International Perspectives on Social Policy, Administration, and Practice

Steven L. Arxer
John W. Murphy *Editors*

Community-Based Health Interventions in an Institutional Context

Springer

International Perspectives on Social Policy, Administration, and Practice

Series Editors

Sheying Chen
Pace University, New York, NY, USA

Jason L. Powell
Department of Social and Political Science, University of Chester, Chester, UK

The Springer series International Perspectives on Social Policy, Administration and Practice puts the spotlight on international and comparative studies of social policy, administration, and practice with an up-to-date assessment of their character and development. In particular, the series seeks to examine the underlying assumptions of the practice of helping professions, nonprofit organization and management, and public policy and how processes of both nation-state and globalization are affecting them. The series also includes specific country case studies, with valuable comparative analysis across Asian, African, Latin American, and Western welfare states. The series International Perspectives on Social Policy, Administration and Practice commissions approximately six books per year, focusing on international perspectives on social policy, administration, and practice, especially an East-West connection. It assembles an impressive set of researchers from diverse countries illuminating a rich, deep, and broad understanding of the implications of comparative accounts on international social policy, administration, and practice.

More information about this series at http://www.springer.com/series/7

Steven L. Arxer • John W. Murphy
Editors

Community-Based Health Interventions in an Institutional Context

Springer

Editors
Steven L. Arxer
Department of Sociology and Psychology
University of North Texas at Dallas
Dallas, TX, USA

John W. Murphy
Department of Sociology
University of Miami
Coral Gables, FL, USA

ISSN 2625-6975 ISSN 2625-6983 (electronic)
International Perspectives on Social Policy, Administration, and Practice
ISBN 978-3-030-24653-2 ISBN 978-3-030-24654-9 (eBook)
https://doi.org/10.1007/978-3-030-24654-9

© Springer Nature Switzerland AG 2019
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, express 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

Contributors

Steven L. Arxer is Associate Professor at the University of North Texas at Dallas in the Department of Sociology and Psychology. He has a PhD in sociology at the University of Florida. Arxer specializes in qualitative methods with a focus on minority populations, intersectionality, and gender. He is co-author of *Aging in a Second Language*.

Karen A. Callaghan earned a BA in sociology at La Salle University (Philadelphia) and MA and PhD in sociology at The Ohio State University. Callaghan's areas of interest include participatory community-based research, community organizing, and service-learning. Callaghan is currently Professor of Sociology and Dean, College of Arts & Sciences at Barry University, Miami Shores, Florida.

Jung Min Choi received his BA at UC Berkeley and finished his PhD at York University in Toronto, Canada. He is Associate Professor in the Department of Sociology at San Diego State University. He has published, all guided by anti-essentialist philosophies and community-based approaches, on critical pedagogy, race and racism, globalization and the bankruptcy of neoliberalism. He is currently President of The Dignified Learning Project, a nonprofit education-based organization in San Diego.

Kyaien O. Conner is Assistant Professor in the Department of Mental Health Law and Policy at the University of South Florida and a faculty affiliate of the Louis de la Parte Florida Mental Health Institute. She received her PhD, MSW, and MPH from the University of Pittsburgh and completed a postdoctoral fellowship in Geriatric Psychiatry at the Western Psychiatric Institute. Her research focuses on factors that influence disparities in mental health service utilization and treatment outcomes for African American older adults.

Ramsey Dahab holds various degrees in the Liberal Arts, including an MA in International Studies from Florida International University and a PhD in Sociology from the University of Miami. His areas of interest include nativism, global inequalities, and social theory—the incorporation/development of pedagogies that help to fulfill potential in the world.

Danielle Dukes is a third year medical student at Ohio University's Heritage College of Osteopathic Medicine. She has research interests in the social determinants of health, food insecurity, women's and infant health, and mental health issues. She obtained an MS in Biology and an MBA with a focus on Health Care Management, from Wright State University before matriculation into medical school.

Berkeley Franz is a medical sociologist whose research and teaching focus on health disparities, hospital–community relationships, and health policy. She is currently Assistant Professor of Community-based Health at Ohio University's Heritage College of Osteopathic Medicine, in Athens, Ohio. She received an MA in religious studies from the University of Chicago and a PhD in sociology from the University of Miami. Berkeley has worked both domestically and internationally on community-based research projects and has published extensively on the theory and development of community-based partnerships.

Dawn Graham serves as faculty in the Department of Social Medicine at Ohio University Heritage College of Osteopathic Medicine. She earned a Doctorate in Counseling Psychology from Purdue University in 2010 and Master of Arts in Applied Behavioral Science from Valparaiso University in 1999. Clinical experience includes work in the University of Chicago Hospitals, Michigan City Area Schools, Purdue University, Porter Starke Community Mental Health, and Logansport State Psychiatric Hospital. Previously, she served as the Principal Investigator on a multi-million dollar federal grant to promote maternal/child health in Southeastern Ohio with university and community partnerships in coordination with the Ohio Department of Health. She is a member of the American Psychological Association and previously acted as Chair of the Ohio Psychological Association Public Sector Issues committee. Graham has been involved in multiple studies involving the impact of compassion fatigue for health care professionals working with underserved patients. She conducts national and international talks on health, psychology, and research.

Charlene Holkenbrink-Monk received her MA in sociology from San Diego State University and is currently enrolled in a joint doctoral program (San Diego State University and Claremont). Her research interests include community-based education and critical pedagogy. Currently, she teaches at California State University, San Marcos, San Diego Mesa College, and San Diego City College.

Elaine Hsieh has been involved in research on bilingual health communication for over a decade. She has conducted ethnographic studies, in-depth interviews, focus groups, surveys, and multi-phase studies that examine the interactions between providers and patients who do not share the same language. The three aspects that she has investigated are: (a) the discrepancies between the beliefs and the practice of medical interpreters, (b) interpreters' influences on the quality of health care services, and (c) interpreters' mediation of conversational partners' identities and communicative goals. She also has received funding from the National Institutes of Health to further expand her Bilingual Health Communication model, exploring providers' expectations and needs for medical interpreters.

