Qigong" (the traditional Chinese "breathing" therapy, working with subtle bioenergy) in the evening and at night he will not be sexually active. And the fresh morning air in the park will be the setting where he will partake in "Taijiquan" "shadow boxing", another way of working with subtle bioenergy) with his colleagues or with a master. If his resistance is normal, if he has had enough experience in the practices mentioned above, and if the weakening agent is not unusually strong, his cold will have almost vanished the next day.

Alternately, the patient in the West will go to the doctor on the 4th day of his cold and, depending on his job situation, will take a week off from work. He will be pumped full with superfluous drugs—superfluous because most of them don't help—which are really just a means to cover up the doctors own helplessness. And he will not exert any effort to be active in any way. Only a small, slowly growing number of patients and doctors has a different view of more resilience. If one inquires about "nature healing methods" most doctors will condecendingly retort that these methods have at most a placebo effect, and further, that there are no double blind trials that are statistically significant and scientifically recognized. The latter is sometimes true, as there are no big companies giving money for something, where they cannot make a lot of profit. And universities rely on money from the outside.

As a matter of fact it seems hard to imagine or understand as well as to explain sufficiently for the critics that the very traditional Chinese herbal medicine is mostly prepared for the person’s individual disease that can hardly be compared with other peoples. Additionally, the nonsynthesized drugs have in their natural composition other and mostly better and more well known effects than in their purified chemical synthesis.

But in accordance with the newest drug regulations in West Germany most of the natural means cannot be authorized or licensed if they are not submitted to detailed analyses with respect to their categorizable and provable effects. To put this into terms of everyday life and to exagerate the point, the doctor cannot recommend that his patient eat an apple a day, but rather only the corresponding chemically synthesized quantity of vitamins whose effects one supposedly knows down to the very last detail.

40.2.3 How Research on Modern Nature Healing Can Explain TCM and Person Centered Approaches

The one and main subject in medicine and psychiatry is the diseased person. We now see more and more aspects, causes and perspectives of illness and disease. This brings us back to become more modest. Not every new discovery is more important than the others and gives me the nobel price. It all is just one small stone to the house of medical wisdom. So we can also respect and evaluate the other stones equally and look what other cultures and other times discovered. Many of these have been hitherto evaluated only by our modern arrogant view, that we are the top of intelligence now, and so we do not try hard enough to understand what lies behind other explanations and knowledges. Thus we miss important messages, which in part could help us with our problems.

Griesinger talked 1861 about his idea, that all the vibrations, all the electrical and mechanical in the brain, would however not yet be a state of the soul, or the imagination. Nowadays we are trying to explain with genetics, biochemistry and neurophysiology more into the depths what could be hidden. But like the physicists, who divided the undividable “a-tom” and finally only found different kinds of energy and energetical states, so in medicine and psychiatry we are about to come to the same ends. And suddenly we meet here the so far misunderstood traditional healers and the way how they tried to put their experiences into their specific medical systems using their history and culture bound language and expressions. At this point of the story we come to ask another important question. What is more predominant: The isolation or the connectedness? Do we only have to rely on explicite and strictly separated epochs of history or diagnoses of medical subspecialities more and more into the details and not seeing what else is around? The development of historiography and international classification of diseases (at least until ICD 10) was mostly like that in the last decades. Did we neglect too much the interconnectedness of things and processes, in culture [9], man, and nature? Scientists who tried to remind us of this have been scolded and ridiculed. The brandnew results of their intrinsic top research would already explain nearly everything, says the mainstream scholar. Just put more money and effort in it and like nowadays "give more vaccinations". —But they have been mistaken! After one corner comes the next. Not more of the same kind of research will help, but another paradigme in quality of research and therapy will show us an additional framework to better understand all the important findings we got until now. We have to look at the building from the inside AND the outside. As every individuum is unique, the medicine applied for him must be unique and thus person-centered as well, not regarding from what kind of medical system it derives from. But of course Newton's results remain valid in everydays life, even when they are complemented by Albert Einstein, Max Planck and others. The same is valid for the different approaches and findings in the fields of medicine and healing. Newton does not help to understand quantumphysics, traditional Chinese medicine, information medicine or homeopathy. Another approach is needed for that. This does not mean "anything goes" and is in any way meant as the result of research and therapy linked to a moral and sincere behaviour, to oneself, the next and the nature.

Harold Saxton Burr (1889–1973), chair for anatomy since 1929, discovered besides other things already 1935 a change of the electrical tension at the time of ovulation and in cases of cancer [11]. The German physician Reinhold Voll found in his acupucture research, that the electrical skin impedance was enhanced with inflammations and decresased with degenerative changes or necroses. 1973 [12] they found a 18-fold increased impedance at the acupuncture point liver 8 at the knee, in case of liver disease and a 30% decrease in lung points in cases of lung cancer. —Traditional Chinese medicine [13] has a holistic and systemic view. The functions of e.g. liver and lung cover the somatic-physiological-psychological-spiritual field and thus they are represented in the whole system and can be diagnosed and treated accordingly, especially in the meridian system. Continued research showed that changes in cancer tissue were depending on the frequency and got worse by a final degeneration [14]).

An "electrical-pulse-mediated drug delivery" against breast cancer was discovered [14–16]. Metabolic active cancer cells in blood apparently had a singular electrostatic surface and positive loaden nano parts could bind them in the labaratories [17].

The high percentage of salt in the blood makes it a good conductor. 1820 Hans Christian Oersted discovered that the electromagnetic field of an active electrical conducting agent reaches into the surrounding space. This is true as well for the heart as shown by Gerard Baule and Richard McFee in 1963. The predicted "tunnel-effect" by Brian Josephson could later be shown for the heart as magnetocardiogram [18]. The heart radiates our strongest biomagnetic field, but every organ and each cell does likewise in a smaller manner, creating Josephson-effects. In meditation, yoga, qigong and many traditional healing and spiritual rituals etc. can our will train the hovering awareness systematically to produce healing effects in us and others. This scientifical explanation is further inhanced by the research of the perception and influence of the magnetic field proven in many animals already and likely working to a nowadays smaller extent in modern man likewise. Research of the histologist Alfred Pischinger 1975 [19], about the importance of the triade of capillarvessel, matrix and cell in the system of regulation, finally led to the bioelectronic and a new understanding of the cell [20]. Albert Szent-Györgyi proposed proteins were semiconductors and the water would carry the energy. Now we know meanwhile, that water carries also information and each crystal drop thus is different. Robert Becker [21, 22] researched the anthropological much older perineural nervous system (besides the well known digital working neurons) which communicates by direct current and is very susceptable to magnetic fields. In case of injury it creates a currence of low tension to start healing processes and it probabely has many more regulating functions for the nervous system and the consciousness [21, 22]. Even the meridians of TCM will be connected to those. Herbert Fröhlich and collegues showed that vibrations of different frequencies including all lightwave lengths are spreading in and out of the body. Of course influence from the outside like all electromagnetic waves can thus give us harm. Fritz-A. Popp [23] found out about the ultraweak lightphoton radiation of the living cell, giving further evidences about the working principles of our system and thus giving more possible hints, how traditional medicines [9] work in a very individual person-centered way for the very individuum.

40.3 Traditional Medicine in India

It seems that the development of medical ideas in the Indian subcontinent was guided by three influences. These influences concerned the Indus valley culture, the Dravidian people, and the immigrating Arians. For the Dravidian people, the jungle as a place for contemplation and meditation played an important role. Woods, groves, caves and hunting were of significance for the prevedic gods Kālī or Durgā and Ayyappan. The temples they used for whorshipping snakes were in some parts of Southindia called kāvu, meaning grove. Early Vedic scriptures thus gave meaning to both traditions by explaining which studies and procedures could be done out of sight of their housing in the village (grāmya) and which had to be done in the wood (āraṇya). The offering of the Soma libation was the essential element in the vedic rituals of the Arians for connecting with the gods. After connecting, these festivities developed into seasonally important days and assumend a public dimension, whereby—alongside the private venerations—metaphysical contemplation as well as philosophical and medical concepts emerged. The Arians—who previously had nearly only male gods—apparently started to accept again female gods as a result of this non-vedic influence [24].

As the immigrating Arians of about 10,000 years ago were warriors, they gathered knowledge in anatomy and surgery, whereof accounts are given in the Rigveda (1200 BC—900 BC) (http://de.wikipedia.org/wiki/Samhita). In 1000 BC, one of the two oldest and well-known medical centers of knowledge was in Taxila. Its most famous physician—Charaka, and also Sushruta, from the second famous place in Benares—both wrote down their scriptures, which came to be known as Samhita. Here a very person-centered medicine was already taught in various elaborated specialisations. Some of those specialisations—such as cutting out urinary bladder stones, as well as skin and cataract surgery—arrived in Europe only in the Middle Ages [25].

The basic teachings of Ayurvedic medicine were written down in the Charaka Samhita and the Sushruta Samhita. The first of those works describes in 184 chapters 1120 diseases, 700 medical plants, 64 mineral recipes and 57 recipes prepared from animals, and also presents anatomical studies. The second work deals in 120 chapters in eight parts with general principles and rules of diagnosis—and is to that extent similar to Chinese traditional medicine—as well as with physiology and prognosis, healthy food and social behaviour; furthermore, it describes methods for anti-aging, as it is called today, and more. In addition, a small presentation of a seated Yogi was found on a seal from Mohenjo-daro which dates from the third millenium BC ([25], p. 215; [26], p. 24, 28). The first dental care was found in Mehrgarh from 6500 BC [27].

According to the sources that are written down in the Rigveda, the world was viewed from the ritual, cosmic and psycho-physiological side. Its inherent relatedness between all dimensions of nature and the individuum was understood in a person-centered as well as a holistic way, including subtle energetical and karmic experiences.

Thus the five elementary forms water, earth, fire, air, ether—the "Panchamahabhutas"—are composed in every person very individually and must, in case of disease, accordingly be treated in a person-centered manner. The "influencing factors"—Dosha—show an individual mixture of "the principle of movement"—Vata—"the principle of fire and metabolism"—and "the structuring principle"—Kapha (http://de.wikipedia.org/wiki/Ayurveda).

Today, there are in India three co-existing systems of medicine, which are equally recognised: the Western system, the Ayurvedic system and the Homeopathic system. We thus have at least two systems which are completely person-centered in their way of thinking and healing. The third system will hopefully in the future discover its own limitations and learn from the other two systems, so that a more valuable medicine, grown from its cultural roots, can emerge and lead us to a better understanding of the sensible depths of medicine and enable us to achieve more effective care for our patients.

40.4 Traditional Medicine in the Americas

According to modern genetic analyses, the conquista killed at least half the original indigenous population in the Americas [28]. Hence many parts of the traditional cultures, including their medical dimensions, have been destroyed or at least severely mutilated.

In a comparison we can for example see that many names of diseases of the former Maya have disappeared or were changed. In the Codex Pérez, from the Mani in Yucatán, we find the indication of time, day and month—the “katunes”—when it is most likely for a certain disease to strike. The ritual of the Bacabes from the end of the sixteenth century is a very essential medical text without European influence. Apparently, it seems to come from the Nunkiní in Campeche and has some relationship with the Codex Calkiní and the Chilam Balam from Chumayel. It deals mostly with healing incantations and manifests therein a combination of medical, botanical, magical and religious knowledge.

Only little is known about the precolumbian medicine. Special gods dealt with the different diseases. The energies of supranatural causes and winds are responsible for diseases; and the diseases are represented by certain animals, which in turn are associated with the winds and the directions. The concept of time was very spiritual, having its influence on the world and men. Diseases were divided in hot and cold, in a close relationship with the respective gods. Thus, in a holistic world view, medical tasks and religious tasks were actually not perceived as distinct. Diagnosis was conceived by examination, person-centered interrogation of the patient and of the divine by divination. As a consequence, a mixture of these aspects was used to heal. Healing thus took the forms of incantations, application of medical plants, and blood letting ([29], p. 19f.).

Nowadays Maya traditions in Chiapas say that the gods need soul energy from the living beings to nourish themselves; and in that tradition, this soul energy is not any more set free by human sacrifices, but by animals. Nature and gods vary locally, but there is always the struggle between good and evil. Therefore, not only the balance between warm and cold, sufficient food, and the shelter of nature‘s power are important, but also individual, moral behaviour, taking care of your immediate family, as well as of society overall. As local contingencies and differences prevail, travelling may be hazardous.

If the usual treatment with diatetics and herbs is not working, the healer—“curandero”—is looking for the supranatural causes of illness. The gods of death, mostly “ik‘al”—a black person of infant size—and its followers are responsible for all inherited diseases including schizophrenia. The spirit animal, which is a good company for everybody, has the more power, the higher the social rang of a person or healer is, and is represented by a respective position in the holy mountain.

The concept of nourishing the gods by special energies also is very specifically followed by the Kogi from Columbia. To render the soil fertile, their sacrifices are laced with the secretion of the vagina or with male semen. Their healers have a very elaborated cosmogenic-spiritual concept; it is put into practice in everydays life as well as in all their rituals. Individual, personal responsibility is connected to mnemotechnic teachings and an individually taught wisdom. Thereby a complete self analysis, in a dynamic relation vis- à-vis the law of the “Great Mother”, is achieved. Here the individual moral is of higher importance than superficial good behaviour [30].

Other people have other traditions. The tribe of the Desana lives as hunters and fishers patrilinear and virilocal in the Amazonas area. Their shamanic healers use hallucigenous plants for diagnosing a patient whom they have first led into a trance. Psychedelic visions are discussed, and a culture bound interpretation leads to healing.

Norms of behaviour and spiritual cosmic integrating factors are emphasised. Different kinds of crystal stones and their representation in the human anatomy play an important role. The more practical side of healing is performed by the women and the experienced elders. The incantations of the shamans bring about a direct communication with the spiritual powers and show an overwhelming creativity [30].

The Callawaya-culture of the Bolivian Andes in its self-understanding *is*—not *has*—its cosmology, which in its white healing aspects shows diverse relationships to the concrete daily experience and conduct of life.

Patterns of thinking are determined by multi-causality, collectivity, balance, wholeness, reciprocity. As things are not subject to a linear logic, there is never only one cause of illness. But these multiple causes of illness interact, flow into one another, and influence—or even attack—one another. Causes of illness may also be loss of soul or being the victim of a debt, coming from an unknown past, which thus show its effects in the present and determine the future. The effects of those causes of illness do not follow a clear line. Hence, an illness may derive from my father, but affect the cattle of my cousin. The men and the non-human, the living and the things—everything is connected, and it is also the case with diseases. The single person and the society—in being embedded in nature, mother earth and places of spiritual power—should all be in reciprocal harmony. Otherwise disease results ([31], p. 706 f.). The Bolivian vice president David Choquehuanca gave a profound inauguration speech in November 2020 reflecting spiritual and cultural values in fraternity for a society full of respect for human beings and nature (https://www.youtube.com/watch?v=gcOKNs8hfsU; accessed on 9 September 2021).

This presentation is intended to give only some examples of the traditional medicines in the Americas, which coexist with Western medicine and are often used in combination. It may also show that such medical ideas do not exist if they are not person-centered and put into a holistic cosmogenic worldview, in which the individual exists within the wholeness of nature, society and the world. It is consistently understood that if this reciprocal balance is disturbed, disease will happen. This will come to the person in this life or in another life, and to society at large.

40.4.1 Traditional Andean Medicine

American Indian medicine, where traditional Andean medicine is located, all of them are alive in Today and are based on the understanding of the complexity of life and the human being, they have a holistic and transcendent vision of life, although each one preserves its own particularities (WHO 2005; [3]).

The Andean Traditional Health System is based on the Andean worldview, which describes and explains the relationship between human beings and nature (tangible elements), as well as the role of supernatural powers within the spiritual world (intangible elements) and the way in which natural processes occur. This conception was forged from the pre-Inca cultures in South America (3000 years BC to 1300 years BC). Later it was synthesized and strengthened by the Inka culture, one of the 6 cultures that made a great contribution to the knowledge of humanity [32, 33].

This vision is alive today and symbolically presents the world through ritual and celebration [34]. It shows the link of everything with everything, it is symbolic, affective and integrating, it is based on the living totality. The Andean man behaves like an articulator or bridge (chacana). That is why there is a great affinity when it comes to Person-Centered Medicine—PCM, where the human being is also the center, from him they are woven as interrelationships first with himself and second with everything that surrounds him (family, community, environment, universe) both in the physical world and in the intangible world.

From this worldview, the universe is interrelated through different cardinal axes: a spatial one between the top (hanaq) and the bottom (ukuy) with its center (kay), between the left (lloq'e) and the right (paña); and another temporary one between the before (ñawpaq) and the after (fit), the time is cyclical. It is about dualities that are not oppositions but complementary polarities. A third ordering axis is the sexual polarity between the feminine and the masculine. In Andean thought, there are no hierarchies but correspondences [35].

In this conception, the human being is the "caretaker" or "guardian" of the Pacha and its cosmic order, defined as space-time; and the Ayllu, as that space that has what it takes to sustain itself. His logic transcends the thinking of the Western world: false, true and becomes trivalent: true, false and uncertain [36].