Lesli Johnson is Associate Professor. After a successful clinical career in mental health, Lesli joined Ohio University's Voinovich School of Leadership and Public Affairs in 1997 to lead the Planning, Evaluation, Education, and Research team, providing services to public and nonprofit organizations throughout the region and beyond. She has 20 years of experience working in community programs, including mental health, health, education, and child welfare. Dr. Johnson has been the lead evaluator on a number of state and federal efforts to improve health through community and integrated efforts. Areas of emphasis include promoting collaborative efforts, evaluating systems development, and engaging stakeholders in meaningful conversations and actions.

Eric Kramer has research interests that include mass media, international and intercultural communication. He is author of seven books including *Modern/Postmodern: Off the Beaten Path of Antimodernism*, *The Emerging Monoculture: Assimilation, and the "Model Minority"* and several journal articles and award winning papers. He has served on the review and editorial boards and has reviewed for several journals including *The Harvard International Journal of Press/Politics*, *The Journal of Communication*, *Communication Studies*, *The Journal of Applied Communication*, *The Journal of Intercultural Communication*, *Journal of International and Intercultural Communication*, *International Journal of Intercultural Relations*, *The Howard Journal of Communications*, and so forth.

Airín D. Martínez is Assistant Professor at the School of Public Health & Health Sciences at the University of Massachusetts—Amherst. Her research examines the sociopolitical and institutional arrangements that produce chronic disease disparities among Latinx immigrants and their US-born children. Her current research examines how the local implementation of immigration enforcement policies creates material deprivation and psychosocial stress among Latinx mixed-status families. She hopes her research can reverse policies excluding US immigrant populations and inform community-based prevention strategies.

Kathleen Moore is a research professor in the Department of Mental Health Law and Policy at the University of South Florida and Executive Director of the Louis de la Parte Florida Mental Health Institute. She received her MA and PhD in social/health psychology from Kent State University and completed a postdoctoral fellowship at Duke University Medical Center. For the past 20 years, she has worked on numerous community-based research projects with local addiction and mental health providers.

John W. Murphy has a PhD in sociology from Ohio State University. For the past 30 years he has been writing on and working in community-based projects in both the United States and several countries in Latin America. Most recently he worked on a health project on the Island of Grenada. Currently, he is Professor of Sociology at the University of Miami. Along with several of his colleagues, he is author of the book, *Narrative Medicine and Community-Based Health Care and Planning*.

Krista Mccarthy Noviski is a health coach and graduate student in the Department of Sociology and Anthropology at the University of Toledo in Toledo, Ohio. She received her BS in Pre-Medicine from Bowling Green State University in Bowling Green, Ohio and completed her health and wellness coach training through *Wellcoaches*. Her interests include social connection and health and the patient's experience of illness. Her current research is focused on empathy in medicine and the lived experience of teaching empathy to medical students.

Karie Jo Peralta is Assistant Professor in the Department of Sociology and Anthropology at the University of Toledo in Toledo, Ohio. She received her PhD from the University of Miami in Coral Gables, Florida. Her areas of interest are community-based research, third sector organizations, and applied sociology. Most recently, she worked in the Dominican Republic on a household survey of Haitian immigrant families and a growth assessment of their children.

Khary K. Rigg is Associate Professor in the Department of Mental Health Law and Policy at the University of South Florida and a faculty affiliate of the Louis de la Parte Florida Mental Health Institute. He received his PhD from the University of Miami and completed a postdoctoral fellowship in health services research from the University of Pennsylvania, Perelman School of Medicine. The overall goal of his research is to generate findings that improve the way drug prevention, treatment, and harm reduction interventions are developed and delivered.

Amanda Sharp is a PhD student in the College of Behavioral and Community Sciences at the University of South Florida. She received her BA from Humboldt State University and earned an MPH from Boston University. Her research focuses on how to make interventions more patient-centered through approaches such as motivational interviewing.

Kerri Shaw is the Social Work Field Director and the director of the Community Health Worker Training Program at Ohio University. She has been recognized as the 2014 Athens Foundation Woman of the Year for her work in the community, including the development of the Athens County Peanut Butter and Jelly Project. She earned both a bachelor's and master's degree in social work from Ohio University, is a Returned Peace Corps Volunteer, and is a fierce advocate and activist for women and children in Appalachia.

Daniel Skinner is Assistant Professor of Health Policy in the Department of Social Medicine at Ohio University, Heritage College of Osteopathic Medicine, on the Dublin, Ohio campus. He earned his PhD in political science from the City University of New York. The author of more than two dozen peer-reviewed academic articles in health policy, medical education, and political theory, Dr. Skinner is also co-editor of *Not Far from Me: Stories of Opioids and Ohio* (Ohio State University Press, 2019) and author of *Medical Necessity: Health Care Access and the Politics of Decision Making* (University of Minnesota Press, 2019).

Tashina J. Vavuris has a Master's in Sociology from San Diego State University where she explored educational inequities and community-based philosophy. Since then, she has been studying community-based practices and has collaborated in projects in Ecuador and Grenada centering on community health. Currently, she is a doctoral student at the University of California at Santa Cruz in the Environmental Studies Department, where she studies notions of sustainability, transformative pedagogical practices, and the process of community-based practices.

Chapter 1
Introduction

John W. Murphy

Community-based work is becoming quite popular nowadays. But since the passage of the Community Mental Health Act of 1963, health and other services were supposed to be attuned to the needs of communities (Lefkowitz, 2007). Local norms and definitions are important and should be consulted when planning interventions. This viewpoint was reinforced by the Alma-Alta conference in 1978 (Rifkin, 2009). As a result of this deliberation, local participation in service planning and delivery is deemed crucial for relevant and equitable health care.

Since Alma-Alta, two principles have come to characterize community-based projects (Murphy, 2014). The first is that local knowledge matters. The idea is that communities consist of reservoirs of knowledge that their members create and use as referents for judging health and illness, along with other elements of social life. Phenomenologists, for example, refer to these knowledge bases as "stocks of knowledge," while others refer to them as "worlds" (Schutz & Luckmann, 1973). In each case, the general theme is that persons define their situations, and that the accompanying values, beliefs, and commitments should guide the design, implementation, and evaluation of any program of action.

Community-based services should be built from the "ground-up" to enhance their relevance, due to the local nature of knowledge. To facilitate this strategy, the second principle of community-based work comes into play; that is, community members should control all projects. The goal of this change is to ensure that local customs and practices are not violated, and through their involvement communities are able to realize their skills and desires. Some critics refer to this outcome as empowerment (Geiger, 2016; Rappaport, 1984). But the practice is only logical: local persons understand the worlds that are operative and how they can be entered. Following this entrée, the assumption is that services or research will improve.

J. W. Murphy (✉)
Department of Sociology, University of Miami, Coral Gables, FL, USA
e-mail: j.murphy@miami.edu

© Springer Nature Switzerland AG 2019

S. L. Arxer, J. W. Murphy (eds.), *Community-Based Health Interventions in an Institutional Context*, International Perspectives on Social Policy, Administration, and Practice, https://doi.org/10.1007/978-3-030-24654-9_1

This shift in orientation represents a great advance. Not long ago local involvement was thought to be detrimental (Rifkin, 1996). After all, these persons are not professionals and thus lack essential skills. Recent research and practice, however, demonstrate that such claims are false. Local persons have exhibited skill levels thought to be beyond their station, and have been very helpful in dealing with health and related issues (Frank, 2010). Moreover, they have access to knowledge and social networks that are beyond the reach of outsiders, even those who are diligent and well-intentioned.

But a key element has been overlooked in those discussions of community-based work. Although community agency has been emphasized, the institutional framework of interventions has received scant attention. In other words, a key component has been ignored. That is, health and other interventions occur in institutional contexts that should receive attention. This conclusion is also consistent with the spirit of Alma-Alta. Despite this insight, the impact of community-based philosophy and practice on institutions is seldom mentioned. The purpose of this volume is to remedy this situation.

As might be suspected, emphasizing local participation changed the philosophy and configuration of service delivery. Practitioners, clients, and agencies, for example, are cast in a new light. Roles are changed and the usual organizational hierarchies are challenged. New sources of knowledge are exposed and consulted, while the nature of services and their delivery are rethought. For example, hospitals, research programs, training, and funding schemes are significantly altered. Nothing, in short, is unscathed by this shift to a community-based philosophy.

What Is an Institution?

Institutions have been conceived traditionally in realistic terms (Stark, 1963). Any organizations that have been institutionalized, therefore, have adhered to a particular formula designed to promote their legitimacy. Specifically, these organizations have been lifted above or removed from contingency. In other words, the illusion is created that they are divorced from partisan perspectives and thus provided with a unique, almost timeless status that reflects the common weal.

When portrayed in this way, institutions are bestowed with a “foundational” character (Fish, 1989). The point of this maneuver is to create a façade that can instill order and enlist loyalty. In fact, realists contend that order can be preserved only if institutions have a status superior to their inhabitants. As a result, these organizations appear to be normative and stable, beyond the political fray, and worthy of widespread recognition. Detached from any particular group or bias, institutions are presumed to have universal appeal.

To borrow from Herbert Marcuse, legitimate and lasting institutions have an “affirmative character” (Marcuse, 1969). Due to this status, they can impose durable customs and rules that stifle critique and thwart opposition. To make organizations seem substantial, and thus formidable, they are institutionalized through the use of structural imagery. Serious organizations, for example, have a chain of command, a system of roles and statuses, and communication channels that reflect a particular logic. Given these descriptives, threats to the prevailing order can be controlled relatively easily.

Organizations that are institutionalized in this way have so-called binding power (Funk, 1998). That is, they can restrict choices and establish a sense of cohesion. Behavioral parameters can thus be imposed with little resistance, because of the power and prestige attributed to these organizations. As described by Erich Fromm (2005), everyone is diminished by these institutions; their legitimacy is simply undeniable and overwhelming.

Basically, a state of asymmetry is established between these institutions and almost everyone else. Those with power, and cultural or economic supremacy, can claim some association with these organizations and related privileges. But the remainder of persons are expected to be intimidated and readily conform to institutional requirements. In this regard, institutionalized organizations are transformed effectively into idols (Sung, 1989). What this designation means, in this context, is that they are not necessarily worshiped but that their imperatives are uniformly followed and seldom questioned. Institutions speak with unrivaled authority.

Such organizations, according to Karl Marx, would be treated as alienating (Marx, 1973). In other words, they have assumed a timeless and adversarial character that is unwarranted. Nonetheless, most persons are enthralled and dominated by their creations. The obvious question, however, is how does this distortion occur? How are persons led to believe that the products of their labor should control their lives? At this juncture, the simple answer is that through a subtle philosophy, institutions are granted the illusion of autonomy.

Institutionalization and Dualism

At first glance, community-based work appears to be mostly a practical undertaking. Organizing an intervention, indeed, demands that attention be directed to solving various technical problems. Likewise, learning to navigate institutions requires pragmatic awareness, a tolerance of tedium, and a willingness to compromise. Philosophy seldom comes to mind when considering these issues.

Nonetheless, at the core of institutionalization is a philosophical theme that is problematic. How do institutions achieve the appearance of autonomy? The answer to this question rests on Cartesianism, or dualism (Bordo, 1987; Leder, 1992). As noted earlier, once an organization is institutionalized, a specific arrangement of roles, jobs, and norms is superior to other forms of human organization. Put differently, people and their associations that stand outside of institutions are contingent and lack the presumed stability and obligations intrinsic to institutions. Cartesian philosophy enters at this point, as institutions are understood to be severed from their creators, given their unique structural status.

Cartesianism encourages the separation of subjectivity from objectivity. The rationale behind this separation is that subjectivity, based on interpretation, represents an unreliable source of knowledge. Through scientific methodology, for example, subjectivity can be overcome, thereby bringing objectivity into view. In this Cartesian picture, not only is subjectivity problematic, this source of information must be overcome for truth to be encountered.

Dualism allows particular information, or processes, to be severed from basic human expressions, such as choices, values, or interpretations. An organization that is institutionalized, accordingly, can be treated as autonomous, as if human agency is ancillary to the rules or hierarchies that are enforced. Through dualism, however, these organizations can become impediments to the ambitions of individuals or communities. In the language of sociologist Emile Durkheim (1983), institutions come to be viewed as existing "sui generis" and capable of providing constraints.

As should be noted, this version of institutionalization is antagonistic to community-based work. When predicated on realism, institutions are regularly insensitive to local demands, while community initiative is treated as a threat. When institutions are viewed as autonomous, local history and participation pose challenges to the *status quo* and are dismissed as uninformed distractions (MacDonald, 2016). Sound policy reflects institutional standards that are objective and rational, thereby minimizing community input. Community control, of course, is not part of the agenda.