The principles that sustain the Andean Cosmovision are [37, 38]:

Living Totality: everything that exists is alive, the mountains, the water, the animals, the plants, the human being; therefore, we must respect everything that exists.

Link: there is an interconnection between all beings or elements of the universe, without hegemony or domination, in permanent circular movement. An aspect that is also considered by person-centered medicine, when it refers to the fourth component "doctor-patient relationship", in which an encounter is woven between the health professional, the person, their family, the community and the universe, generating a therapeutic alliance in health care.

Correspondence: the different aspects correspond in a harmonious and proportional way. The macrocosm is reflected in the microcosm and vice versa. When there is a harmonic balance, health occurs, if it does not exist, disease occurs.

Complementarity: no entity or event exists individually, but always having a complement. They are not opposites, they are complementary, like those required to engender life.

Reciprocity: also called Ayni, it corresponds to cosmic justice. The giving, receiving and returning. It is the basis of community relations that encourages giving back what has been received and receiving what has been given in return, building a culture of solidarity care, from the premise that we are community human beings (Ayllu runa) [39].

The Principle of Integrality, of Unity in diversity: enriching and complementing unity based on diversity. In PCM, the comprehensive understanding of the person as a whole is also sought, as a system that works in unison. This includes awareness on the part of the patient of his position in the life cycle and of the context in which he lives.

The Principle of Agrocentrism: understanding life as a great chakra, where everyone cares and is cared for, where the mountains or the apus are silent guardians of the life of those who inhabit the ayllu, is to understand the union with mother earth or mama pacha.

From the Andean worldview, being healthy integrates two key elements: the individual and the collective condition. The individual condition is "to be well" (there cai). It is a dynamic harmonic balance of the physical, mental, emotional and spiritual aspects. The personal abilities to act are observed, according to age and sex, depending on it, physiognomy and texture, serene emotionality and expressiveness, spirituality of approach and dialogue. The collective condition not only has to do with being well, but with "living well" (there kaway), living in accordance and with strict compliance with the ethical principles of community life, respecting hierarchies (adult-child, among others), roles (husband-wife), nature (Pachamama) and solidarity (mingas) [37].

The Eurocentric theory of Cartesian and Newtonian knowledge is insufficient to explain the complexity of most of the knowledge systems and practices of the indigenous peoples of the Americas and therefore it is essential to understand the worldview of the Andean peoples.

The fact, of applying some of the principles of quantum physics in the way of doing science today, allows us to open our minds to better understand the ontological uncertainty, since it is known that in experimental form matter and light are presented as waves, or at other times, as particles, from western causal logic this would be a paradox. But this really forces us to accept much knowledge of native peoples, about their own reality, understood between the multiple relationships between an intangible and empirically not accessible or verifiable reality and our causal world, explained from quantum physics [4, 5]. Also, it would be seen that an ethical change is required, based on good living, with a deeper and spiritual understanding of the place of humanity in the cosmic order [38].

This system, like all other traditional health systems, prioritizes activities aimed at promoting health, such as circular dances that connect people with nature, since everything moves in the Pacha, because it is alive and rewarding, there are various dances related to cyclicality and the variability of forms; Another method used is music, as the language that generates encounters between members of an ayllu from the sensible world. In addition, there are also diets, purges, individual fasting or sasi, which are collective fasts; the clean and flourishing baths; the payment to the pachamama, activities that serve to balance the human being with himself and to take care of him within the bond of the community and nature in a ritual way [40].

The diagnosis was conceived by examination, interrogation centered on the person of the patient and of the divine by divination. As consequence, a mixture of these aspects was used to heal, and the healing took the form of incantations and the application of medicinal plants [4, 5]. The methods used in the diagnosis are varied, from the use of tangible elements, such as animals, vegetables and minerals (egg, guinea pig, coca leaves, corn, beans, alum, incense, among others); or also through master plants, Erythroxylum coca (Coca), Echinopsis pachanoi (San Pedro) and Banisteriopsis caapi (Ayahuasca); plants that produce an altered state of consciousness, allowing a better understanding of the patient's situation [40].

Diseases were classified into those of hot and cold origin, closely related to the respective gods. Therefore, in a holistic view of the world, medical and religious tasks were not actually perceived as different [4, 5].

The methods used for healing are diverse, but among the most used are the energy cleansings where various elements are used (guinea pig, alum, egg, sulfur, among others), the allowances that are forms of collective psychotherapy directed by the healers, the use of medicinal plants from a warm and cold balance approach, used by herbalists, the most recognized currently being the itinerant herbalist Callawayas that are still present in the area of Bolivia and Peru [41].

Medicinal plants, from this approach, do not work only because of the active principles they possess, but because of two more aspects: (1) concept of phytocomplex defined as the mixture of active substances and other companions that act together to achieve the same therapeutic purpose. It would not be the same if they were administered separately, that is, as mono substances [42] and (2) related to the concept of energy, classifying the plants as cold and warm; using them in order to achieve the harmonic balance of the person to regain their health.

Thermal springs, the use of minerals such as medicinal clays, the sounds of huacos or rain sticks useful to achieve relaxation and an altered state of consciousness, as well as various massages, cupping and psychotherapy [40].

As the conquest killed at least half of the original indigenous population in the Americas and destroyed or mutilated severely their cultures, it is thanks to archeology, looms, ceramics, and indigenous historians that some of that knowledge was preserved, and now traditional Andean medicine is being rebuilt.

Traditional Andean medicine, as described, has basic principles that are related to person-centered medicine: the holistic vision, the creation of links between the person and the health professional, which encompasses the family, community, environment and universe; the meeting of a common ground in relation to the care of the person, where both weave their part to achieve the most precious loom that is the care of their health.

At present, Traditional Andean Medicine continues to be used by a large part of the Andean population, especially at the first level of care. This is certainly also the case for many other forms of traditional medicine.

40.5 Traditional Medicine in the Sahul Continent: Australia, Tasmania and Papua New Guinea

Apart from the disastreous consequences which have followed upon the interventions by Europeans [43] in this Southern continent, that was originally formed by the combined masses of Sahul until 8000 years ago, we observe a nearly undisturbed development of its unique cultures since at least 60,000 years. It appears that there may be two events of immigration, discussed controversely: a nearly neglectible islamic one and at the time of the Kimberley paintings a more dominant one of unknown origin.

To be healthy has for the Australian Aborigin some equivalence with being happy. Red is the colour of the lifeforce and ocre the blood of the earth, which—if mixed with the fat of animals on cords of hair that are bound around the aching limb, or directly rubbed on the body—help against all sorts of physiological and psychological pain and enhance the spiritual power, which is especially needed for ritual ceremonies and dances.

Black is the healing colour which comes from the earth, and yellow is the healing colour from the sun. The healing power of the earth is related to the songlines of the dreamtime. It is connected to so-called lay lines, which have also magnetic importance, that cross the continent. Earth‘s special spiritual and energetic power can be enforced by stone settings that further the health and well being of all [44]. This theory and practice finds its parallels in the well known neolithic menhirs and stone settings of France, the British Isles and elsewhere around the world.

In Papua-Newguinea, they say, that if the body-soul goes for a short leave, disease happens. If it leaves for ever, death occurs. Therefore it is important to have a good sleeping position. Otherwise the body-soul is annoyed and might stroll around during sleep, making its owner more vulnerable to attacks from the energetic dimensions [45].

In some parts of Melanesia, the eastern horn of Newguinea and some close islands there exists the Kumo magic. This is performed by using these other energetic dimensions [46].

40.6 Traditional Medicine in Africa

In Africa there still exist two cultures today, whose roots go back into the remotest times. The Pygmy hunter-gatherers in Uganda developped in their own way since about 70,000 years ago [47, 48]. The geometric art in pedroglyphs of long ago tell about the idea of a communion and exchange between men and the spiritual beings, also in order to create fertility. This still finds its present-day parallels in special ceremonies [49].

The roots of the San “bushmen” are of equal antiquitiy. Many representations of their rock art are related to trance dancing [50]. The society and its daily living and healing has been investigated thoroughly, especially from the group of the !Kung [51]. So if the children survive till the 15th year, their life expectancy is 55 years, like in paleolithic times [52], and 10% of the !Kung are more than 60 years old, inspite of wide spread malaria and tuberculosis [53]. Problems of blood pressure or heart diseases are unknown. Healing ceremonies enhancing their spiritual and energetical healing power (num), lead to a special state of mind or altered state of consciousness (Kia), which showed astonishing examples of successful healing [54, 55].

Besides these two specific examples, traditional healing is practiced everywhere in Africa in locally varying manners. In Ghana for example, they distinguish betweeen the spiritual healer (Akomfo), who also deals with psychiatric problems, the herbalist (Adunsifo), the bone setter and the midwives. The education to become a spiritual healer takes 3 to 7 years, in which no sexual contacts are allowed [56]. James Hall, a New Yorker, who wrote the biography of "Mama Africa", the famous singer Miriam Makeba, started in South Africa an education like this. He finally became a famous sangoma, spiritual healer, what had been foreseen by Makeba [57].

40.7 Discussion and Practical Implications

Traditional medicines cannot be imagined but by going inside ourselves in a person-centered manner, and including the outside in a holistic way. So it should be conducted between the healer's person and the diseased person. For prevention, emphasis should sometimes be placed on the responsibility of the patient and sometimes on the exterior causes of illness.

Learning from traditional medicines and integrating its knowledge base with modern knowledge one could imagine its integration through an allegoric pyramid. Illustratively, the *Golden Pyramid of Healing* [6] articulates three important domains, the Individual, Society/Culture and Nature, as fundamental to understanding health and healing (see Fig. 40.1). This perspective is also consistent with the Andean cosmovision that understands health as harmonic equilibrium of a person's internal world, social world and natural world [37, 38]. Recent research stimulated by traditional medicines may suggest additional domains for the development of new paradigms.

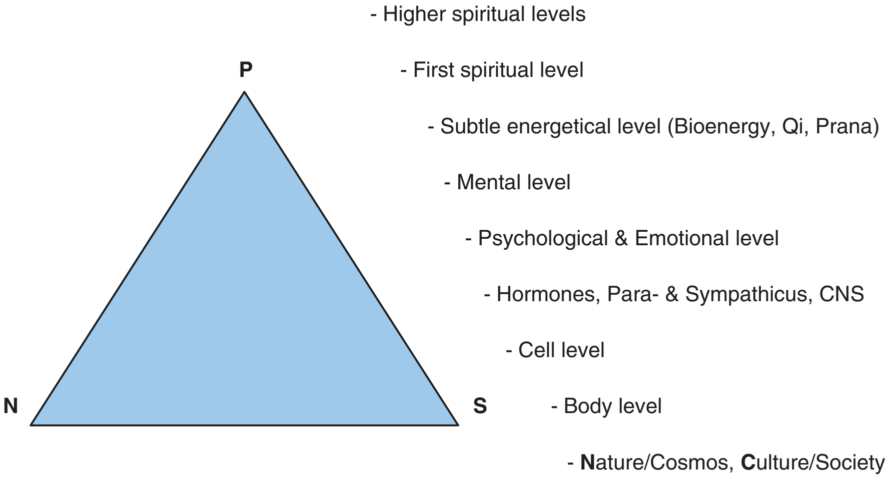


Fig. 40.1 The Golden pyramid of healing. (Modified from [6]) (***P*** the person, ***N*** nature, ***S*** society/culture)

It may be interesting to mention that after the Paleolithic era, age expectancy of 55 fell to about 35 in neolithic times [58] till more recent times. The causes seem related to the more pronounced neolithic factors, like urbanisation, cultivation of grains with augmented intake of carbohydrates which are metabolized into sugar, poorly balanced food with a lot of sugar, zoonoses which can easily spread through closer contacts between people and animals, social imbalances (particularly affecting women) and intergroup hostilities leading to wars. All of this seems to be heading to a climax, even in medicine. We seem to need throughout more person-centered and holistic perspectives and policies.

On one hand we are about to find scientific explanations on how traditional medicines work. Also, many are now thinking of a history without conventional fixed epochs [59], more focused on transdisciplinary approaches (Heise 2016). In psychiatry there are movements towards abandoning the drawers of fixed ICD-10 diagnoses in favor of seeing the complete patient and undertaking transdiagnostic interventions in psychotherapy [60]. Traditional medicines can similarly broaden our views and encourage us to take up what has been effective for many generations in order to achieve a new and more appropriate person-centered medicine.

Concerning cooperation between Western academic medicine and traditional forms of medicine, there are uneven developments across Western and Eastern countries and there is much room for improvement [61] (https://www.swissinfo.ch/ger/alternative-therapie_auch-geistheiler-praegen-schweizer-kultur/34125960, acceded 12.10.2020). There are also traditional folk healers working at home in Western countries, such as in the German-speaking Appenzell area. They use individually prepared herbal medicines, manual orthopedic procedures as well as psychic and spiritual healing approaches according to their personal abilities and talents [62].

40.8 Conclusions

At the XIVth World Congress of Social Psychiatry in 1994, it was emphasized that therapy is the art of caring. This art of caring has as many facets as there are companions and accompanied persons. And it has as many faces as there are cultures, which contribute their forms and rituals [63]. We should integrate their specific knowledge, often ignored in the Western world, so that we may dive into the depths of medicine to dare to understand and commit to its fundamental character and mission. Therefore medicine must transcend its eurocentristic view and the old fashioned idea of Sciences, which medicine and pharmacology are still defending. Two more just published works by Heise on “Corona: Das Syndrom” and “Unsere Gesundheit und das System” (Our Health and the System) discuss several of these issues.

Disclosures The principal writer of the Abstract was O. Salaverry, of C 2 Traditional Andean medicine it was M. Villar-Lopez, and of the others it was T. Heise.

All authors were self-financed in preparing this chapter and declare no conflicts of interest in the process.

References

1. Baudin L. El Imperio Socialista de los Incas. 8th ed. España: Editorial Zig-Zag; 1978. p. 89–107.
2. Perez I. Poblamiento humano, diferenciación ecológica y diversificación fenotípica en América. Runa. 2011;32(1):83–104, junio.
3. WHO. Organismo Regional de la Salud—ORAS. Aún nos cuidamos con nuestra medicina. 2010. http://www.orasconhu.org/documentos/SI%20Aun%20nos%20cuidamos%20con%20nuestra%20medicina%20ORAS%20Oscar%20Velasco.pdf. Organismo Mundial de la Salud—OMS. Estrategia de la OMS para Medicina Tradicional para el 2002 al 2005. 2005. http://apps.who.int/iris/bitstream/handle/10665/67314/WHO_EDM_TRM_2002.1_spa.pdf;jsessionid=DA3788EC1E2DC4B85DC7C08F7C1509BF? sequence=1. Accessed 21 Jun 2021.
4. Heise T, editor. Transkulturelle Beratung, Psychotherapie und Psychiatrie in Deutschland. Das transkulturelle Psychoforum, vol. 5. Berlin: VWB; 2002a.
5. Heise T. Transcultural psychotherapy. In: Hersen M, Sledge WH, editors. Encyclopedia of psychotherapy. New York: Academic Press, Elsevier Science; 2002b. p. 841–50.
6. Heise T. Don't separate body, mind and soul. The medical concept research of "Elektrobio Transcultural Nature Healing". In: Heise T, Golsabahi S, editors. Mit Leib und Seele ankommen. Das transkulturelle Psychoforum, vol. 18. Berlin: VWB; 2011.
7. Heise T. Qigong in der VR China: Entwicklung, Theorie und Praxis. Berlin: VWB; 1999.
8. Heise T. Qigong und Maltherapie. Komplementärtherapien Psychosekranker. Berlin: VWB; 2009.
9. Heise T. Kulturen der Menschheit: Woher und wohin? Transdisziplinäre Perspektiven unserer Vergangenheit. Würzburg: Königshausen & Neumann; 2016, 2018.
10. Rosner E. Die Heilkunst des Pien Lu. München: Steiner; 1991.
11. Burr HS. Blueprint for immortality: the electric patterns of life. London: Neville Spearman; 1972.
12. Bergsmann O, Woolley-Hart A. Differences in electrical skin conductivity between acupuncture points and adjacent skin areas. Am J Acupunct. 1973;1:27–32.
13. Heise T. Chinas Medizin bei uns. Einführendes Lehrbuch zur traditionellen chinesischen Medizin. Berlin: VWB; 1996.
14. Smith SR, Foster KR, Wolf GL. Dielectric properties of VX-2 carcinoma versus normal liver tissue. IEEE Trans Biomed Eng BME. 1986;33:522–4.
15. Gowri Sree V, Udayakumar K, Sundararajan R. Electric field analysis of breast tumor cells. Int J Breast Cancer. 2011;2011:235926. https://doi.org/10.4061/2011/235926.
16. Moarefian M, Pascal JA. Fundamental mathematical model shows that applied electrical field enhances chemotherapy delivery to tumors. Math Biosci. 2016;272:1–5. Epub 2015 Dec 2. https://doi.org/10.1016/j.mbs.2015.11.003.
17. Chen B, et al. Targeting negative surface charges of cancer cells by multifunctional nanoprobes. Theranostics. 2016;6(11):1887–98. https://doi.org/10.7150/thno.16358.
18. Oschmann JL. Energiemedizin. Konzepte und ihre wissenschaftliche Basis. München: Urban & Fischer, Elsevier; 2009. (Original: Energy Medicine. The Scientific Basis. Churchill Livingstone, imprint of Harcourt Publ. Ltd, 2000.
19. Pischinger A. Das System der Grundregulation. Grundlagen einer ganzheitsbiologischen Medizin. Stuttgart: Haug; 2004.
20. Ling GN. A revolution in the physiology of the living cell. Malabar: Krieger Publishing Company. Zit.n. Oschmann, JL; 1992.
21. Becker RO. Der Funke des Lebens. Elektrizität und Lebensenergie. München: Scherz; 1991a. (Original: Cross Currents, 1990).
22. Becker RO. Evidence for a primitive DC electrical analog system controlling brain function. Subtle Energies. 1991b;2(1):71–88.
23. Bischof M. Biophotonen: Das Licht in unseren Zellen. Leipzig: Zweitausendundeins; 2008.
24. Raja CK. Pre-vedic elements in Indian thought. In: Radhakrischnan S, et al., editors. History of philosophy, eastern and western. London: George Allen & Unwin; 1957.