But because community-based projects emphasize participation, particularly local knowledge and control, Cartesianism is revealed to be untenable. Neither knowledge nor organizations are autonomous because the standard location of these abstractions no longer exists. In community-based philosophy, dualism is undermined by the insight that individuals and communities create worlds of knowledge and that these domains can never be objective or timeless in the Cartesian sense. In short, their significance is always situated.

Institutions, therefore, must be approached differently in community-based work than in the past. Rather than autonomous, they should be viewed as narratives that simply inscribe a perspective on valid knowledge, order, and how health or any other issues should be conceptualized and addressed (Polkinghorne, 1988). As narratives, the Cartesian influence on institutionalization is rendered passé. Nonetheless, institutionalization and the related organizations do not vanish, but instead must be approached in a manner compatible with the anti-dualism prescribed by local participation.

Institutions and Community-Based Work

Community-based work subverts dualism by placing participation, or human agency, at the center of knowledge production and institutional life. As a result, organizations and their supports are removed from the pedestal reserved traditionally for institutions. In the absence of their usual autonomous status, institutions are not prescriptions but possibilities linked to local practices. As some social philosophers might say, institutions are now local constructions (Gergen, 2009).

In the previous section, institutions were compared to narratives that serve to illustrate how social life might be ordered. Clearly, community-based work should thrive in this environment, since institutional control is transferred to local actors. But this recommendation depends on a particular thesis on language gaining recognition.

In terms of Cartesianism, language is envisioned to be a tool, particularly a pointer. The function of language, accordingly, is to highlight objects in the world, most notably their differences. Consistent with dualism, language does nothing but illustrate the traits of natural referents. The role of narratives, in this philosophy, is to describe the world in the most accurate way possible.

In a non-dualistic framework, on the other hand, language is not mimetic but creative. As Roland Barthes says, there is nothing outside of language that may emerge as objective (Barthes, 1977). There is no other option but to treat reality as a linguistic convention. Given the murkiness of language, narratives strive to bring clarity out of possible interpretations. Institutions, accordingly, stabilize a particular interpretation until further notice. Consequently, institutions are no longer ominous but subject to local control and (re)interpretation. The legacy of an organization, therefore, does not have to weigh heavily on an individual or community, but can be reinvented to meet local definitions and needs.

A hospital, neighborhood, clinic, or training center, for example, is expected to have a new identity and different relationship with clients. None of these institutions should be intrusive and obscure the worlds present in a community, but emerge from local interaction. Without support from dualism, organizations can return to being local constructions or stories, generated through discourse, that tell how a community defines health, the appropriate delivery of services, and acceptable outcomes (Charon, 2006). Such institutions are not obstacles but facilitate health care.

Organization of Book

This book examines as its central issue the impact that a community-based philosophy has on institutions and the institutionalization of community health delivery. Chapters in this volume explore how institutional arrangements can be rethought in ways conducive of a community-based approach. The volume considers how community partnerships, funding schemes, curriculum for health workers, the status of patients and clients, and community research programs, among other organizational features, are framed and designed from a community-based philosophy.

Chapter 2 addresses the broad question of what is a community-based organization. Here John W. Murphy explains how the focus of community-based work is local knowledge and community control of health projects. To deliver services in accordance with these principles, community-based organizations must be instituted. What these organizations require, separate from the past, is a different management style and unique division of labor. Most organizations that are employed to provide health services in a community-based manner, however, have a traditional structure, and thus have difficulty fulfilling their aims. A new organization must be created that is consistent with the philosophy that underpins community-based work. Such an organization, for example, would be less hierarchical and not focused on a specific division of labor as in the past.

In Chap. 3, Karen A. Callaghan discusses how community-based partnerships are established within a new institutional framework. Community-based health services are not provided by stand-alone organizations. Simply put, a network of providers must be available. Accordingly, a variety of organizations must enter into partnerships. This arrangement is not necessarily novel, but traditionally these associations have been fraught with conflicts and struggles for power, thus undermining their effectiveness. Community-based partnerships, on the other hand, must be predicated on dialogue and mutual respect. Instead of fighting for dominance in a community, these new organizations must be integrated around the plans established by communities. A new way of conceptualizing and carrying out this process must be established.

Jung Min Choi, John W. Murphy, Ramsey Dahab, and Charlene Holkenbrink-Monk, in Chap. 4, explore the issue of funding and budgeting. Often funds are directed to community organizations in ways that are either irrelevant or difficult to use. Additionally, budgets are formulated by agencies that are disconnected from the communities where services are needed. Community-based funding and budgeting, accordingly, are beginning to receive serious attention. Communities, accordingly, are given the latitude in some cases to establish budgets and spending strategies, along with identifying and pursuing sources of funds that are consistent ethically with these priorities and desires. Community-based funding and budgeting, in this way, are vital to supporting interventions in a community-sensitive manner.

Clearly, research plays a key role in community-based health work. Understanding the health needs of a community is vital to the success of any health-care project. From an organizational perspective, however, the focus of a research program is often methodological. That is, developing scientifically sound data collection instruments is often the focus. However, such an emphasis leaves little room for appreciating how knowledge is socially produced and legitimized. Moreover, an overemphasis on methodological concerns can diminish the ability of researchers to appreciate the underlying assumptions of a community's worldview and frustrate their entrance to that world. Chapter 5, by Steven L. Arxer, examines the philosophical and practical considerations of implementing a research program in health projects that preserves the knowledge production of community members.

Chapter 6 focuses on the training of community-based health workers from a participatory organizational perspective. Tashina Vavuris argues that health practitioners receive a significant amount of training before and after they enter the field. But often, this education is mostly pragmatic, that is, focused on how to conduct needs assessments, evaluate interventions, or implement accreditation standards. Of course, these tasks are important. But this education does not necessarily begin with the philosophy that sustains community-based work. When beginning with the principle that community knowledge matters, training must be initiated on how to enter the world constructed by a community's members. Every task, accordingly, must be thought of as a mode of engaging a community, instead of simply gathering data or making observations. Valid knowledge, communities, and norms, for example, must be rethought in the training process to produce persons who can work effectively in community-based interventions. This shift in orientation is not often the centerpiece of training.