25. Thorwald J. Macht und Geheimnis der frühen Ärzte. München/Zürich: Droemer-Knaur; 1962.
26. Brentjes B. Alte Siegelkunst des Vorderen Orients. Leipzig: VEB Seemann; 1983, p. 24, 28.
27. Coppa A, Bondioloi L, Cucina A, Frayer DW, Jarrige C, et al. Early neolithic tradition of dentistry. Nature. 2006;440:775.
28. Fehren-Schmitz L, O'fallon B. PNAS. 2011. http://www.nationalgeographic.de/aktuelles/eroberung-amerikas-rottete-die-haelfte-aller-ureinwohner-aus.
29. Garcia H, Sierra A, Balam G. Medicina Maya tradicional. México: EDUCE; 1996. p. 19f.
30. Reichel-Dolmatoff G. Das schamanische Universum. München: Diederichs; 1996.
31. Rösing I. Dreifaltigkeit und Orte der Kraft: die Weisse Heilung. Nördlingen: Greno; 1988. p. 706 f.
32. Quispe M. Ensayo Sechín, Paracas y Mochica: Aportes al Desarrollo de la Medicina y la Salud en el país y el Mundo. Voces en Salud Pública. Universidad Nacional Mayor de San Marcos; 2020. Noted in: https://vocesensaludpublica.blog/curso/historia-de-la-salud/.
33. Shady R. Caral-Supe, la civilización más antigua de América. Primera edición, vol. 2006. Lima: Proyecto Especial Arqueológico Caral-Supe/Instituto Nacional de Cultura; 2006. p. 4–7.
34. Sobrevilla D. La filosofía andina del P. Josef Estermann. Quito: Abya-Yala, Rev. Solar. N° 4 (4) Lima; 2008. p. 231–247; 359 pp. http://revistasolar.org/wp-content/uploads/2020/06/SOLAR-4-206-222.pdf.
35. Campohermoso O, Soliz R, Campohermoso F. Lógica Aimara Trivalente y Cosmovisión Andina. Revista "Cuadernos". 2015;56(2):89–97. [Citado el 20 junio 2021], http://www.scielo.org.bo/scielo.php?script=sci_arttext&pid=S1652-67762015000200019&lng=es&nrm=iso>. ISSN 1562-6776.
36. Estermann J. Ecosofía andina: Un paradigma alternativo de convivencia cósmica y de Vivir Bien. Revista FAIA. 2013;2(9):2–1. [citado el 23 de junio 2021]. Noted on: file:///D:/Users/USUARIO/Downloads/Dialnet-EcosofiaAndina-4714294.pdf.
37. Alvarado D. Una comprensión andina del cuerpo. Lima: Ediciones Multigrafik; 2019. p. 31–49.
38. Stefano V. Los fundamentos éticos de las cosmologías indígenas», Amérique Latine Histoire et Mémoire. Les Cahiers ALHIM [En línea], 36 | 2018, Publishes on 21 January 2019. 2019. http://journals.openedition.org/alhim/6899. Accessed 23 Jun 2021. https://doi.org/10.4000/alhim.6899.
39. Milla C. Ayni. 5ta edición ed. Bolivia: Ediciones Amaru Wayra; 2007. p. 47–9.
40. Cabieses F. Apuntes de Medicina Tradicional, la racionalización de lo irracional. Consejo Nacional de Ciencia y Tecnología-CONCYTEC; 1993. p 167–300.
41. Cabieses F. Cien siglos de Pan, 10,000 años de alimentación en el Perú. 4ta ed. Editorial Asociación Peruana Fernando Cabieses; 2015. p 75–155.
42. Avellano L, Cisternas F. Fitoterapia, sus orígenes, características y situación en Chile. Rev Med Chil. 2010;138(10):1288–93. https://doi.org/10.4067/S0034-98872010001100014.
43. Barth B. Genozid: Völkermord im 20. Jahrhundert: Geschichte, Theorien, Kontroversen. München: Beck; 2006.
44. Cerny C. Heilgeheimnisse der Aborigines. Bergisch Gladbach: Lübbe; 2002.
45. Konrad G. Von den Asmat. In: Heinrich Harrer (Hg): Unter Papuas. Mensch und Kultur seit der Steinzeit. Frankfurt/M: Fischer; 1978.
46. Sterly J. Kumo. Hexer und Hexen in Neu-Guinea. München: Kindler; 1987. p. 23f.
47. Patin EG, et al. Inferring the demographic history of African farmers and Pygmy hunter-gatherers using a multilocus resequencing data set. PLoS Genet. 2009;5(4):e1000448. https://doi.org/10.1371/journal.pgen.1000448.
48. Quintana-Murci LH, et al. Maternal traces of deep common ancestry and asymmetric gene flow between Pygmy hunter-gatherers and Bantu-speaking farmers. PNAS. 2008;105(5):1596–601.
49. Namono C. Pongo symbolism in the geometric rock art of Uganda. Antiquity. 2011;85:1209–24.
50. Lewis-Williams JD, Pearce DG. The southern San and the trance dance: a pivotal debate in the interpretation of San rock paintings. Antiquity. 2012;86:696–706.
51. Lee RB, Devore I, editors. Man the hunter. Chicago: Aldine; 1968.
52. Lee RB, Devore I, editors. Kalahari Hunter-Gatherers: Studies of the !Kung-San and Their Neighbors. Cambridge: Harvard University Press; 1976.

53. Howell N. The Population of the Dobe-Area. In: Lee RB, Devore I, editors. Kalahari Hunter-Gatherers: Studies of the !Kung-San and Their Neighbors. Cambridge: Harvard University Press; 1976.
54. Katz R. Num. Heilen in Ekstase. Spiritualität und uraltes Heilwissen: Die faszinierende Welt der San im südlichen Afrika. Interlaken: Ansata; 1985.
55. Mutwa VC. Indaba. Ein Medizinmann der Bantu erzählt die Geschichte seines Volkes. München: Dianus Trikont S; 1983. p. 145.
56. Ansu S. Traditionelle Heilmethoden bei psychiatrischen Problemen in Ghana. Die Dormaa Fallstudie. In: Bock T, et al., editors. Abschied von Babylon. Verständigung über die Grenzen in der Psychiatrie. Bonn: Psychiatrie-Verlag; 1995.
57. Hall J. Sangoma. Eine Reise zu den Geistern Afrikas. München: Knaur; 1996.
58. Price TD, et al. Das bandkeramische Gräberfeld von Stuttgart-Mühlhausen: Neue Untersuchungsergebnisse zum Migrationsverhalten im frühen Neolithikum. S. 6. In: Funda DT, editor. Fundberichte aus Baden-Würtemberg. Stuttgart: Konrad Theiss; 2003. p. 23–58. http://discovery.ucl.ac.uk/15502/1/15502.pdf.
59. Le Goff J. Must we divide history into periods? New York: Columbia University Press; 2016.
60. Hessler JB, Fiedler J. Transdiagnostische Interventionen in der Psychotherapie. Stuttgart: Schattauer; 2019.
61. Heise T. On traditional Chinese medicine and some implications For European medicine, vol. 42. Bochum: Zentrum für Medizinische Ethik Bochum; 1990.
62. Karrer T. Zwischenwelten (Film). 2020. https://www.zwischenwelten-film.ch/.
63. Engelmann I, Heise T, Machleidt W. Die Kunst des anderen Umgangs. In: Bock T, et al., editors. Abschied von Babylon. Verständigung über die Grenzen in der Psychiatrie. Bonn: Psychiatrie-Verlag; 1995.

Part IV
Empowerment Perspectives

Chapter 41
Empowerment of Community Members

Austen El-Osta, Pete Smith, Christine C. Leyns, Otto W. Steenfeldt-Foss, and David Webber

41.1 Introduction

Studies have shown that there are many different influences on a person's health and wellbeing [1, 2]. For example, our genetic construct and biology are estimated to be only responsible for 15% of our overall health and wellbeing, compared to 10% from the environment and 25% from healthcare input (e.g., treatment by a healthcare professional or using over-the-counter products), with the largest contribution of 50% emanating from our ability to make healthy lifestyle choices,

---

A. El-Osta (✉)
Self-Care Academic Research Unit (SCARU), School of Public Health, Imperial College London, London, UK
e-mail: a.el-osta@imperial.ac.uk

P. Smith
Self-Care Forum, London, UK

C. C. Leyns
Department of Public Health and Primary Care, Faculty of Medicine and Health Sciences, Ghent University, Ghent, Belgium

Fundación Vida Plena, Sacaba, Cochabamba, Bolivia

Faculty of Social Sciences, Universidad Mayor de San Simon, Cochabamba, Bolivia

Physician and Community Educator, Cochabamba, Bolivia
e-mail: christine.leyns@ugent.be

O. W. Steenfeldt-Foss
University Health Service of Oslo, Oslo, Norway

Norwegian Medical Association Human Rights Committee, Oslo, Norway

D. Webber
International Self-Care Foundation, London, UK
e-mail: davidwebber@isfglobal.org

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_41

self-care and self-manage for common and treatable conditions as we go about our life course [3].

From a person-centred medical practitioner's perspective, recognising the relevance of a subject's complete range of self-care and inter-care actions and capabilities and their contexts is essential. Addressing these factors from the perspective of the whole contextualised person helps ensure the sharp relevance to today's health challenges of person-centred medicine.

41.2 Self-Care and Inter-Care and Three Levels of Contextualization

41.2.1 Whole Contextualised Individuals

The Western analytical tradition aims to reduce things to their essential elements. Medicine in the West thus has a reductionist, analytical, object-oriented and interventionist approach which involves identifying the malfunctioning part and removing or altering it using medicines or surgery. Experts—doctors—are trained and given responsibility for implementing this approach, with client subjects or 'patients' doing what they are told. This has been termed the 'biomedical model' of healthcare which is the basis of today's healthcare systems around the world. This model of a paternalistic doctor-patient relationship may be good in many respects, but it suffers from two fundamental problems, one being universal affordability. Secondly, and particularly relevant to the present discussion, the biomedical model does not look at the whole contextualised person and tends to discourage people from taking responsibility for their own health and wellbeing.

A person-centred approach by contrast considers the healthy person, positive health, as well as their condition(s), and the part they play in managing their own health. A holistic framework for understanding a person's health-relevant activities and behaviours, is the concept of "self-care", in which activities over time (daily and throughout the life course), and behaviours based on a person's capabilities, opportunities and motivation, are key. Also relevant at that level is the concept of inter-care and self-driven healthcare- two emergent concepts relevant to living in the 21st Century.

41.2.1.1 Self-Care

To define the relationship between self-care and person-centred medicine, it is important to define and contextualise self-care in the first instance. This is because self-care is the oldest type of care, and necessarily encompasses a wide range of person-centred activities related to lifestyle, hygiene and our personal relationship with the self, others and external environmental and socioeconomic factors. But what is self-care?

A seminal paper by Godfrey [4] identified a 168 different definitions of self-care in the academic literature. The definition used by the WHO has also changed over time, including the following from 2009:

Table 41.1 Evolution of the WHO definition of self-care

1983	Self-Care in health refers to the activities individuals, families and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health. These activities are derived from knowledge and skills from the pool of both professional and lay experience. They are undertaken by lay people on their own behalf, either separately or in participative collaboration with professionals [6]
1998	Self-Care is what people do for themselves to establish and maintain health, and to prevent and deal with illness. It is a broad concept encompassing hygiene (general and personal), nutrition (type and quality of food eaten), lifestyle (sporting activities, leisure etc.), environmental factors (living conditions, social habits, etc.), socio-economic factors (income level, cultural beliefs, etc.) and self-medication [7]
2009	"Self-Care is the ability of individuals, families and communities to promote health, prevent disease, and maintain health and to cope with illness and disability with or without the support of a health-care provider." [5]
2013	WHO has defined "self-care" as "the ability of individuals, families and communities to promote health, prevent disease, maintain health, and to cope with illness and disability with or without the support of a health-care provider. The scope of self-care includes health promotion; disease prevention and control; self-medication, providing care to dependent persons; seeking hospital/specialist care if necessary; and rehabilitation including palliative care [8, 9]
2019	Self-care is the ability of individuals, families and communities to promote health, prevent disease, maintain health, and cope with illness and disability with or without the support of a healthcare provider [10]
2021	Self-care is the ability of individuals, families and communities to promote health, prevent disease, maintain health and cope with illness and disability with or without the support of a health worker. The scope of self-care in this definition includes health promotion, disease prevention and control, self-medication, giving care to dependent people, seeking hospital, specialist or primary care when needed, and rehabilitation, including palliative care [11, 12]

"Self-Care is the ability of individuals, families and communities to promote health, prevent disease, and maintain health and to cope with illness and disability with or without the support of a health-care provider." [5]. This definition was first introduced as a working definition in the WHO paper on 'self-care in the context of primary health-care' of 2009. As definitions expanded, they became more inclusive of health and well-being and the relationship between the self- and the environment (see Table 41.1).

Rather than being limited by definitions, it is perhaps more helpful to conceptualise self-care instead. There are two easily accessible models to conceptualise self-care: The Self-Care Continuum and the Seven Pillars of Self-Care Framework. Both models were eventually unified in the Self-Care Matrix which is illustrated later in this section.

The Self-Care Continuum

The Self-Care Continuum (https://www.selfcareforum.org/about-us/what-do-we-mean-by-self-care-and-why-is-good-for-people/) was originally expounded by the Self-Care Forum UK, and considers the inverse relationship between self-care and resource utilisation. It shown the ideal placement of an individual as being on the far left of the continuum since they usually do not require significant support from healthcare professionals as they go about their daily life. Conversely in this model, the placement of an individual who has one or more long-term conditions but is still able to self-care with intermittent support from healthcare professionals is represented at the mid-point of the continuum. The placement of individuals who are unable to self-care (e.g., incapacitated following trauma or an exclusion for poor mental health etc.,) is represented on the far right of the continuum.

The Seven Pillars of Self-Care

In reality, self-care is a practical, person-centred set of *activities* that we should all be undertaking to maintain our health, wellness and wellbeing. Self-care can therefore only be undertaken by individuals themselves, although the broader environment can provide vital assistance or present significant barrier. Self-care activities can be conveniently grouped into seven ‘pillars’ or ‘domains’ as represented by the Seven Pillars of Self-Care framework: https://isfglobal.org/practise-self-care/the-seven-pillars-of-self-care/.

1. Pillar 1: Knowledge and Health Literacy—described the capacity of individuals to obtain, process and understand basic health information needed to make appropriate health decisions and engage with services.
2. Pillar 2: Mental Wellbeing—includes self-awareness as for example knowing your body mass index, cholesterol levels, blood pressure or engaging in health screening.
3. Pillar 3: Physical activity—such as walking, cycling, or participating in sports or walking up the stairs etc.
4. Pillar 4: Healthy eating—including a nutritious, high fibre balanced diet with appropriate levels of calorie intake.
5. Pillar 5: Risk avoidance—and mitigation strategies, such as quitting tobacco, limiting alcohol use, getting vaccinated, practicing social distancing, or using sunscreens etc.
6. Pillar 6: Good hygiene practices, such as regular hand washing/use of hand sanitiser, oral and dental hygiene, good sleeping practices and digital hygiene (such as limiting exposure to blue light before bedtime) etc.
7. Pillar 7: The rational use of products and services– including to proper adherence to medical regimen when needed, completing a course of antibiotics as prescribed for example, and the responsible use of over-the-counter products, services, digital health tools and community assets (which could include parks and green spaces).