Chapter 7 continues the discussion regarding health worker training, with Dawn Graham, Kerri A Shaw, and Leslie Johnson outlining key dimensions of developing a community-based curriculum for health worker training. The previous chapter explored the use of community-based health workers in interventions and the importance of integrating local experts into planning. In this chapter, they share the experience of developing a training curriculum for the State of Ohio. Given new rules regarding certification in different areas of the United States and internationally, developing a curriculum that can be approved and disseminated is of increasing importance. In these programs, significant institutional support is needed to develop curricula and train additional trainers, so that training can be shared with communities interested in integrating community health workers into their programming. The goal of this chapter is to present the challenges faced in creating a certified training curriculum and the potential for future curriculum development efforts.

Non-profit hospitals have the potential to be strong partners in community-based projects. Since the Affordable Care Act was passed in 2010, hospitals have new requirements to engage communities in identifying health needs and developing new community health programs. In Chap. 8, by Berkeley Franz, Daniel Skinner, and Danielle Dukes, a case study approach is used to explore how hospitals are developing new partnerships and the challenges they face in fostering relationships with the communities where they are located. Potential strategies will be suggested for improving communication between hospital employees and community members in the planning of community-based projects.

Karie Jo Peralta and Krista McCarthy Noviski investigate the political dimension of community-based organizations in Chap. 9. A central way institutions gain legitimacy and the ability to guide human behavior is through claims of value-neutrality and objectivity. Institutions are often thought to be bureaucratic and based on formal rules that facilitate decision-making in any sphere of life. In the case of health organizations, the language of science, technology, and standardization guide how community needs and the authority of health practitioners are understood. In this context, health professionals attain their unique status vis-à-vis patients and community members. But this dichotomy can contradict the aims of community-based health interventions. In particular, health organizations become the center of health assessments, while medical professionals attain greater power to direct health initiatives as opposed to patients. Nonetheless, community health workers, for example, require respect and legitimacy. In this chapter, the political dimension of community-based health organization is discussed, along with the challenges this model presents to conventional depictions of health institutions.

Chapter 10, by Khary K. Rigg, Amanda Sharp, Kyaien O. Conner, and Kathleen A. Moore, examines how the patient-provider relationship has evolved over the years. Patients are now thought to play a central role in the provision of treatment, especially within the context of community-based interventions. In both theory and practice, the role of the patient is supposed to differ from traditional biomedical approaches to treatment with patient input introducing a new level of transparency and relevance into service provision. Specifically, patients are to play an increasingly active role in health-care delivery and their backgrounds treated as central in any intervention. In short, a new form of participation between patient and provider is key to interventions that claim to be patient-centered and community-based. The current health-care system, however, does not promote such participation and obstacles to involving patients in their own care exist. The chapter traces the history of the patient-provider relationship and discusses the recent shift toward elevating the importance of persons receiving care. The authors also discuss obstacles to genuinely involving patients in their own treatment and make recommendations for how these barriers can be overcome. They conclude by discussing promising strategies for meaningfully involving patients in treatment, as well as how the role of patients in community-based care might be re-thought.

In Chap. 11, Elaine Hsieh and Eric Kramer focus on the health-care system, specifically highlighting the nature of debates about universal care. Of importance to the authors is not the arguments launched themselves but rather how polemics are being used to rationalize particular visions of health care. How communities are presented and imagined in relation to their work status, for example, is a central way in which arguments related to universal health care are forged and barriers erected. Hsieh and Kramer contend that a deeper examination of the philosophy behind current work-eligibility arguments to health care can promote dialogue on this hotly debated issue.

Airín D. Martínez continues the discussion regarding universal health care in Chap. 12. The focus is how a community-based health-care institution reimagines the basic operation of health care. Because a community-based model understands knowledge to be locally produced, the basic operations of identifying and exploring health needs changes, as well as the ways in which treatment is approached. Specifically, patients and communities do not internalize the directives of professionals, but rather collectively legitimize health initiatives and direct the process of community healing. Simply put, an entirely new model is proposed for identifying illness, formulating interventions, defining health, and evaluating outcomes.

The final chapter emphasizes the need for a re-evaluation of institutionalized health care. Drawing from the chapters described above, the benefits of institutionalizing community-based health projects is illustrated. To the extent that community-based efforts are described as substantially different from conventional health practices, health institutions must be conceptualized and operationalized anew to preserve the intentions of communities. Furthermore, an entirely new ethic of health care must be promoted. In short, a careful examination of how community-based projects can be institutionalized has the prospect for advancing effective strategies for community health planning.

Conclusion

The paradigm that has been operative in health care is changing (Foss, 2012). Persons and communities that were once marginal to this process are moving to the center. To paraphrase supporters of this move, local persons are becoming the experts (Kretzman & McKnight, 1993). But an overlooked facet of this process are the institutions where services are delivered. For this shift to be complete, these organizations must respond in a manner that is consistent with a community-based philosophy on research and treatment interventions.

Institutions can be resistant to change, however, when they are perceived to be autonomous. When conceived in this manner, these organizations are intimidating and may contravene local efforts to make health projects relevant and effective. But in the realist context, this obstinance is considered to be an asset for preserving tradition and order.

This autonomy, however, is sustained by a philosophy that is called into question by community-based work. Deprived of support from dualism, institutions are contingent, malleable, and adaptable to local worlds. In other words, these organizations can be treated as local inventions that serve persons and their communities. Researchers and health practitioners, accordingly, are no longer trapped by intractable institutional goals and practices. An open horizon of choices is thus presented to those who engage in community-based work. Therefore, in addition to dealing with human agency, community-based researchers and practitioners should focus on institutional factors that influence local participation.

With this new outlook on institutions, how will health projects be affected? How are typical organizational practices challenged? The aim of this volume is to provide some answers to these questions. In this way, another step can be taken to bringing community-based health care to fruition. The health-care system can thus be better grounded in the communities that are supposed to be served.

References

Barthes, R. (1977). *Image, music, text*. New York: Hill and Wang.

Bordo, S. (1987). *The flight of objectivity*. Albany, NY: SUNY Press.

Charon, R. (2006). *Narrative medicine: Honoring the stories of illness*. Oxford, UK: Oxford University Press.

Durkheim, E. (1983). *Pragmatism and sociology*. Cambridge, UK: Cambridge University Press.

Fish, S. (1989). *Doing what comes naturally*. Durham, UK: Duke University Press.

Foss, L. (2012). *The end of modern medicine: Biomedical science under the microscope*. Albany, NY: SUNY Press.

Frank, A. W. (2010). *Letting stories breathe*. Chicago: University of Chicago Press.