The Self-Care Matrix: A Unifying Framework of Self-Care

The Self-Care Continuum and the Seven Pillars of Self-Care can support stakeholders in conceptualising two different aspects of the concept, but neither model describes the totality of self-care. One approach to address this included a review of

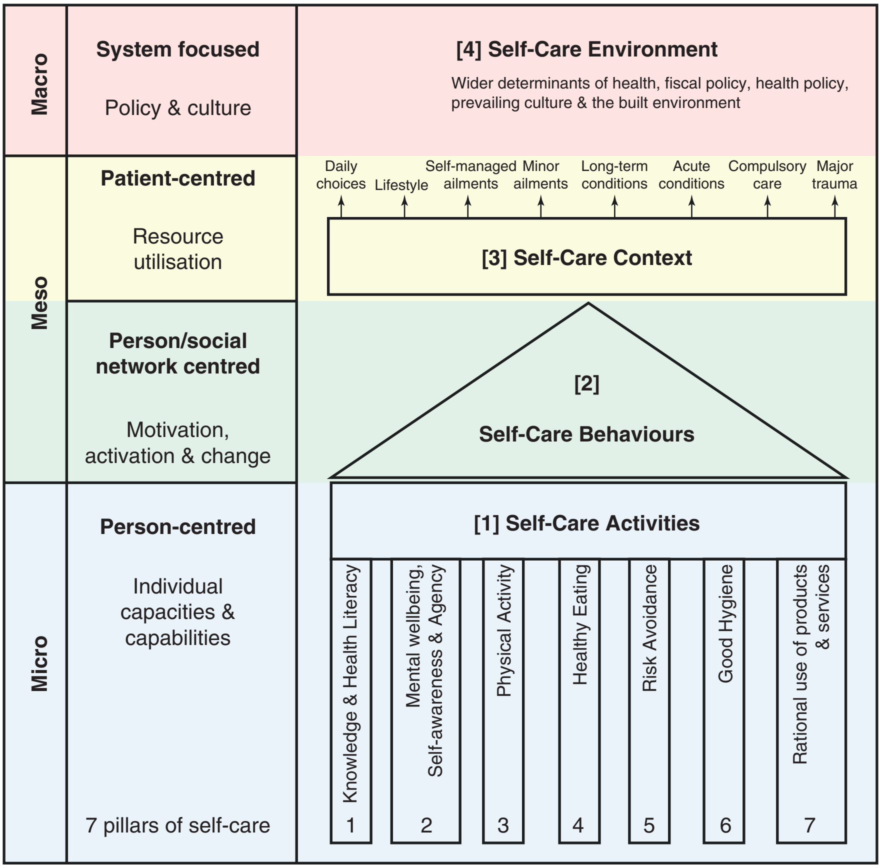


Fig. 41.1 The Self-Care Matrix [13]

the literature resulting in the consolidation of 37 extant theories and models of self-care resulting in the Self-Care Matrix (see Fig. 41.1). The Self-Care Matrix is a unifying framework of self-care and illustrates the four cardinal dimensions of self-care: (1) Self-Care Activities, (2) Self-Care Behaviours, (3) Self-Care Context, and (4) Self-Care Environment. Each dimension operates at a different level and pertains to a different aspect of self-care as follows:

- 1st Dimension: Self-care activities (micro-level: person-centred)
  - The first dimension is concerned primarily with individual activities, capacities and capabilities, and what people know and do to self-care. At this micro-level, self-care is considered from a person-centred perspective. Suitable interventions may be developed to improve and promote health maintenance, monitoring and self-management of common, every-day or long-term conditions. The Health Belief Model, Orem's Self-Care Deficit Nursing Theory [14–16], and the widely used Seven Pillars of Self-Care model 54 are suitable

  candidate models that can be used to explore this cardinal dimension. The first dimension of self-care is necessarily concerned with the 'self', is person-centric and activities therein relate directly to what individuals can do for themselves, as well as the knowledge required to inform suitable self-care choices, such as health literacy and self-awareness.

- 2nd Dimension: Self-care behaviours (meso-level: Individual and group focused)
  - The second dimension is concerned with the principles and actions that support and motivate individuals to engage in positive self-care behaviours and achieve the sustained adoption of health-seeking behaviours and lifestyles choices. Example interventions operating at this meso-level include efforts to improve health literacy levels, Patient Activation Measure (PAM) scores, or the use of digital health technology including nudges, gamification an incentivisation strategies to promote the sustained adoption and maintenance of desirable lifestyle choices and habits [17]. Associated theories include the Middle Range Theory of Self-Care [18] which addresses health promoting practices within the context of the management of a chronic illness. The widely used trans-theoretical model of behaviour change and the Behaviour Change Wheel [19] are also suitable candidate models that adequately describe activation and behaviour change elements relevant to self-care. The second dimension is focused on the individual but may also extend to the social network as it describes the prevailing 'lifestyle' habits, normative attitudes and routine interactions with the immediate environment, including interface with technology and decision support tools.
- 3rd Dimension: Self-care context and reliance on resources (meso-level: patient-centred, health system focused)
  - The third dimension considers the extent to which an individual is reliant on external resources in the home, community, assisted care or professional healthcare settings. Interventions at this meso-level are often health system-focused, whereby an individual, a demography or a segment of society is routinely considered from a 'statist' or medicalised patient-perspective as opposed to a person-centred perspective. Interventions at this level are often concerned with modulating resource utilisation, including access to services, clinical pathways and/or the extent of integration of care. The widely used Self-Care Continuum [20] and the Kaiser Permanente Pyramid of Self-Care model [21] are suitable candidates for this dimension as they dynamically illustrate the inverse relationship between individual autonomy and reliance on external resources or need for increasing support.
- 4th Dimension: Self-care environment, barriers and drivers (macro-level: policy-driven, health system focused)
  - The fourth dimension is concerned with existing drivers and barriers to self-care in relationship to the operating fiscal and policy environment, and in the context of the prevailing culture and normative attitudes that inform self-care

praxis in the wider community. This dimension takes into account the built and natural environment and other mediating factors. At this macro-level, drivers and barriers to self-care operate at scale or at population level. The fourth dimension is thus related to the fiscal, regulatory, policy and public health landscape and informs the 'country narrative of self-care', which is largely influenced by the prevailing cultural and societal attitudes and perceptions concerned with health and wellbeing. Suitable candidate models that could be used to study this self-care dimension include Public Health Theory, Public Management Theory, Public Policy Theory and any existing Health in All Policy (HiAP) prescriptions, including directives for the built environment.

The Inverse Relationship Between Self-Care and Diseases of the Lifestyle

The emergence of chronic noncommunicable diseases (NCDs) like cardiovascular diseases, type-2 diabetes (T2D) and many cancers is significant, as this is frequently and fundamentally the result of a failure of people to lead healthy lifestyles and to self-care. The causative factors involved in these "diseases of the lifestyle", include insufficient physical activity, unhealthy eating and tobacco smoking.

There is a lot of evidence that shows that self-care is effective [1, 22] case for investing in self-care and self-management for people living with long-term conditions [23]. We know that most non-communicable diseases such as diabetes, obesity and cardiovascular disease—also known as 'lifestyle diseases'—are the main cause for deaths globally. We also know the personal and intermediate risk factors associated with NCDs. For example, personal risk factors (such as unhealthy diet, physical inactivity, tobacco use and excess alcohol) and intermediate risk factors (such as raised blood glucose, hypercholesterolaemia, high blood pressure and obesity) can lead to the development of diabetes, stroke, kidney disease, lung disease and some types of cancers.

The WHO estimates that up to 80% of heart disease, stroke and T2D and over a third of cancers could be prevented by people self-caring—that is, by eliminating the risk factors of tobacco use, unhealthy diet, physical inactivity, and excess alcohol. Similarly, other major conditions such as dementia, osteoporosis and arthritis can be usefully addressed through self-care. Controlling or eliminating these shared risk factors through lifestyle behaviour modification and self-care can delay or even prevent the appearance of NCDs.

As we have seen in the earlier section, self-care is part of a continuum of care, starting with the responsibility individuals have in making daily choices about their lifestyle, right through to major trauma where responsibility for care is entirely in the hands of the health care professionals, until the start of recovery when self-care can begin again.

Inter-care extends the concept to the interconnectedness of the self with others by way of their capacity to care for each other related to patients, families, the health and social care workforce, the wider community and the environment at large, connecting to the collective wisdom of ancient cultures.

Positive social interaction as a critical enabler of self-care is perhaps best exemplified when individuals participate in group activities or in self-care communities of practice. This includes active participation in health facilities including gyms, other sporting facilities and food shops.

41.2.1.2 The Emerging Concept of Inter-Care

The concept of inter-care or mutual care is being studied and formulated by Fabrega [24] and collaborators. It extends the notion of care to the interconnectedness of the self with others by way of their capacity to care for each other. It broadly involves patients, families, the health and social care workforce, and the wider community including that connected to the environment at large.

The historical and contemporary base of this notion is predicated to be the collective wisdom of ancient civilizations across the globe and the live experience of ancestral communities. Illustratively, the African concept of Ubuntu, translates incompletely as "existing with and through others". It champions both the person and groups of persons by virtue of an interconnectedness expressed, for example, the isiZulu expression "Unmuntu Ngumuntu Ngabantu": "I am because you are and you are because we are" [25].

In Bolivia and other Andean countries, this interconnectedness is described with the phrase "to live well" ("buen vivir" through "being whole") a translation from the Aymara expression "Suma Qamaña"; known in Quechua as "Sumaq Kawsay". Wellbeing comes from understanding that our existence is related to the world; we do not only depend from mother earth or *Pachamama,* but we are also part of it. In *Sumaq Kawsay* the relation and balance with the community and the natural environment is fundamental. It contrasts with the individualism of Euro American cultures where the individual attempts to improve his life in a self-centered manner. Instead, *Sumaq Kawsay* urges communities to organize themselves and function in a way that the whole community benefits collectively to achieve a satisfactory life. Another difference is that the *Pachamama* is not seen as a resource to use without limits but as a living reality with whom one learns to live in harmony. If we destroy our environment, we destroy ourselves. Thus,"To live well" means being in harmonious equilibrium with social and environmental contexts and living together wisely (http://www.planificacion.gob.bo/uploads/Vivir_bien.pdf).

41.2.2 The Community Level of Contextualization

In this section the impact of community as defined as the group of people within a bounded geographic territory, such as a neighbourhood or city, and its influence on self-care and inter-care are considered. In this context, the community also includes people who may socially interact with one another, for example, as family members, friends, colleagues, peers or neighbours. Person-centred medicine needs to take into account the value of social relationships and the interpersonal relationships, institutions, and other social assets of a community as these can significantly influence an individuals' capacity and capability to self-care.

Broadly, the community also includes local voluntary and community groups, health professionals and non-health professionals with health-related and health-relevant functions. This concept is well represented by Rogers et al. [26] System of Support.

Human beings are social creatures and collectively these other community members have a strong effect on an individual's mental and physical wellbeing and health. The advantages of using this understanding of social networks and social capital [27] are that it brings into view different types of support, and the affinities between relationships and community belonging. Whilst traditionally case and disease management remain the province of health professionals, a social-network approach means that the main focus of self-management shifts to the person (i.e., the indivisual '*self-carer*') with the condition, members of their personal communities, support and community groups, the workforce allied to health and social care.

41.2.2.1 Social Prescribing

Social prescribing is a key component of Universal Personalised Care (NHS), and is one way for local agencies to refer people to a link worker. Link workers give people time, focusing on 'what matters to me' and taking a holistic approach to people's health and wellbeing. They connect people to community groups and statutory services for practical and emotional support. Link workers also support existing community groups to be accessible and sustainable, and help people to start new groups, working collaboratively with existing community assets and local partners. Social prescribing works for a wide range of people, including people with one or more long-term conditions, who need support with their mental health, who may be feeling lonely or isolated and/or who have complex social needs which affect their wellbeing. When social prescribing works well, people can be easily referred to link workers from a wide range of local agencies, including general practice, pharmacies, multi-disciplinary teams, hospital discharge teams, allied health professionals, fire service, police, job centres, social care services, housing associations and voluntary, community and social enterprise (VCSE) organisations. Self-referral is also encouraged. A standard model of social prescribing (Nursing RCO) has been developed in partnership with stakeholders, which shows the key elements that need to be in place for effective social prescribing. The model is based around streamlining 'easy' referral from all local agencies, collaborative commissioning and partnership working, support for community groups, the creation of a personalised plan centred around 'what works for me' with reference to common outcome framework, and workforce development to ensure streamlined and dedicated input from social prescribing link worker which is usually anchored in primary care.

Social prescribing complements other approaches, such as active signposting which is a 'light touch' approach where existing staff in local agencies provide information to signpost people to services, using local knowledge and resource directories. Active signposting works best for people who are confident and skilled enough to find their own way to services after a brief intervention.

Individuals participating in these self-care communities of practice in one way or another appreciate that health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity [28], and that the healthcare system and healthcare professionals cannot bring about this state of health in the community alone; to achieve this requires the full involvement of individuals looking after themselves through self-care where possible and the support of professionals and the healthcare system.

A congruent person-centred approach must therefore recognise all these other influences and how social interactions and people will link to them because people-centred healthcare emphasizes that persons live together with other individuals organized in families, communities and diverse populations around the world and can work together to support or impede both individual and collective well-being. In this regard, the perspectives of person-centred and people-centred care are therefore universal and egalitarian.

Moreover "People-centred care" broadens the care concept from the individual seeking care to an active outreach towards hard to reach and vulnerable groups or communities. As such, it is a rights and equity approach, promoting universal access to self-care. These groups often lack access to information tailored to their beliefs or reality as well as access to health services because of cultural, administrative or economic barriers. The inclusion and empowerment of these vulnerable communities can have a huge impact on their health, but must be carried out in a sensible way, respecting their beliefs, knowledge and sometimes hierarchical structure [29, 30].

People centred or community centred care and empowerment are complementary to person centred care, including self-care and inter-care as a prerequisite towards the right to health for all and not only for the individual seeking care (NHS Delivering universal personalised care; Nursing RCO Social prescribing models). It takes into account the factors outside the self, described by the WHO as Social Determinants of Health (SDH), the non-medical non-individual factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems.

SDH have an important influence on health inequities - the unfair and avoidable differences in health status seen within and between countries. In countries at all levels of income, health and illness follow a social gradient: the lower the socioeconomic position, the worse the health. The following list provides 10 examples of the social determinants of health, which can influence health equity in positive and negative ways: (1) Income and social protection, (2) Education, (3) Unemployment and job insecurity, (4) Working life conditions, (5) Food insecurity; (6) Housing, basic amenities and the environment, (7) Early childhood development, (8) Social inclusion and non-discrimination, (9) Structural conflict and (10) Access to affordable health services of decent quality. Research shows that the social determinants can be more important than health care or lifestyle choices in influencing health [11]. For example, numerous studies suggest that SDH account for between 30 and 55% of health outcomes. In addition, estimates show that the contribution of sectors outside health to population health outcomes exceeds the contribution from the health sector. Addressing SDH appropriately is fundamental for improving health and reducing longstanding inequities in health, which requires action by all sectors and civil society (WHO Social Determinants of Health).

41.2.3 The Broader Environment Level of Contextualization

Another vital element in approaching the whole contextualised person is the environment in which they exist and act. This includes the broad elements concerned with living in the built and green environments which may either encourage or inhibit healthy physical activity or social interactions [31]. The range of environmental factors that impact health is remarkably broad. The WHO European Healthy Cities programme identified 12 key health determinants, including access to services, healthy food, open spaces, safe environments, healthy air, physical activity, and social cohesion [32]. The UN illustrates the broad range of factors that affect health maintenance and disease prevention as follows:

> *…effective non-communicable disease prevention and control require leadership and multisectoral approaches for health at the government level, including, as appropriate, health in all policies and whole-of-government approaches across such sectors as health, education, energy, agriculture, sports, transport, communication, urban planning, environment, labour, employment, industry and trade, finance and social and economic development;"* - U.N. General Assembly. Political declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases. September 2011, Article 36 [33]

41.2.3.1 City Health

Today, over half of the world population lives in cities posing new challenges to countries related to urban planning and food security. In regions like Latin America the shift has been very brusque, from 40% living in cities in 1950 to 80% today. A people-centred approach recognises and factors in these changes. Urbanization has brought about changes to the lifestyle and living environment of city dwellers. Among such changes are loss of community support, degrading air and water quality, crowded housing, traffic congestion, and waste management, to name a few. In a social context, urbanization has brought about changes in terms of community, family and working styles. These changes cause a disruption in community structures where the elderly had a clear leadership role and in families and where traditional role models change with working and independent women. Work stress in general is higher in cities due to competition for jobs and work circumstances like night-time or informal work. In addition, the reduction of wildlife habitat and the advances in mobility that facilitate the movement of people and goods, promote the emergence and propagation of infectious diseases, even more efficiently among urban populations. Various social and environmental changes are intertwined and affect the health of people in cities [34, 35].

The WHO recognises that "health is created and lived by people within the settings of their everyday life; where they learn, work, play, and love" [36]. This statement is at the heart of the Healthy Settings approach, which has its roots in the WHO Health for All strategy [36] and, more specifically, the Ottawa Charter for Health Promotion [37, 38]. The goal is to maximize disease prevention via a "whole system" approach, which integrates multi-disciplinary action across risk factors. The key principles of all Healthy Settings include community participation, partnership, empowerment and equity. The Healthy Cities programme is the best-known example of a successful Healthy Settings approach. Initiated by WHO in 1986, Healthy Cities have spread rapidly across Europe and other parts of the world. A healthy city is "one that is continually creating and improving those physical and social environments and expanding those community resources which enable people to mutually support each other in performing all the functions of life and in developing to their maximum potential." [39]. A Healthy City aims to: (1) create a health-supportive environment, (2) achieve a good quality of life, (3) provide basic sanitation and hygiene needs, and (4) to supply access to health care.

These ideas are perhaps best exemplified by the Alliance for Healthy Cities, an international network aiming at protecting and enhancing the health of city dwellers. The Alliance is a group of cities and other organizations that try to achieve the goal through an approach called "Healthy Cities". The Healthy Cities approach is based on the concept that the social, economic and physical environment is the key to the health of city dwellers. The Healthy Cities program aims to cope with health issues that have emerged with urbanization. While urbanization is underway at an alarming pace worldwide, urban health issues become complex, and this complexity requires cooperation between the conventional health sector and non-health sectors. Under the Healthy Cities initiative, the WHO encourages local governments to incorporate health issues and health concerns into all aspects of public policy, and stresses to link public health policy to the rest of urban policy such as economic promotion and community development. Since these fields are conventionally considered to be irrelevant to public health, the Healthy Cities approach sharply contrasts with the traditional health approach.

Various healthy city initiatives increase the opportunity for individuals to self-care and increase physical activity levels by utilizing urban resources including dedicated cycle lanes, active commute to work schemes, parks and green places. For example, the UN World Cities Day [40] on 31 October, first celebrated in 2014 is expected to greatly promote the international community's interest in global urbanization, push forward cooperation among countries in meeting opportunities and addressing challenges of urbanization, and contributing to sustainable urban development around the world [41]. Similarly, WHO Europe Healthy City Initiative (WHO European Healthy Cities Network) is a global movement working to put health high on the social, economic and political agenda of city governments.

Another crucial development relevant to city health is represented by the Health in All Policies (HiAP) concept [8, 9] which was introduced in 2014. HiAP is "an approach to public policies across sectors that systematically takes into account the health implications of decisions, seeks synergies and avoids harmful health impacts in order to improve populations health and health equity". This framework provides countries with a practical means of enhancing a coherent approach, particularly at a national level. Some countries have already adopted a HiAP approach, even though this may not be explicit, whereas in other countries the concept is new and has yet to be operationalized. This framework has also been developed so that it can be adapted for supranational level decision-making and for governments structures at the national level, as well as the local level as decentralisation of government functions has empowered local authorities in many areas [8, 9].

An appropriate economic analysis should look at the negative costs and income foregone (e.g., tobacco taxes) of people living longer. But the above potential areas of impact, like community empowerment supported by an enabling environment, must be identified and evaluated with a likely positive net benefit for self-care, whilst reducing pressure on the health system. Thus, overall, at the individual and societal levels, self-care has the potential for enormous benefits.

41.2.3.2 WHO Guideline on Self-Care Interventions

The WHO Consolidated Guideline on Self-Care Interventions for Sexual and Reproductive Health and Rights (SRHR) was published in June 2019 [10]. This initial guideline comprised of 24 recommendations to promote self-care across five categories: (1) improving antenatal, delivery, post-partum, and new-born care, (2) providing high-quality services for family planning and infertility services, (3) eliminating unsafe abortion, (4) Combating sexually transmitted infections, including HIV, reproductive tract infections, cervical cancer, and other gynaecological morbidities, and (5) promoting sexual and reproductive health and rights. The consolidated guideline was published as a living document, and refreshed in June 2021 resulting the WHO Guideline in Self-Care Interventions to Promote Health and Wellbeing which includes 37 recommendations in total [11, 12]. Whereas the updated WHO Guideline focuses primarily on self-care in the context of SRHR, this second iteration also includes additional recommendations for self- monitoring of blood glucose, blood pressure and blood coagulation in the community and home settings, thus encroaching on the value of self-care using technology and task-shifting approach as the key to tackling the rising burden of NCDs.

41.3 Conclusions

In this chapter we have shown that self-care and inter-care may significantly improve the quality of life of individuals and has a substantial financial and social return on investment potential. Through self-care people can live longer, remain healthy well into old age, be better equipped to self-treat common minor conditions and successfully self-manage chronic diseases.

Interest in self-care has exploded in recent years, and the publication of the WHO Guideline in Self-Care Interventions was a signal moment to self-care stakeholders and policy makers internationally. Until recently, health experts were still looking to make "the absolute case for self-care", but today we find that self-care has availed itself as the critical answer to the COVID-19 pandemic, and in tackling the rising NCD pandemic. A country which fully encourages person and people-centred approaches exemplified by self-care and inter-care can expect to have a healthier population, and would be enabled to effectively redeploy scarce resources to priority areas. Self-care is therefore a crucial and powerful lever to help tackle and abate the emergence of pandemics and global health problems. The opportunity is to develop self-care and inter-care as fundamental core assets in health, and not just as a support mechanism. By extension, the empowerment of communities through self-care and inter-care can also strengthen resource-poor and humanitarian settings, as well as high resource countries where loneliness, social isolation and mental health problems may be highly prevalent.

The resurgent interest in self-care and more recently inter-care as well as the advent of the lifestyle medicine speciality are showing health experts that outcomes can be improved if people take more interest and responsibility in their health, adding to health equity by freeing up scarce healthcare resources for other people with more needs. Yet the accessibility of self-care and inter-care is not up to the individual alone but is rather dependent on the support of governments and policymakers to ensure their deliberate integration of self-care into health policy, program and practice. This direction of travel and the commitment for universal health coverage could bridge the existing divide between health and social care systems and would help communities in dealing with some of society's "wicked problems" including inequalities, mental health stigma and social isolation and loneliness by leveraging community assets and self-care and inter-care communities of practice.

The strong relationship between the health of a country's population and the country's economic performance is now better understood in economic as well as personal and social terms. Investing in health and person-centred approaches to promote self-care and inter-care should be seen as an excellent investment as this would support individuals and communities "to produce their own health". Any such commitment will have a significant return on investment potential in both the short and long term. In view of the benefits that self-care and inter-care provide, it is necessary to place them as a fundamental component of healthcare and make them part of national healthcare policies in such a way that person-centred approaches can be promoted for all people in all segments of society.

Acknowledgements and Disclosures The authors do not report any conflicts of interest in the preparation of this manuscript.

References

1. Ford ES, Bergmann MM, Kröger J, Schienkiewitz A, Weikert C, Boeing H. Healthy living is the best revenge: findings from the European Prospective Investigation Into Cancer and Nutrition–Potsdam Study. Arch Intern Med. 2009;169:1355–62.
2. Perera N, Agboola S. Are formal self-care interventions for healthy people effective? A systematic review of the evidence. BMJ Glob Health. 2019;4:e001415.
3. Thompson L. Enabling patients to take control of their own health is key to transforming the Health System [Online]. 2018. https://health-coachingacademy.com/enabling-patients-to-take-control-of-their-own-health-is-key-to-transforming-the-health-system/. Accessed.
4. Godfrey CM, Harrison MB, Lysaght R, Lamb M, Graham ID, Oakley P. Care of self-care by other-care of other: the meaning of self-care from research, practice, policy and industry perspectives. Int J Evid Based Healthc. 2011;9:3–24.
5. WHO. Self-care in the context of primary health care. Geneva: WHO; 2009.
6. WHO. Health education in self-care: possibilities and limitations. Geneva: WHO; 1984.
7. WHO. The role of the pharmacist in self-care and self-medication: report of the 4th WHO Consultative Group on the Role of the Pharmacist, The Hague, The Netherlands, 26–28 August 1998; 1998.
8. WHO. Health in all policies: framework for country action. Geneva: WHO; 2014a.
9. WHO. Self-care for health: a handbook for community health workers & volunteers. Geneva: WHO; 2014b.
10. WHO. WHO consolidated guideline on self-care interventions for health: sexual and reproductive health and rights. Geneva: WHO; 2019.
11. WHO. Social determinants of health [Online]. 2021a. https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1. Accessed 4 Dec 2021.
12. WHO. WHO guideline on self-care interventions for health and well-being. Geneva: WHO; 2021b.
13. El-Osta A, Webber D, Gnani S, Banarsee R, Mummery D, Majeed A, Smith P. The self-care matrix: a unifying framework for self-care. Self Care. 2019;10:38–56.
14. Hartweg D. Dorothea Orem: self-care deficit theory. Thousand Oaks, CA: SAGE; 1991.
15. Orem D, Taylor S, Renpenning K. Nursing: concepts of practice. St. Louis: Mosby; 1995. p. 242–4.
16. Orem DE. A concept of self-care for the rehabilitation client. Rehabil Nurs. 1985;10:33–6.
17. PAGB. Harnessing the potential of technology to transform self care [Online]. https://www.pagb.co.uk/policy/self-care-technology. Accessed.
18. Riegel B, Jaarsma T, Strömberg A. A middle-range theory of self-care of chronic illness. Adv Nurs Sci. 2012;35:194–204.
19. Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. Implement Sci. 2011;6:1–12.
20. Webber D, Guo Z, Mann S. Self-care in health: we can define it, but should we also measure it?. Self Care J. 2013;4(5):101–106.
21. Roland M, Abel G. Reducing emergency admissions: are we on the right track? BMJ. 2012;345:e6017.
22. Loef M, Walach H. The combined effects of healthy lifestyle behaviors on all cause mortality: a systematic review and meta-analysis. Prev Med. 2012;55:163–70. https://committees.parliament.uk/writtenevidence/326/html.
23. The Health Foundation. Helping people help themselves. London: Health Foundation; 2011.

24. Fabrega R. Self-care and inter-care policies in pandemic times. In: Paper presented at the 13th Geneva Conference on Person Centered Medicine, International College of Person Centered Medicine, Geneva 2021; 2021.
25. van Staden CW. African approaches to an enriched ethics of person-centred health practice. Int J Pers Cent Med. 2011;1:14–7.
26. Rogers A, Vassilev I, Sanders C, Kirk S, Chew-graham C, Kennedy A, Protheroe J, Bower P, Blickem C, Reeves D, Kapadia D, Brooks H, Fullwood C, Richardson G. Social networks, work and network-based resources for the management of long-term conditions: a framework and study protocol for developing self-care support. Implement Sci. 2011;6:56.
27. Kawachi I, Subramanian SV, Kim D. Social capital and health. In: Kawachi I, Subramanian SV, Kim D, editors. Social capital and health. New York, NY: Springer; 2008.
28. WHO. Constitution of the World Health Organization. Geneva: WHO; 1946.
29. Durand MK, Heideman ITSB. Social determinants of a Quilombola Community and its interface with health promotion. Rev Esc Enferm USP. 2019;53:e03451.
30. Luisi D, Hämel K. Community participation and empowerment in primary health care in Emilia-Romagna: a document analysis study. Health Policy. 2021;125:177–84.
31. Barton H, Grant M. A health map for the local human habitat. J R Soc Promot Health. 2006;126:252–3.
32. Barton H, Grant M, Mitcham C, Tsourou C. Healthy urban planning in European cities. Health Promot Int. 2009;24(suppl 1):i91–9.
33. United Nations. General Assembly Proceedings. 2012.
34. WHO. European Healthy Cities Network [Online]. https://www.euro.who.int/en/health-topics/environment-and-health/urban-health/who-european-healthy-cities-network. Accessed.
35. WHO. Health promotion action means [Online]. https://www.who.int/teams/health-promotion/enhanced-wellbeing/first-global-conference/actions. Accessed.
36. WHO. Global strategy for health for all by the year 2000. Geneva: WHO; 1981.
37. WHO. The 1st International Conference on Health Promotion, Ottawa. 1986a. https://www.who.int/teams/health-promotion/enhanced-wellbeing/first-global-conference. Accessed.
38. WHO. Alliance for health cities. 1986b. https://www.alliance-healthycities.com/. Accessed.
39. Hancock T, Duhl L. Promoting health in the urban context. WHO Healthy Cities Papers. Geneva: WHO; 1998.
40. United Nations. World Cities Day 31. https://www.un.org/en/observances/cities-day. Accessed.
41. Liu C. Preserving spontaneous order: a normative reflection of community building in post-reform China. Philosophy Soc Crit. 2021;47(4):534–47.
42. Nursing RCO. Social prescribing models [Online]. https://www.rcn.org.uk/clinical-topics/public-health/self-care/social-prescribing/social-prescribing-models. Accessed 4 Dec 2021.
43. Reeves D, et al. The case for investing in self care and self-management for people living with long term conditions. PLoS One. 2014;9(6):e98340. https://doi.org/10.1371/journal.pone.0098340.
44. UK National Health Service. Delivering universal personalised care [Online]. https://www.england.nhs.uk/personalisedcare/upc/. Accessed 4 Dec 2021.

Chapter 42
Empowerment of Health Professionals
Promoting Well-being and Overcoming Burn-Out

C. Robert Cloninger, Drozdstoj Stoyanov, Kristina K. Stoyanova, and Kimberly K. Stutzman

42.1 Introduction

Person-centered medicine recognizes that health care is most effective for its recipients and most satisfying for its providers when it engages each person in personally valued activities and meaningful social relationships. Life involves our inseparable relationships with all living organisms and the surrounding world in which we are embodied, embedded, enactive, and extended [1]. It is inadequate to reduce health care to materialistic treatments of disease because health is more than the absence of disease [2] and well-being only flourishes when a person recognizes their communion with something greater than their individual self [3, 4]. Empirically, the physical, emotional, cognitive, social, and spiritual aspects of the well-being of each person are interdependent and only partially dissociable [5]. In turn, the well-being of individual persons depends on the collective well-being of their extended network of relationships [6].

Consequently, it has been suggested that the cultivation of self-transcendence has a crucial role in the promotion and care of health for recipients and providers [5].

C. R. Cloninger (✉)
Department of Emergency Medicine, Department of Psychiatry, Washington University School of Medicine, St. Louis, MO, USA

D. Stoyanov
Division of Translational Neuroscience, Department of Psychiatry and Medical Psychology, Medical University of Plovdiv, Plovdiv, Bulgaria

K. K. Stoyanova
Research Institute, Medical University of Plovdiv, Plovdiv, Bulgaria

K. K. Stutzman
Family Medicine Residency of Idaho (FMRI), Boise, ID, USA
e-mail: Kim.Stutzman@FMRidaho.org

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0_42

Self-transcendence refers to the process by which human beings can grow in awareness of their relationships and participation in something greater than their individual self, such as community, humanity, nature, the universe, or the divine [3, 4]. The interconnectedness and inseparability of living things is not just a matter of philosophy, belief, or opinion. An increasingly large body of evidence from rigorous modern research in biology and ecological systems has shown that symbiosis and cooperation are more involved in the healthy functioning of ecosystems than competition [5, 7]. Research on the microbiome in humans and in soils has discovered that the deep interconnections within the biosphere are necessary for the body and communities of organisms to function properly [8]. Research on inheritance, development and evolution of human personality and adaptability has documented the crucial role of self-transcendence for physical, mental, and social aspects of health and for resilience to disease, injury, and aging [9–11].

On the other hand, much of contemporary disease care is built on a paradigm that assumes people are separate from nature and under attack from pathogens or traumas that are specific causes of discrete diseases. The Western medical model originated from scientific efforts to identify separate diseases with a distinctive set of symptoms, discrete clinical boundaries from other diseases, a predictable natural course and outcome, and a specific causal abnormality [12–15]. This paradigm is appropriately applied to disorders with a specific and consistent cause, such as acute infections by specific bacteria, acute physical injuries, or other disorders with a single specific abnormality (e.g., genetic, metabolic). In the rare cases in which diagnostic discreteness and causal specificity can be documented, the effective acute treatments (e.g., drugs or procedures) depend almost entirely on the specific and discrete diagnosis, not on the person or their psychosocial, economic, or ecological circumstances. Then evidence-based treatment attacks the single specific pathogen or tries to correct the defect or injury by specific drugs and/or procedures.