Fromm, E. (2005). *On being human*. New York: Continuum.

Funk, R. (1998). Erich Fromm's concept of social character. *Social Thought and Research, 21*(1–2), 215–229.

Geiger, H. J. (2016). The first community health center in Mississippi: Communities empowering themselves. *American Journal of Public Health, 106*(101), 1738–1740.

Gergen, K. J. (2009). *An introduction to social construction*. New York: Sage.

Kretzman, J., & McKnight, J. (1993). *Building communities from the inside out*. Chicago: Acta Publications.

Leder, D. (1992). *The body in medical thought and practice*. Dordrecht, Netherlands: Kluwer.

Lefkowitz, B. (2007). *Community health centers: A movement and the people who made it happen*. New Brunswick, NJ: Rutgers University Press.

MacDonald, J. J. (2016). *Primary health care*. Oxford, UK: Earthscan.

Marcuse, H. (1969). *Negations*. Boston: Beacon Press.

Marx, K. (1973). *The economic and philosophical manuscripts of 1844*. New York: International Publishers.

Murphy, J. W. (2014). *Community-based interventions: Philosophy and action*. New York: Springer.

Polkinghorne, D. E. (1988). *Narrative knowing and human sciences*. Albany, NY: SUNY Press.

Rappaport, J. (1984). Studies in empowerment: Introduction to the issue. *Prevention in Human Services, 3*(2), 1–7.

Rifkin, S. B. (2009). Lessons from community participation in health programmes: A review of the post- Alma-Ata experience. *International Health, 1*(1), 31–36.

Rifkin, S. B. (1996). Paradigms lost: Towards a new understanding of community participation in health programs. *Acta Tropica, 61*(2), 79–92.

Schutz, A., & Luckmann, T. (1973). *The structures of the life-world*. Evanston, IL: Northwestern University Press.

Stark, W. (1963). *The fundamental forms of social thought*. New York: Fordham University Press.

Sung, J. M. (1989). *La idolatría del capital y la muerte de los pobres [The idolatry of capital and the death of the poor]*. San José, Costa Rica: DEI.

Chapter 2
A Community-Based Organization

John W. Murphy

Introduction

Becoming community-based is not easy, although this idea has become quite de rigueur nowadays (Murphy, 2014). But most often, this maneuver is treated as logistical. Service agencies, for example, are placed in communities, while local persons are selected to sit on their governing boards. Although these steps are important, they deal mostly with technical matters. The aim of these and similar tactics is to bring services and any accompanying research closer to communities. Nonetheless, these changes overlook a significant factor in the process of becoming community-based.

There is no doubt that this shift in orientation requires that very pragmatic issues be addressed. Along with referral links, supervision, and treatment options, the location of a service center is important and should not be brushed aside. But with this focus on practical matters, the philosophy behind community-based work is regularly downplayed or missed. However, knowledge of this philosophy, and how to implement the related ideas, is crucial to successfully making this change.

The principle at the core of community-based interventions is participation (Fals Borda, 1988). The basic idea is that all persons create their respective realities in concert with others; no-one is an atom that acts alone. Broadly speaking, community-based philosophy is an off-shoot of constructionism (Gergen, 1999). Social facts and norms, accordingly, are not viewed to be objective but framed by communities in one way or another. The result is that communities consist of interpretive worlds that must be entered, if service or research is to have relevance (Gadamer, 1996). Local knowledge and control, therefore, are the cornerstones of community-based practice.

J. W. Murphy (✉)
Department of Sociology, University of Miami, Coral Gables, FL, USA
e-mail: j.murphy@miami.edu

© Springer Nature Switzerland AG 2019

S. L. Arxer, J. W. Murphy (eds.), *Community-Based Health Interventions in an Institutional Context*, International Perspectives on Social Policy, Administration, and Practice, https://doi.org/10.1007/978-3-030-24654-9_2

In philosophical terms, community-based work is anti-Cartesian, or non-dualistic (Bordo, 1987). Traditional planning, on the other hand, is dualistic, with a differentiation made regularly between subjectivity and objectivity. But within this typology, emphasis is placed on objectivity, since subjectivity is considered to be an unreliable source of information. The desire to enact "evidence-based" medicine is an example of this trend (Howick, 2011). The use of rigorous methodology, for example, is presumed to promote appropriate service delivery through the discovery of data divorced from the errors introduced by interpretation. Given this bias, communities participate minimally in planning activities, since they are situated and biased.

The elevation of local knowledge in importance reflects this anti-dualistic stance. Consistent with the outlook that persons are constructing knowledge, including so-called medical facts, the resulting body of information should guide all clinical interventions and research. In this sense, local knowledge matters, along with local control of any community project. With persons actively shaping their communities, and thereby specifying preferences and promoting select perspectives, these changes are entirely logical.

What is important is that community-based projects or interventions begin with an epistemological shift. Accordingly, the status of knowledge should be reviewed, along with the identity of evidence. Discussions should be initiated about local knowledge and how this information should be used, and why local guidance is imperative. For the most part, however, service planning and delivery does not begin in this manner. In short, philosophy does not play a foundational role.

This new philosophy, nonetheless, has not been applied to an important area, that is, the development of organizations that are expected to deliver health care and other services in a community-based manner (Lune, 2010). Most important to remember at this juncture, considering anti-dualism, is that communities should no longer be treated merely as places. Health-care facilities, additionally, should not be viewed as anchors that hold these locations together. This imagery obscures the existential or constructionist character of these organizations and their surroundings.

Contradicting a standard portrayal, a community-based organization is not a linchpin in communities that disseminates health services. What is omitted from this depiction is the participation that creates both organizations and communities, and in the end joins them together. A perspective on organizations must be unveiled that is compatible with this thesis, or health facilities will not become community-based. To use a pertinent term proposed by Philip Selznick (1948) some time ago, a community-based organization must have a proper "character." Specifically, a move must be made away from the realism that sustains the traditional rendition of organizations and toward a position that values human agency.

Realism Is Problematic

In the traditional description, organizations are expected to bring about stability and order. To accomplish this aim, they are provided with a unique status in the context of realism. Predicated on dualism, organizations are assumed to be autonomous;

they are touted to represent closed systems (Scott, 2002). With this stature, they are divorced from daily contingencies and can impose control. The survival of social order, in fact, depends on the lasting impact of this institutional effect.