However, the Western medical paradigm has limitations as a comprehensive clinical approach because the most prevalent medical disorders have fuzzy clinical features that frequently overlap with one another, have variable natural course and outcome, and causes that are heterogeneous with complex contributions from multiple biological, psychological, social, and environmental influences [12, 14, 16, 17]. It also has severe limitations from a public health perspective because there are often, if not always, differences between individual persons in their susceptibility, response to treatment, and long-term outcome, as is well known even for infectious diseases, including SARS-CoV-2 for which the socioeconomic determinants are indistinguishable from average all-sources mortality [18]. The paradigm assuming a specific cause and discrete symptom pattern has proven to be generally inadequate when extended to conditions in which there are multiple heterogeneous causal factors and biopsychosocial influences on vulnerability and resilience; it is inadequate because evidence-based treatments, which are based on the standard of average differences between groups, yield weak and inconsistent benefits that are similar for diverse evidence-based or alternative treatments [19]. Consequently, a biopsychosocial approach is needed for health promotion, disease prevention, and treatment of complex disorders that are strongly influenced by the unique characteristics of a person, including their personality, lifestyle, and socioeconomic conditions

[20–23]. Evidence that the paradigm for discrete diseases with specific causes is inappropriate as a general model in medicine is provided by the resulting dehumanization and monetization of disease care and the chronic underfunding of health promotion and disease prevention, which are the fundamental basis for the burn-out crisis, the high prevalence of people with multiple chronic diseases, and the weak and inconsistent results obtained from depersonalized evidence-based treatment [24].

Put another way, health and well-being are more than the absence of disease, and so they need to be addressed in a person-centered way as complex biopsychosocial processes. To promote well-being and prevent complex biopsychosocial disorders, rather than attacking a pathogen or correcting an injury, it necessary to help the person learn to live more healthily and harmoniously with people, other living organisms, and the world as a whole. The ill person has a proactive, emotionally intelligent, and creative role to play in their own recovery, but that recovery also depends on the quality of the milieu and the community in which a person lives and works, including variables that are biological (e.g., pollution, environmental toxins, climatic extremes), psychological (e.g., personality, emotional intelligence), social (e.g., socioeconomic inequity, alienation), and spiritual (e.g., respect for self-transcendent values, autonomy).

Human well-being, as well as resilience and recovery from disease, depend on self-regulation (intrapersonal awareness), cooperation (interpersonal awareness), and creative imagination (transpersonal awareness), which may be described in a variety of terms. For example, intrapersonal awareness can be described as self-directedness or adaptive coping strategies (viz., being purposeful and responsible), interpersonal awareness as cooperativeness or emotional intelligence (viz. being helpful and empathic), transpersonal awareness as self-transcendence or intuitive insight and intersubjectivity (viz. altruistic and contemplative) [25]. When the intrapersonal, interpersonal, and transpersonal aspects of human intelligence are underdeveloped or impaired, individuals become highly vulnerable to burn-out [25–27] and their communities become vulnerable to social injustice, which jointly lead to increased mortality, multiple chronic diseases, mental disorders, and social distrust in individuals and their communities [28–30].

In what follows we will describe how to promote well-being (which is associated with self-transcendence, emotional intelligence, and engagement) and to overcome ill-being (which is associated with immoderate self-interest, emotional reactivity, and burn-out). This requires a deep understanding of the interaction of multiple biopsychosocial processes underlying health and well-being.

42.2 What Is Burn-Out?

Contemporary industrial societies tend to disparage the value of self-transcendence in favor of individualism, competition, and consumption, even when that is unsustainable and unhealthy [31, 32]. As a result, contemporary societies have become highly dehumanized and monetized like businesses, including health care, but also government, education, science, the arts, sports, social media, marketing, and agriculture [33]. The treatment of disease and injury has become a business aligned with industries that prioritize profit over the well-being of people with little or no commitment to social justice, as has occurred around the world extensively during the past four decades (i.e., since the time of Reagan in the USA and Thatcher in the UK when burn-out began to be rise in prevalence) [34–36]. Then, because the main desire of owners and corporate administrators is financial gain, the people in the hired workforce are more and more often viewed as replaceable automatons whose health and human values are regarded as a costly nuisance and source of inefficiency [37–39]. Physicians are often designated as RMUs (replaceable medical units) for planning and program development by hospital administrators, which is intentional depersonalization in action. Likewise public health promotion and disease prevention are undervalued and chronically underfunded at every level of organization (local, national, and international) because it is not a means for private profit. Medical education, training, and practice are typically reduced to focus on treatment of separate diseases and organs, rather than taking an approach that recognizes the importance of the whole person in an extended psychosocial and ecological context.

Burn-out among physicians, nurses, and other health care professionals has become highly prevalent under these dehumanized conditions. Prevalence estimates are predominantly in the range of 40 and 60% in health care professionals in systematic reviews of surveys around the world [40, 41]. According to the Maslach Burn-out Inventory, which is used in more than 80% of surveys, burn-out is characterized by emotional exhaustion (reduced vigor), feelings of dehumanization (depersonalization, lack of community), and lack of accomplishment and fulfillment (inefficacy) (Table 42.1) [43, 44]. The development of burn-out has been attributed to several drivers that may contribute to lack of engagement and meaning in work, including impaired work-life balance and integration, lack of social support and community at work, a lack of influence, control and flexibility at work, pressure from workload and job demands, and lack of needed resources for safety, efficiency, and efficacy [45, 46]. In particular, the work environment and relationships are crucial for fostering cooperation, empathy, and shared values [47, 48].

For example, the correlations among the three aspects of the Maslach Burn-out Inventory and perceived features of the work environment using the Psychological Climate Inventory in health care workers at a University Medical Center in Bulgaria is summarized in Table 42.2 [22, 26, 27]. These results indicate that the strongest contributors to burn-out in health care workers are related to pressure felt from

Table 42.1 What is burn-out according to the Maslach Burn-out Inventory? [42]

Three Aspects of Burn-out	Descriptors
Emotional exhaustion	Tired, drained, exhausted, unenthusiastic
Dehumanization/depersonalization	Cynical, callous, treating others as objects
Low sense of accomplishment	Dissatisfied, unfulfilled, having no influence

Table 42.2 Correlation between aspects of burn-out and health care workers's perceived work environment in 302 medical center staff, Plovdiv, Bulgaria [27]

Perceived work environment	Emotional exhaustion	Callousness (social alienation)	Sense of accomplishment
Autonomy			0.36
Cohesion		−0.15	0.20
Trust	−0.17	−0.20	0.22
Pressure	0.46	0.27	
Support	−0.22	−0.18	0.26
Recognition			0.14
Fairness	−0.18		0.21
Innovation	−0.15		0.22

heavy work demands (r = 0.46 with exhaustion), lack of autonomy (r = 0.36 with low sense of accomplishment), and several indicators of a lack of communal relationships (low cohesion, support, trust, and fairness).

However, individuals vary in their susceptibility to the stressors that lead to burn-out. Specifically, burn-out has been found to be lower in health care workers with resilient personality profiles characterized by high Self-directedness, high Persistence, and low Harm Avoidance in samples from the Europe, Australia, and USA [26, 49, 50]. High risk of burn-out occurs in individuals who are fragile (i.e., low in Self-directedness, high in Harm Avoidance, and low in Persistence) or perfectionistic and worried (i.e., low in Self-directedness, high in Harm Avoidance, and high in Persistence), as described in Table 42.3. More generally, the strongest predisposition to well-being regardless of stress is a combination of a creative character profile (i.e., high Self-directedness, Cooperativeness, and high Self-Transcendence) and resilient temperament traits (particularly high Persistence and low Harm Avoidance) [9, 11, 51].

Of course, the personality and environmental variables that protect against burn-out vary for different physicians in different situations. For example, general practitioners who seek rural practice are typically more venturesome (i.e., higher in Novelty Seeking) and confident (i.e., lower in Harm Avoidance) than those in urban settings [52]. Female general practitioners are typically higher in Cooperativeness (i.e., helpful, empathic) and Reward Dependence (i.e., sociable, value close friendships) than male general practitioners, as is true in the general population [52]. Accordingly, it is understandable that female physicians working in rural practices report that they need strong social support networks to maintain healthy work-life balance [53]. They emphasize the importance of careful selection of their life partner and practice partners, and the importance of negotiating a work contract that is consistent with their own values, practice style, and family life. The one thing that consistently sustained female rural physicians was the close and meaningful relationships they formed with their patients and their families [53]. The example of rural female physicians illustrates that a person-centered approach that recognizes the goals and values of each person is essential to health promotion.

Table 42.3 Descriptors of high and lower scorers on scales of the Temperament and Character Inventory (TCI) [3]

TCI scales	TCI subscales	High scorers	Low scorers
Novelty seeking	NS1 excitability	Exploratory	Reserved
	NS2 impulsivity	Impulsive	Rigid
	NS3 extravagance	Extravagant	Thrift
	NS4 disorderly	Rule-breaking	Orderly
Harm avoidance	HA1 pessimism	Pessimistic	Optimistic
	HA2 fearfulness	Fearful	Risk-taking
	HA3 shyness	Shy	Outgoing
	HA4 fatigability	Fatigable	Vigorous
Reward dependence	RD1 sentimentality	Sentimental	Objective
	RD2 openness	Warm	Aloof
	RD3 attachment	Friendly	Detached
	RD4 dependent	Approval-seeking	Independent
Persistence	PS1 eagerness	Enthusiastic	Hesitant
	PS2 hard-working	Determined	Spoiled
	PS3 ambition	Ambitious	Underachieving
	PS4 perfectionism	Perfectionistic	Pragmatic
Self-directedness	SD1 responsibility	Responsible	Blaming
	SD2 purposefulness	Purposeful	Aimless
	SD3 resourcefulness	Resourceful	Helpless
	SD4 self-acceptance	Unpretentious	Pretentious
	SD5 self-actualizing	Self-actualizing	Unfulfilled
Cooperativeness	CO1 social tolerance	Tolerant	Prejudiced
	CO2 empathy	Empathetic	Self-centered
	CO3 helpfulness	Considerate	Hostile
	CO4 compassion	Forgiving	Revengeful
	CO5 conscience	Principled	Opportunistic
Self-transcendence	ST1 self-forgetfulness	Engaged	Self-concerned
	ST2 transpersonal identification	Joyfully connected altruistic	Separate individualistic
	ST3 spiritual acceptance	Faithful	Skeptical
	ST4 contemplation	Contemplative	Conventional
	ST5 idealism	Idealistic	Cynical

In addition to individual personality traits and the psychological climate of organizations, well-being is dependent on what is happening in our communities and the world more broadly because individual well-being depends on the collective social, cultural, and ecological climate in which we live. The conditions causing burn-out in health professionals are a pervasive societal and global problem that is not limited to medicine and health care. Most institutions in contemporary societies have been monetized and dehumanized with the increasing industrialization of society around the world. For example, contemporary education focuses on preparing workers with knowledge and skills to get a job and then work in a dehumanized and monetized society, rather than encouraging a love of learning and discovery, appreciation for the values and meaning expressed in humanistic culture and art, the ability to think creatively, and other opportunities to cultivate character strengths. To get a job, many people become expendable employees who can be purchased like an impersonal object without long-term commitment or benefits. Leaders in government become biased to support special interests by their dependence on contributions for election, rather than devoting themselves to their meaningful and moral duty to do what is good for public well-being [54]. Disinformation is promoted in media owned and controlled by special interests with little or no enforcement of social duty for public well-being. Drugs are developed primarily depending on what is most profitable in the judgment of marketers, not scientists and physicians, and review of safety and efficacy in some countries like the USA is by an agency that is highly dependent on funding by the industry being reviewed. At the same time inexpensive psychological, physiological, natural, pharmacological, and procedural remedies, such as acupuncture and herbal remedies, are criticized as not evidence-based even after many decades or centuries of beneficial use, and minor variations are introduced to drugs to extend patents in order to keep profits high with little real benefit to the public. Public health infrastructure is chronically under-funded so there is minimal investment in preventive medicine and health promotion. Pressure and financial influence is exerted by ultra-wealthy individuals to privatize health care services in ways that further socioeconomic inequity despite our undeniable knowledge of the socioeconomic determinants of health [18].

Health professionals who feel disengaged, alienated, and burned-out have increased risk for making medical errors in patient care, lower patient care quality, lower patient satisfaction ratings, reduced productivity, higher job turnover, and high rates of divorce, depression, substance abuse, suicide, and higher level of job turnover [55–59]. Their functional impairment stands out in society mainly because they have been selected for their intelligence, persistence, and commitment to serving others and because their impairment is costly. They have the strengths to be high in well-being, but when they burn-out in toxic environments, most attention is focused on trying to enable them to cope with toxic environments with dehumanized values and priorities rather than humanizing the work environment. In other words, there is an effort to increase their individual resilience, but there has been little attention to increasing the self-transcendence of people in all aspects of the health care field, perhaps because self-transcendence is the spiritual aspect of human character and is systematically devalued in materialistic societies.

Nevertheless, according to Maslach and Leiter,

> *Burn-out is an index of the dislocation between what people are and what they have to do. It represents an erosion of the value, dignity, spirit, and will -- an erosion of the human soul. It is a malady that spreads gradually and continuously over time, putting people into a downward spiral from which it is hard to recover* [44].

We agree with the assessment that burn-out is an erosion of intrinsic dignity, spirit, or soul of a person. In other words, it is a failure to provide the living conditions appropriate for human nature, which are needed for health and well-being. The strengths that need to be cultivated to assure that a person can both shape and adapt to the conditions needed for well-being have been described as the creative character profile, which is comprised of strong development of self-directedness, cooperativeness, and self-transcendence, as described more fully later [9–11, 31]. However, we disagree with their pessimistic assessment in 1997 that it is hard to recover from burn-out. Since that time, much has been learned in psychology and person-centered medicine about how to empower the cultivation of character strengths and well-being because the basic underlying mechanisms have been uncovered [9–11, 31]. The early phases of burn-out can be recognized and addressed in a person-centered way that promotes well-being, which is beneficial for individuals, health care organizations, and society in general [22, 45].

42.3 What Are the Basic Processes for Professionals' Empowerment of Health and Well-Being?

Until recently efforts to empower well-being and overcome burn-out relied upon efforts to educate people to improve their work-life balance, increase their resilience to stress and lack of control, and sometimes efforts to strengthen the sense of community and trust at work by greater social support and provision of employee advocates and resources, and sometimes to address their religious or spiritual needs and values [45]. These efforts correspond to the major contributors thought to drive burn-out and impair well-being. Unfortunately, such efforts tended to shift responsibility for change and adaptation to the individual employee and to maintain the monetized and dehumanized cultural priorities of the workplace that are the crux of problem. Introduction of employee advocates as supports and provision of resources to help employees cope did not alter the basic values and priorities of the medical workplace or the extended society. For example, the electronic health record (EHR) may be beneficial in administration of coordinated care across specialties, automating patient workflow, monitoring and encouraging compliance with algorithms designed to guide and standardize decisions about care, and monitoring productivity and efficiency. However, EHRs have nearly all been designed with minimal consultation with practicing physicians about how they work, and EHRs place a heavy clerical burden on providers to enter data [60]. In fact, there are renewed efforts to use clinical megadata to design algorithms using artificial intelligence to guide decision making, which directly undermines the autonomy of physicians and respect for their expertise and their unrivaled capacity for person-centered and practical wisdom compared to any deterministic algorithm for changing conditions and people with unique characteristics and values [61]. In addition, EHRs please bureaucrats but lack a personalized account of personal information that distinguishes one person from another in their history and treatment. The person-centered care of individuals cannot rely only on past differences between the averages of groups (the standard of evidence-based medicine, which is only adequate for clinically homogeneous diseases with a single cause) because averages are not an adequate basis to guide treatment of any individual person. Consequently, what is convenient for bureaucratic audits and business administration to encourage standardization of practices devalues the autonomy and expertise of highly trained professionals and produces suboptimal and depersonalized health care.

Individual recipients and providers of care are also not interchangeable or expendable because there is value in continuity of person-centered care for both the recipients and providers of that care. The quality of working relationships is often the major predictor of clinical outcomes, particularly in general practice and non-procedural specialties. Likewise, it is disheartening to the human nature of health care providers to recognize that administrative decisions in medical programs are often prioritized by what is profitable rather than what improves equitable access to care and the quality of life of people and/or reduces the long-term burden of disease. Providers in procedural specialties, such as surgeons, are often paid much more than providers in less lucrative but time-intensive fields, like family practice and pediatrics. The attempt to managing health care by profit-driven and competitive business principles has failed to control costs or to improve the quality of care, but monetization has precipitated a burn-out crisis in which most health care providers are suffering from burn-out, retiring early, and would not recommend a career in health care to their children because the dehumanized health care environment is considered as toxic to human nature. That is what Maslach and Leiter [44] meant by describing burn-out as an index of the dislocation between “what a person is and what they do”. This basic discrepancy is not addressed by higher pay or provision of support and skills so that health care workers become less sensitive or more tolerant of a monetized and dehumanized milieu that does not fulfill the needs of their human nature to serve others with compassion, flexibility, and expertise.

The toxicity of the health care environment is not unique. Burn-out is frequent in most workers in other fields also, so that some skeptics recently have suggested that burn-out is an unavoidable fact of life. We suggest that burn-out is a consequence of the maladaptive habits, goals and values of persons and societies that prioritize self-interest over self-transcendence by emphasis on insatiable desires (such as seeking ever-greater individual wealth, power, fame, and consumption) rather than the fulfillment and meaning that derives from serving others with self-transcendent values, flexibility, and creative awareness.

Therefore, to empower people to flourish in well-being and to overcome rather than manage their burn-out, we must appreciate what is unique about human nature. Recent studies of human personality and learning confirm the insights of ancient wisdom traditions about the nature of the path to well-being [5, 6, 9–11, 62]. Specifically, modern humans have a unique capacity to integrate self-control and self-awareness so that they can self-regulate their habits, emotions, goals, and values coherently, which promotes their health and well-being through self-actualization. Furthermore, the intersubjective awareness of *Homo sapiens* (literally, wise man) allows them to palpably feel their connection with other people and nature, which allows them to distinguish between self and other while consciously identifying with other people and nature. Together these capacities allow a person to develop in their health and well-being by cultivating self-awareness and intersubjectivity with flexibility, creativity, and prosocial values. On the other hand, the healthy expression of human self-awareness can be impaired under toxic conditions, as in response to fear, inequity, neglect, or violence. Social norms in monetized and dehumanized societies may interfere with the cultivation of natural human capacities and needs to serve others, to let go of fighting, and to grow in awareness of our connections with other people and nature. Consequently, to flourish in health, a person needs to understand their own processes of thought and to cultivate coherence among their habits, goals, and values.

The genetic basis for modern human awareness depends on RNA genes that regulate the expression of protein-coding genes in three distinct systems of learning and memory: habits, intentionality, and self-awareness [9, 11]. The three genotypic systems for human personality evolved in a cumulative stepwise manner. The most primitive arose in monkeys and apes about 40 million years ago and is responsible for emotional reactivity. Specifically, it regulates impulses, learning habits, social attachment, and conflict resolution. Less than two million years ago, the second network emerged in a common ancestor of Neanderthals and modern humans, enabling the regulation of intentional self-control, that is, self-direction and cooperation for mutual benefit. Finally, about 100,000 years ago the network of creative self-awareness emerged in behaviorally modern humans with a capacity for narrative art, science, and spirituality.

These new findings uncover the basic mechanisms required for promoting healthy personality development and, remarkably, physical, mental, and social wellbeing. It turns out that a healthy personality is the foundation for all aspects of wellbeing in general because it provides the regulatory processes by which we learn to integrate our habits, goals, and values so that they are congruent, reasonable, and beneficial for ourselves, others, and the world in which we live. The genes for personality are nearly all expressed in learning circuits in the brain, and about 70% of them are also expressed in nearly all the other organ systems of the body (see Fig. 42.1) [9].

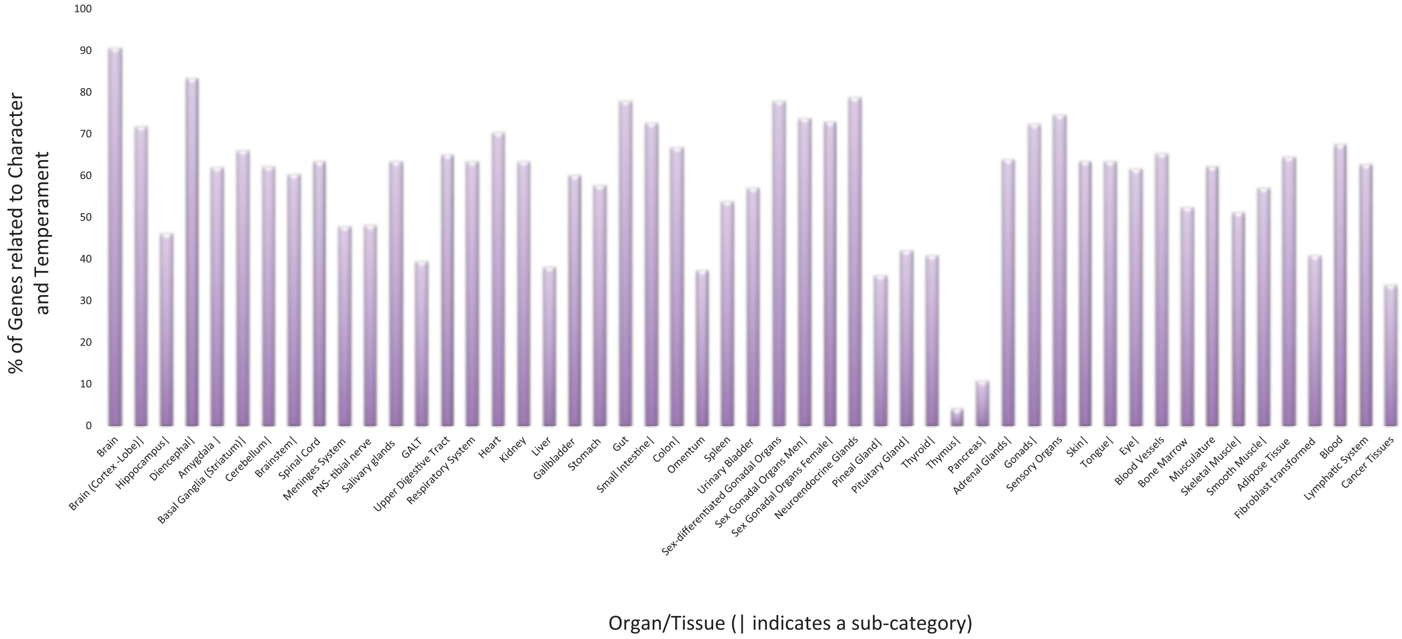


Fig. 42.1 Regions of body in which 972 genes accounting for nearly all the heritability of human personality are expressed [9]

42.4 Practical Methods for Promoting Well-Being

Prospective studies indicate that the cultivation of self-transcendence and well-being involves the dynamic interplay of three processes: the awakening of plasticity (i.e., being able and willing to change), virtue (i.e., having intuitive insight into what is good for a person's self and others), and creative functioning (i.e., being innovative, responsible, and kind so that our habits are congruent with our goals and values) [5]. The cultivation of self-transcendence by these three processes describes the essential features of the path to a life that is healthy, happy, and good.

Plato represented the process of cultivating well-being by his metaphor of the charioteer and other related metaphors (Table 42.4) [63]. In Plato's metaphor, the charioteer guides the chariot pulled by an obedient white horse and an unruly black horse. Plato's charioteer symbolizes the integrated intelligence and intuitive insight of Reason, which strives to do what is good and prudent. Reason is more than logical analysis from axioms and observations, both of which may be wrong or biased: Reason corresponds to the wise insight and judgment of awakened self-awareness of someone with a creative character profile. A person with a creative character profile is high in Self-directedness (resourceful, purposeful, self-accepting, responsible, and self-actualizing), high in Cooperativeness (tolerant, helpful, empathic, principled, and compassionate), and high in Self-Transcendence (i.e., idealistic, self-forgetful, joyful from identifying with others, contemplative, and spiritual). The unruly black horse represents the appetites, which are a person's undisciplined emotional drives and hypersensitivities; the appetites correspond to the emotionally reactivity of a person with little character development (i.e., emotionally labile, hypersensitive, impulsive, undisciplined). The obedient and courageous white horse

Table 42.4 Plato's 3 aspects of human functioning in relationship to their temperament and character components and to virtue and vices

	Appetites (*Epithumia*) (HA, NS, RD)	Feelings/dedication (*Thumos*) (SD × PS × ha)	Reason/insight (*Logistikon*) (SD × CO × ST)
Chariot Metaphor (*Phaedrus*)	Black Horse	White Horse	Charioteer
Body Metaphor (*Timaeus*)	Gut	Heart	Head
Class in Society (*Republic*)	Self-interested Merchants and Producers (lovers of gain)	Courageous and Noble Soldiers (lovers of honor)	Philosophical Rulers (lovers of wisdom)
Desires	self-gratification	Preservation of order and values	Practical Wisdom and the good life
Outstanding Virtue	Moderation	Fortitude	Prudence
Vices	Greed Gluttony Lust	Sloth Wrath Envy	Folly Arrogance

corresponds to the fortitude of a person with high persistence and determination to intentionally control their goals and habits by following the guidance of Reason. Fortitude corresponds to the joint interaction of the TCI traits of Persistence (PS, i.e., vigorous, eager to work, determined) with Self-directedness and low Harm Avoidance (HA, i.e., calm, optimistic, outgoing), which creates both flexibility and resilience. This is a dynamic process in which each aspect of temperament and character has an interactive role on the path to well-being by means of promoting virtue, creative functioning, and plasticity [63].

How are these mechanisms applied in practice with individuals, organizations, and communities? The work must begin in the individual person and be carried out in conditions that permit consistent coherence in habits, goals, and values. The notion that "practice makes perfect" is perhaps no truer than in the domains of health care and well-being. The philosopher Will Durant explained, "We are what we repeatedly do. Excellence, then is not an act, but a habit [64]." There may also be gifts of grace and inspiration that inspire us, but to put virtue into action we must cultivate and practice it repeatedly so that it becomes second nature to us. This is the process of self-actualization, which requires the awareness of what we really value from introspection and contemplation, and persistence in intentionally practicing what we value, so that it becomes a strong and spontaneous habit. This is the role of cultivating fortitude, which, as previously mentioned, can be represented by Persistence serving as a bridge between Reason and the moderation of unruly and selfish appetites in Plato's Charioteer metaphor. Consequently, we must avoid activities and experiences that are incompatible with our human nature and values, as is unfortunately happening often in commercialized society.

Furthermore, good habits do not arise without growth in awareness (e.g., by cultivating Reason to develop a creative character). One way a person's awareness can increase is through contemplative experiences, which can help a person examine their own thinking and make conscious what was previously unconscious. Another related way is to cultivate union with nature by activities like gardening, nature walks, or other ways of heightening awareness of our inseparable connections with the natural world. Such enhanced awareness can be described as mindfulness when it helps a person to let go of judging and blaming by recognizing what biases their perceptions and thereby understanding the processes of their thought [3]. Increasing awareness also leads to self-transcendence by increasing the range of our existential experiences as described by existential philosophers like Heidegger (participation in Being, which encompasses both the objective and subjective aspects of what exists). Thus, a self-transcendent perspective enriches a person's vision and understanding of what has value and meaning by facilitating identification with all that exists while retaining awareness of our individuality.

The outlook of a person with a creative character still needs to be actualized by intentionally expressing their values in their actions with perseverance. However, the TCI trait of Persistence is a component of the habit system itself. It measures the Partial Reinforcement Extinction Effect (PREE), which results in greater persistence (i.e., resistance to extinction) of behaviors that are only intermittently reinforced (i.e., that initially are successful only occasionally) compared to behaviors that are initially continuously successful [65, 66]. People who are persistent are described as hard working and determined, but persistence and other habits are blind—they are done automatically without any awareness of the value or long-term consequences. For example, active alcoholics who are highly persistent in their habits are highly likely to continue their alcohol abuse, but once they get sober, they are also highly likely to remain abstinent [67]. Physicians required to use an EHR will gradually adopt the embodied perspective that prioritizes compliance with bureaucratic requirements and recommendations for the average case with a particular diagnosis, even though the boundaries of diagnoses are fuzzy and subjects with a particular diagnosis vary greatly in their symptoms, treatment needs, and values. Consequently, to develop well-being and health-promoting habits, people need to inform their intensions with the guidance provided by the good intuitive insight and judgment of Reason while respecting the freedom and dignity of each person to act autonomously.

Accordingly, when people are seeking to find healthier and more satisfying ways to live, we have found it beneficial to begin the process with two steps. The first is to observe and reflect on their own personality by completing the Temperament and Character Inventory, which is a comprehensive and reliable self-report personality test with well-documented genetic, neurobiological, psychosocial foundations, and spiritual foundations [11, 68, 69]. This helps a person to be aware of how various components of their personality may contribute to their strengths and vulnerabilities. If they desire to change their way of living to better reflect what they value, we may next encourage them to practice living in ways similar to those of people with creative characters (that is, who are high in Self-directedness, Cooperativeness, and Self-Transcendence) as an initial experiment. For example, it is often beneficial for people to practice acts of love, hope and faith, much as is described in positive psychology with acts of kindness or gratitude, because this stimulates people to realize what they personally value. More generally, we encourage people to explore what they value through reflection and meditation on the subject, and to consider how much they act on what they value most in their daily lives. Contemporary lifestyles have often put too much emphasis on things we value the least to the detriment of what we value the most. It is essential for our own well-being, therefore, to practice activities that most, if not all people, find effective for cultivating the expression of virtue in their lives. These virtuous and health-promoting practices are broadly described as (1) working in the service of others (e.g., practicing acts of kindness, which expresses an understanding of love), letting go (e.g. letting go of resentments and fights with one's self and others, which expresses an understanding of hope), and growing in awareness (e.g., acts of faith about what is not tangible or objectively proven, such as meditation to cultivate serenity, mindfulness, insight and impartial judgment, which express an understanding of faith and humble acceptance of the imperfection of the human condition) [3]. In addition, it is helpful to teach most people about the processes of thought so that they can be more aware of what biases our perceptions, intentions, and values, and thereby interferes with their functioning.

The third crucial component of the path to well-being is plasticity (i.e., the capacity for change) [19, 70]. Recall that our genetic research showed that the genes for human personality are over-expressed in nearly all the tissues and organs of the whole body, not just in the brain (Fig. 42.1). It should not surprise anyone, consequently, that coherent living requires plasticity of a person's whole being, including fluidity and resilience of the body, flexibility and creativity of thought, and freedom of will (i.e., detachment from selfish desires and maladaptive habits). To follow the dictates of our inner voice and conscience, we must be free and flexible in putting that inspiration into action [63, 71]. Put another way, in order to practice living in a healthy, satisfying, and virtuous way, we must have the insight to recognize what is good and the plasticity to change what is not good for ourselves and others. When we start a process of self-actualization, we may encounter frustration when trying to do something that we are not yet skilled at doing, so we need to learn to accept that humbly and cheerfully as an unavoidable aspect of the self-actualization process. Success in acquiring a new skill has been shown to generalize to hopeful attitudes in other aspects of our life [72, 73]. Awakening our awareness of the body by health-promoting self-care and exercises promotes self-respect, resilience, and improved self-regulation of emotions. Rather than holding onto old habits, customs, and traditions, we begin to function more flexibly and creatively, like a trapeze artist who must let go of the bar behind her in order to be free to grasp the bar ahead.

Overall, the path to well-being is a path of self-transcendence in which there is dynamic interplay by which virtue inspires creative thinking, and plasticity allows its free expression. Empirically, in prospective studies we have found that the initial personality characteristic that leads to the most change in personality is high Self-transcendence; there are additional contributions from high Persistence and Novelty Seeking [32]. Self-Transcendence and Persistence are also positively correlated with nearly all character strengths and virtues, as expected from their expected roles in the cultivation of virtue that we have described. Large-scale randomized controlled trials of our recommended methods for promoting well-being show benefit of promoting health in ways that are attentive to the physical, mental, social, and spiritual aspects of human well-being [74, 75].

42.5 How Can Medicine Regain Its Person-Centered Values and Practices?

Ultimately, each of us must look within ourselves to listen to the "small quiet voice" within us to know what we value, to know what gives us a sense of coherence, meaning, purpose, and satisfaction [3, 70]. Each of us must personally discover what we really value for our actions to be authentic and persistent. In wellness coaching or person-centered medicine, we validate every person's ability to know their own self, we encourage them to explore what they value through contemplation and direct experience, and then we help them consider how to implement their own intentions in practice with compassion for all, so that everyone can eventually have many opportunities to grow in self-transcendence and well-being [70].

In contrast, contemporary medicine is experiencing a crisis of burn-out because health care has been monetized by industries who prioritize profit, efficiency, and bureaucratically regulated standards over the principles of person-centered medicine and over the expert insight and judgment of health care professionals who are attentive to the unique characteristics of individual persons and strive to identify treatments that are most beneficial for a particular person. In addition, contemporary medicine in many countries is impaired by its inadequate commitment to person-centered medicine and equitable health care [54]. The pervasive discrepancy between healthy human nature and how health care is currently being done cannot be changed by fiat or persuasion because few of the contemporary leaders with authority are motivated to listen.

However, the resistance of materialistic people in positions of authority to a person-centered workplace is out of step with the direction of cultural evolution [76, 77]. Most people born after the late 1970s are post-materialists who are described as culturally creative because of their active protest and dedication to egalitarian, communal, and self-transcendent values [78], which are crucial for optimal human well-being [11, 31]. Consequently, one could expect that a renewal of person-centered medicine would occur ultimately because the current dehumanized systems are unsustainable and will fail. Meanwhile, each individual health care worker will need to cultivate their own well-being using the principles that have now been well-documented in objective ways that confirm long-respected traditions of wisdom.