A façade must be provided, in other words, that creates the illusion of organizational invulnerability. To have gravitas, organizations must appear to be substantial and transcend the uncertainties of everyday life. Rules, for example, must have universal legitimacy and should not favor a particular group or seem to be applied willy-nilly. Order will falter unless a sense of universality is cultivated and unbiased authority is maintained.

So, how is this image created? Usually, organizations are described by using structural metaphors (Perrow, 1979). In this way, their functioning and lines of authority are reinforced. A quick glance at an organizational chart in most healthcare facilities reveals the logic and chain of command that is operative. Most often, this imagery is hierarchical, with precise paths of interaction specified between departments. With such a depiction, the message is conveyed clearly that such an organization has a purpose and operates according to reliable principles.

Following such a realistic portrayal, persons are expected to adjust to organizational requirements (Fromm, 1959). Certain parameters are illustrated that should not be violated. For example, an organization is accorded fixed boundaries, an exact division of labor, and purposeful norms. Accordingly, all those who enter should know their place, the tasks they are supposed to perform, and the network of authority. These expectations are thus clear, without ambiguity, so that an organization operates smoothly.

Obviously, discipline can be enforced with this strategy, but other problems begin to arise. The desired autonomy, for example, begins to separate organizations from their communities. Specifically, organizational identity is sustained by focusing on their unique traits and capacities. In the case of health care, these organizations are thought to have specific functions that preserve a community. What they are expected to accomplish should not be confounded by the intrusion of demands associated with other organizations. Blurred boundaries can only cause problems—the meaning of health care cannot be institutionalized effectively if contested. The equilibrium of a community would be disrupted by such a mistake.

This realism also has impact on the internal operation of an organization (Burrell & Morgan, 1979). Due to the rigid division of labor, jobs are narrowly designed, while the range of persons who can perform specific roles is restricted. The result is the gradual professionalization of care delivery, with an accompanying hierarchy of knowledge (Freidson, 1970). As might be expected, emphasis is placed on professional medical education and the associated knowledge base.

As long as organizations are conceptualized in these ways, they will never become community-based. Indeed, their identities are secured by remaining autonomous. Becoming thoroughly integrated into a community would only cause confusion brought about by conflicting interpretations and demands. When couched in realism, a reliable organization must rise above this cacophony. For example, even choosing the name of a hospital may be problematic, with respect to identifying who is welcome and the tasks performed (Wu, 2011). A fuzzy identity is not helpful.

A proper sense of autonomy must be promoted to guarantee that a clear label or brand is presented.

The division of labor that is usually prescribed, however, militates against any significant change. The professionalization of most tasks means that local knowledge tends to be sidelined, along with the participation of everyday persons in meaningful ways in health-care organizations. So-called laypersons are thus consigned to the periphery of service delivery and, most likely, merely asked periodically for input that has little impact.

The standard realism must be abandoned before health-care organizations can become close to a community. New imagery is necessary that is less imposing and exclusionary. Organizational integrity must be preserved, but while incorporating local knowledge and control. In other words, a mode of organization must be proposed that is reliable, in the absence of the typical institutional effect brought about by realism.

Realism Is Not Needed

The general aim in community-based work is to make an organization concrete—accessible and reliable—without reification. Important to remember is that a community is not a place but comprised of various interpretive worlds (Dussel, 2008). Consistent with the principle of participation, a community should not be viewed as an object. What this discovery means is that a community must be engaged but not merely through contact with an organization. But rather, a form of entanglement must be achieved that is not possible with objects.

New imagery is needed that defies the bounded and structural character of traditional organizations. The purpose, however, is not to deconstruct organizations and transform them into an array of periodically interlocked activities. Although Karl Weick's (1976) position on sense-making, and loose-coupling, at first glance looks to be compatible with a community-based philosophy, such a conclusion would be premature. Simply calling for flexibility is not enough. Instead, and truly significant, persons must be able to construct and preserve an organization through their agency. Through their participation, they must be able to create an organization that has longevity and embodies the goals of a community.

As should be noted, dualism is overcome in a community-based model. There are no insiders or outsiders, but only those who unite, as an organization, to promote health care. Any job design that results, for example, is an outgrowth of the interaction that takes place during this process. The resulting organization is not merely loosely coupled but real and demanding, but only because of the agreements of the participants. In this regard, some critics argue that such organizations are held together by trust (Luhmann, 2017). But the glue that is present is not this vague. What unites these organizations is the solidarity that is engendered through the day-to-day activities of solving problems and achieving goals. In this portrayal, an organization is self-created.

Rosabeth Moss Kanter (1983), for example, was once on the verge of proposing this perspective on organizations. In the so-called matrix organization, persons are allegedly capable of writing their own jobs, while authority is dispersed. With this proposal, she wanted to unleash the entrepreneurial spirit of persons. Viewing the members of organizations as entrepreneurs was common during the 1980s, when she advanced this imagery.

But life in the matrix was never this creative. Those who proposed self-managed organizations, on the other hand, certainly had this outlook in mind (Rothschild & Whitt, 1986). In effect, a community-based model borrows from this orientation, whereby average persons are given the latitude to invent and control organizations. From this perspective, their exclusion in the past was not due to a lack of desire or talent but prejudices based on political and other reasons.

There are no organizational *a prioris* in a community-based strategy. The focus is on skill development and the dissemination of information, so that an organization never becomes autonomous and issues demands. Adaptation should thus be eclipsed by invention and self-direction, as an organization is dissolved into a community. True community-based organizations are not simply flexible but a product of their member's desires and actions. Rather than obtrusive, such organizations disappear into a community.

In reality, community-based organizations represent not only a change in the image of an organization but the nature of social relationships. Much more is advanced, in other words, than technical changes. In some ways, these new organizations embody a cultural revolution, a novel and shared vision of valid personal behavior, acting together, and creating knowledge and order.

A Few Practical Concerns

Traditional organizations are semi-permeable, with limited access granted to communities. Community-based organizations, on the other hand, are much more than permeable, although local access is greatly increased. And while access is important, a self-managed organization does more and encourages the exercise of a community's agency (Rothschild & Whitt, 1986). But going beyond access, the point is to promote total transparency through local control.