Individuals are not separate, so materialistic or dualistic models of burn-out, as described elsewhere [45], are inadequate [6]. To be healthy, we really need to cultivate an outlook of unity because we are interdependent social, cultural, and ecological beings. As we progress along the path to well-being, we will find like-minded people with whom to work. We cannot rely upon dysfunctional systems with self-defeating values to promote our health until those systems are fundamentally transformed. For our own health and well-being, as much as we can, we must minimize our interactions with the many segments of health care systems whose effects are toxic because their basic values are dehumanized. When possible, leadership can promote person-centered values in communities or regions, as is being done in South America by many people in organizations aligned with the principles of person-centered medicine. (https://www.personcenteredmedicine.org/doc/2019-Lima-Declaration.pdf). Likewise, local training centers can foster health-promoting person-centered practices and values [53]. In this way, health care workers can become more aware of who they are, what they value, and how they can serve one another in ways without fighting or submission to practices inconsistent with who they are and what they value. Put simply, the contemporary lifestyles and working environments that have led to the burn-out crisis in health care professionals and many other people around the world have put far too much emphasis on things of little value for health and happiness. Consider why rich and powerful elites are so often unhealthy and insatiable in their desires: their outlook on life is filled with false vanity masking their fears and immoderate desires. We can consider their plight with compassion and patience from a distance rather than following or struggling with them, and then we can be ready to help them when they eventually fail. It is essential for our own well-being, therefore, to practice activities that people truly value most in their lives, such as loving service to others, letting go of fights and worries, and cultivating self-transcendence by growing in awareness.

42.6 Conclusions

The empowering of health professionals in the present chapter is based on the promotion of well-being and overcoming burn-out. They are predicated on both the cultivation of each person's well-being and the reorientation of health systems to contribute to the full well-being of their health professionals, as they also must do for the patients and communities they serve.

The principles of well-being appear to be scale-free because they are based on an outlook of unity and harmony characterized by love, hope, and faith. They apply at every level of organization from individual to family, community, state, world, and the universe. We need health care systems to be integrated across multiple levels to respond to the needs of people throughout every aspect of their lives, while delivering care in ways that respect diverse local resources and values [54]. The point is not to force a person-centered approach on anyone, but to facilitate its implementation at the individual and system levels. It is posited that such approaches would diminish dehumanizing practices and lead to greater well-being among human beings from the individual to the society and international levels. Creative personal initiatives and solidarity at all levels seem to be crucial elements for individual and collective well-being, which must be based on personal freedom and responsibility, social trust, community development and ecological sustainability.

Acknowledgements and Disclosures The authors do not report conflicts of interest in the preparation of this manuscript.

References

1. Albert N, de Bruin L, Gallagher S. The Oxford handbook of 4E cognition. Oxford: Oxford University Press; 2020.
2. WHO. Definition of Health: Preamble to the Constitution of the World Health Organization. New York: World Health Organization; 1946.
3. Cloninger CR. Feeling good: the science of well-being. New York: Oxford University Press; 2004.
4. Cloninger CR. Spirituality and the science of feeling good. South Med J. 2007;100:740–3.
5. Cloninger CR, Cloninger KM. Self-transcendence. In: Peteet JR, editor. The virtues in clinical practice. New York: Oxford University Press; 2021.

6. Cloninger CR, Lester N. Personality disorders. In: Boland RJ, Verduin MI, editors. Kaplan & Sadock's comprehensive textbook of psychiatry. Philadelphia: Wolters Kluwer Health; 2021.
7. Albrecht GA. Earth emotions: new words for a new world. Ithaca: Cornell University Press; 2019.
8. Cryan I, Dinan T. Mind-altering microorganisms: the impact of the gut microbiota on brain and behavior. Nat Rev Neurosci. 2012;13:701–12.
9. Zwir I, Arnedo J, Del-val C, Pulkki-råback L, Konte B, Yang SS, Romero-zaliz R, Hintsanen M, Cloninger KM, Garcia D, Svrakic DM, Lester N, Rozsa S, Mesa A, Lyytikäinen L-P, Giegling I, Kähönen M, Hernandez-cuervo H, Seppälä I, Raitoharju E, de Erausquin G, Raitakari O, Rujescu D, Postolache TT, Sung J, Lehtimäki T, Keltikangas-järvinen L, Cloninger CR. Three genetic-environmental networks for human personality. Mol Psychiatry. 2021a;26(8):3858–75. https://doi.org/10.1038/s41380-019-0399-z.
10. Zwir I, Arnedo J, Del-val C, Pulkki-raback L, Konte B, Yang SS, Romero-zaliz R, Hintsanen M, Cloninger KM, Garcia D, Svrakic DM, Rozsa S, Martinez M, Lyytikainen LP, Giegling I, Kahonen M, Hernandez-cuervo H, Seppala I, Raitoharju E, DE Erausquin GA, Raitakari O, Rujescu D, Postolache TT, Sung J, Keltikangas-jarvinen L, Lehtimaki T, Cloninger CR. Uncovering the complex genetics of human character. Mol Psychiatry. 2020;25:2295–312.
11. Zwir I, Del-val C, Hintsanen M, Cloninger KM, Romero-Zaliz R, Mesa A, Salas R, Poblete GF, Raitoharju E, Keltikangas-Järvinen L, de Erausquin G, Tattersall I, Lehtimakäki T, Cloninger CR. The evolution of genetic networks for human creativity. Mol Psychiatry. 2021b;27(1):354–76. https://doi.org/10.1038/s41480-021-0197-y.
12. Arnedo J, Svrakic DM, Del Val C, Romero-zaliz R, Hernandez-cuervo H, Fanous AH, Pato MT, Pato CN, de Erausquin GA, Cloninger CR, Zwir I. Uncovering the hidden risk architecture of the schizophrenias: confirmation in three independent genome-wide association studies. Am J Psychiatry. 2015;172:139–53.
13. Cloninger CR. Establishment of diagnostic validity in psychiatric illness: Robins and Guze's method revisited. In: Robins LN, Barrett J, editors. Validity of psychiatric diagnosis. New York: Raven Press; 1989.
14. Cloninger CR, Martin RL, Guze SB, Clayton PJ. Diagnosis and prognosis in schizophrenia. Arch Gen Psychiatry. 1985;42:15–25.
15. Sydenham T. The whole works of that excellent practical physician, Dr.Thomas Sydenham. Wherein not only the history and cures of acute diseases are treated of, after a new and accurate method. London: R. Wellington; 1705.
16. Cloninger CR, Sigvardsson S, Von Knorring AL, Bohman M. An adoption study of somatoform disorders. II. Identification of two discrete somatoform disorders. Arch Gen Psychiatry. 1984;41:863–71.
17. Sigvardsson S, Von Knorring AL, Bohman M, Cloninger CR. An adoption study of somatoform disorders. I. The relationship of somatization to psychiatric disability. Arch Gen Psychiatry. 1984;41:853–9.
18. Marmot M, Allen J, Goldblatt P, Herd E, Morrison J. Build back fairer: the COVID-19 Marmot review—the pandemic, socioeconomic and health inequities in England. London: Institute of Health Equity; 2020.
19. Cloninger CR, Cloninger KM. Person-centered therapeutics. Int J Pers Cent Med. 2011;1:43–52.
20. Antonovsky A. Unravelling the mystery of health. San Francisco: Jossey-Bass; 1987.
21. Cloninger CR, Cloninger KM. People create health: effective health promotion is a creative process. Int J Pers Cent Med. 2013;3:114–22.
22. Stoyanov DS. New model of burn out syndrome: towards early diagnosis and prevention. Aalborg: River Publishers; 2014.
23. Weizsaecker VV. Social disease and social recovery (volume 8 of collected works, 1986). Suhrkamp: Frankfurt on Main; 1930.
24. Cloninger CR. Person-centered health promotion in chronic disease. Int J Pers Cent Med. 2013a;3:5–12.

25. Stoyanova K. Burn out, emotional intelligence and coping strategies in teachers (PhD dissertation), Blagoevgrad, Bulgaria, South West University; 2020.
26. Raycheva RD, Asenova RS, Kazakov DN, Yordanov SY, Tarnovska T, Stoyanov DS. The vulnerability to burn-out in healthcare personnel according to the Stoyanov-Cloninger model: evidence from a pilot study. Int J Pers Cent Med. 2012;2:552–63.
27. Stoyanov DS, Cloninger CR. Relation of people-centered public health and person-centered health care management: a case study to reduce burn-out. Int J Pers Cent Med. 2012;2:90–5.
28. Marmot M. Health in an unequal world: social circumstances, biology and disease. Clin Med. 2006;6:559–72.
29. Marmot MG, Bosma H, Hemingway H, Brunner E, Stansfeld S. Contribution of job control and other risk factors to social variations in coronary heart disease incidence. Lancet. 1997;350:235–9.
30. Wilkinson R, Pickett K. The spirit level: why greater equality makes societies stronger. New York: Bloombury Press; 2009.
31. Cloninger CR. What makes people healthy, happy, and fulfilled in the face of current world challenges? Mens Sana Monogr. 2013b;11:16–24.
32. Josefsson K, Jokela M, Cloninger CR, Hintsanen M, Salo J, Hintsa T, Pulkki-raback L, Keltikangas-jarvinen L. Maturity and change in personality: developmental trends of temperament and character in adulthood. Dev Psychopathol. 2013;25:713–27.
33. Chomsky N. Profit over people: neoliberalism and global order. New York: Seven Stories Press; 1999.
34. Garnham LM. Public health implications of 4 decades of neoliberal policy: a qualitative case study from post-industrial west central Scotland. J Public Health (Oxf). 2017;39:668–77.
35. Monbiot G. Neoliberalism—the ideology at the root of all our problems. *The Guardian*, April 15, 2016.
36. Ostry JD, Loungani P, Furceri D. Neoliberalism: oversold? Finan Dev. 2016;53:38–41.
37. Coates TN. The NFL's response to brain trauma: a brief history. *The Atlantic*. The Atlantic; 2013.
38. Hayasaki E. Amazon's great labor awakening: the future of work. *New York Times Magazine*. New York: New York Times; 2021.
39. Hill J. Naomi Osaka is part of a larger war within sports. *The Atlantic*. The Atlantic; 2021
40. Chemali Z, Ezzeddine FL, Gelaye B, Dossett ML, Salameh J, Bizri M, Dubale B, Fricchione G. Burnout among health care providers in the complex environment of the Middle East: a systematic review. BMC Public Health. 2019;19(1):1337. https://doi.org/10.1186/s12889-019-7713-1.
41. Rotenstein LS, Torre M, Ramos MA, Rosales RC, Guille C, Sen S, Mata DA. Prevalence of burnout among physicians: a systematic review. JAMA. 2018;320:1131–50.
42. Maslach C, Schanfeli WB, Leiter, MP. Job Burnout. Ann Rev Psychology. 2001;52:397–422.
43. Maslach C. Burn-out: the cost of caring. Englewood Cliffs, NJ: Prentice-Hall; 1982.
44. Maslach C, Leiter MP. The truth about burnout: how organizations cause personal stress and what to do about it. San Francisco: Jossey-Bass; 1997.
45. De Hert S. Burnout in healthcare workers: prevalence, impact and preventative strategies. Local Reg Anesth. 2020;13:171–83.
46. Shanafelt TD, Hasan O, Dyrbye LN, Sinsky C, Satele D, Sloan J, West CP. Changes in burnout and satisfaction with work-life balance in physicians and the general US working population between 2011 and 2014. Mayo Clin Proc. 2015;90:1600–13.
47. Monteiro GMC, Gabbard GO, Hauck S. Risk factors for burnout in physicians. Int J Pers Cent Med. 2019;9:27–43.
48. van Staden W, Appleyard J. Work-life balance and burn out crucially concern the work environment and relationships. Int J Pers Cent Med. 2019;9:1–4.
49. Eley DS, Cloninger CR, Walter L, Laurence C, Synnott R, Wilkinson D. The relationship between resilience and personality traits in doctors: implications for enhancing well-being. PeerJ. 2013;1:e216.

50. Sievert M, Zwir I, Cloninger KM, Lester N, Rozsa S, Cloninger CR. The influence of temperament and character profiles on specialty choice and well-being in medical residents. PeerJ. 2016;4:e2319.
51. Cloninger CR, Zohar AH. Personality and the perception of health and happiness. J Affect Disord. 2011;128:24–32.
52. Eley D, Young L, Przybeck TR. Exploring the temperament and character traits of rural and urban doctors. J Rural Health. 2009;25:43–9.
53. Stutzman K, Karpen RR, Naidoo P, Toevs SE, Weidner A, Baker E, Schmitz D. Support for rural practice: female physicians and the life-career interface. Rural Remote Health. 2020;20:5341.
54. Cloninger CR, Salvador-carulla L, Kirmayer LJ, Schwartz MA, Appleyard J, Goodwin N, Groves J, Hermans MHM, Mezzich JE, Van Staden CW, Rawaf S. A time for action on health inequities: foundations of the 2014 Geneva Declaration on person- and people-centered integrated health care for all. Int J Pers Cent Med. 2014;4:69–89.
55. Dewa CS, Jacobs P, Thanh NX, Loong D. An estimate of the cost of burnout on early retirement and reduction in hours of practicing physicians in Canada. BMC Health Serv Res. 2014a;14:254.
56. Dewa CS, Loong D, Bonato S, Thanh NX, Jacobs P. How does burnout affect physician productivity? A systematic literature review. BMC Health Serv Res. 2014b;14:325.
57. Dewa CS, Loong D, Bonato S, Trojanowski L. The relationship between physician burnout and quality of healthcare in terms of safety and acceptability: a systematic review. BMJ Open. 2017;7:1–16.
58. Shanafelt TD, Balch CM, Bechamps G, Russell T, Dyrbye L, Satele D, Collicott P, Novotny PJ, Sloan J, Freischlag, J. Burnout and medical errors among American Surgeons. Ann Surg. 2010;251:995–1000.
59. Summers RF. The elephant in the room: what burnout is and what it is not. Am J Psychiatry. 2020;177:898–9.
60. Collier R. Electronic health records contributing to physician burnout. CMAJ. 2017;189:E1405–6.
61. Hernandez D, Asa F. IBM's retreat from Watson highlights broader AI struggles in Health. Wall Street J. 2021;22:2021.
62. Stoyanova K. Interview with Professor C. Robert Cloninger. Psychol Thought. 2019;12. https://psyct.psychopen.eu/article/view/385/html.
63. Cloninger CR, Keady B, Lester N, Kedia S, Cloninger KM. Empirical measurement of Plato's model of the human psyche: validation by the neuroscience of personality. In: St. Stoyanov D, editor. Towards a new philosophy of mental health: Perspectives from neuroscience and the humanities. Newcastle upon Tyne: Cambridge Scholars Publishing; 2015.
64. Durant W. The Story of Philosophy. New York: Simon and Schuster; 1991.
65. Cloninger CR, Zohar AH, Hirschmann S, Dahan D. The psychological costs and benefits of being highly persistent: personality profiles distinguish mood disorders from anxiety disorders. J Affect Disord. 2012;136:758–66.
66. Gusnard DA, Ollinger JM, Shulman GL, Cloninger CR, Price JL, van Essen DC, Raichle ME. Persistence and brain circuitry. Proc Natl Acad Sci U S A. 2003;100:3479–84.
67. Sellman JD, Mulder RT, Sullivan PF, Joyce PR. Low persistence predicts relapse in alcohol dependence following treatment. J Stud Alcohol. 1997;58:257–63.
68. Cloninger CR, Svrakic DM, Przybeck TR. A psychobiological model of temperament and character. Arch Gen Psychiatry. 1993;50:975–90.
69. Grucza RA, Goldberg LR. The comparative validity of 11 modern personality inventories: predictions of behavioral acts, informant reports, and clinical indicators. J Pers Assess. 2007;89:167–87.
70. Cloninger CR, Cloninger KM. Person-centered psychotherapy. In: Mezzich JE, Botbol M, Christodolou GN, Cloninger CR, Salloum IM, editors. Person-centered Psychiatry. Cham: Springer; 2016.
71. Keady B. Intuitive Virtue in Plato, Augustine, and Gandhi. PhD Dissertation. Denver, University of Denver; 2011.

72. Baumeister RF, Bauer IM, Lloyd SA. Choice, free will, and religion. Psychol Relig Spiritual. 2010;2:67–82.
73. Baumeister RF, Tierney J. Willpower: rediscovering the greatest human strength. New York: Penguin; 2011.
74. Cloninger KM, Granjard A, Lester N, Lindskär E, Rosenberg P, Cloninger CR, Garcia D. A randomized controlled pilot study using mind-body interventions among refugees in Sweden. Int J Pers Cent Med. 2019;9:19–34.
75. Granjard A, Garcia D, Rosenberg P, Jacobsson C, Cloninger KM, Cloninger CR. Resilience personality profiles among Swedish long-term unemployeed. Psych J. 2021;10(4):670–3.
76. Inglehart RF. Changing values among Western publics from 1970 to 2006. West Eur Polit. 2008;31:130–46.
77. Inglehart RF. Cultural evolution: people's motivations are changing and reshaping the world. Cambridge: Cambridge University Press; 2018.
78. Ray PH, Anderson SR. The cultural creatives: how 50 million people are changing the world, Harmony. New York: Three Rivers Press; 2000.

Index

J. E. Mezzich et al. (eds.), *Person Centered Medicine*,
https://doi.org/10.1007/978-3-031-17650-0