A community-based organization invites more than input; in fact, the term "invite" conveys the wrong impression. In this new framework, an organization is not autonomous, and thus does not generate opportunities for their members. There is no distance between persons and organizations that can lead to conflict with and, possibly, the oppression of their constituents. Rather, this form of organization spreads out laterally like a field (Bourdieu, 1990). There is no separation created by autonomy that is necessary for alienation to occur.

What happens, instead, is that a community-based organization is built from the ground-up, possibly beginning with a local health committee. This base establishes the framework, for example, to identify needs, the required services, and the general policies to be enacted. The delivery of services, simply put, is established from below. In many respects, the aim is to overcome the influence of the so-called "medical emperors" that have dominated service delivery and give more responsibility to those, in the past, who were merely the recipients of services (Cueto, 2004).

At this juncture, readers may begin to think of stakeholder participation (Stufflebeam, 2001). But community-based participants are different from stakeholders. Stakeholders, for example, are much more generic and, most likely, have little to do with the daily affairs of a community, or any organization that is established. Furthermore, their interests are often very personal, even idiosyncratic, and contravene the common good of a community. Community-based participants are neither strategic political appointments nor interested in receiving notice or praise. These persons work for the community and are attuned to the realities that are at play. In organizational parlance, they are mission driven.

Because of this involvement, a community-based organization is never finalized. The guidance provided by a community is ongoing and not restricted, as is often the case, to the beginning of a project or intermittent consultations with stakeholders. A constant flow of advice is underway, thereby preventing services from drifting away from a community.

Community-based organizations, accordingly, are a lot less professionally oriented than is usually the case. In short, these organizations are guided completely by local personnel. The awareness is promoted that local persons have valuable insights into their problems and the types of services that are appropriate. In other words, local knowledge is at the core of these organizations.

For some time, the attempt has been underway to employ in health agencies the members of the communities that are served (Lefkowitz, 2007). In this way, both patients and practitioners would share some history, thus making service delivery more palatable. But because the traditional conception of the organization was not seriously challenged, professionals often remained in control of interventions. Real effort had to be made to include laypersons (Ward Jr. & Geiger, 2017). But in most cases, a strategic plan was inaugurated to search for local professionals who had the requisite credentials, or to get local persons professionally trained. As a result, services may have been dispensed by local persons, but neighborhood control was seriously compromised.

At the outset of a project, however, professionals may be helpful. The point is not to disparage their skills, but to put them in the hands of local persons (Geiger, 2016). The plan, accordingly, should be to expand the knowledge base of a community, without overshowing local insights. And once locals are exposed to this new knowledge, they can decide how much of this information is relevant, the modifications that should be made, and how quickly implementation should proceed. A community-based strategy does not introduce information and cajole community members into accepting certain ideas and goals, but rather inaugurates a discussion that can advance in any number of directions.

Knowledge, in this sense, is not in the possession of any one group. A knowledge base is simply expanded, so that the most locally relevant decisions can be made. The problem is that such growth, often called capacity building, is undertaken regularly in a paternalistic manner (Kretzman & McKnight, 1993). That is, processionals descend on a project with a plan that they tout to be progressive and necessary for a problem to be successfully solved. Therefore, adoption is thought to be logical and thus almost foreordained, and any reluctance exhibited by a community is treated as irrational.

Evidence is mounting, in fact, that local persons can carry out many procedures that were formally restricted to the bailiwick of professionals (Behforouz, Farmer, & Mukherjee, 2004; Rifkin, 2009). Many of these activities are quite complex and require training that locals can master. In many ways, local persons are demonstrating abilities, and gaining expertise, that were thought to be beyond their range. But before this knowledge expansion can have significance in communities, a change in orientation must take place. Learning must be the focus of interventions, rather than looking to the usual, professional sources of knowledge. Many biases must be overcome pertaining to who has important knowledge and is capable of entertaining new or complex ideas and mastering new skills.

The resulting organization is non-hierarchical or, in managerial terms, flat (Lune, 2010). But a flat organization is not necessarily community-based; indeed, in managerial circles, flat organizations have been around for time. Typically, the designation flat simply signals that few status distinctions are made, although control of an organization may still remain in a few hands. Local control, accordingly, is not given serious consideration.

Community-based organizations are considered to be flat because jobs are invented, rotated, and leadership is situational (Murphy, 2014). Skills are learned as persons change jobs and encounter new situations. Hence, a loose division of labor is present. As a result of this practice, the knowledge base of everyone is enhanced.

At this juncture, “task shifting” may come to mind (Campbell & Kerry, 2011). This term is used regularly when discussing the dispersion of knowledge in community-based projects. Similar to job rotation, tasks that were monopolized by medical personnel are shifted to others. But in a community-based organization, tasks are shifted to unskilled persons. An entirely new theory of work is adopted, whereby locals are treated as experts, intensely trained, and encouraged to direct an intervention (Greenhalgh, 2009).

For many persons, however, the origin of their jobs remains a mystery. When they enter an organization, a structure already exists and their job assignments are prescribed. A weighty imagery and practice are present that stifles agency. Contrary to this condition, in a self-managed organization jobs are defined by the collectively negotiated goals and put into practice through the interaction that takes place. For this reason, these organizations are described as invented.

Additionally, in community-based organizations, different persons are expected to step in when leadership is needed. Rather than assume that leaders are born, or emerge from one social class of persons, the point is emphasized that leadership rests on expertise and interest. Therefore, one person may lead in a particular situation and another during a different task. In the end, however, skills are disseminated and support offered to the extent that leadership is no longer monopolized.

But especially noteworthy is that local persons write their jobs. In other words, they establish the division of labor. As mentioned earlier, Kanter (1983) broached this idea. This ability, however, is what makes an organization self-managed, a twist that Kanter never took seriously. In a self-managed scenario, a narrative is proposed that specifies the tasks, logic of production or performance, and the mode of evaluation, not to mention the style of authority. This entire process of organizing, therefore, is a collective invention.

As should be noted, the operation of a community-based organization is thoroughly dispersed. But tasks are not merely assigned to persons who were earlier on the periphery. When this is the case, dissemination likely has little to do with local invention and control. Authority may remain hierarchical and impose tasks. True dispersion, in line with a community-based philosophy, indicates that an organization reflects local agency. Governance is thus embedded in local interaction and represents the will of the community that constitutes an organization. As is required of community-based organizations, dualism is overcome and organizational autonomy is averted.

A Move Away from Philosophy

Organizations must change when they strive to become community-based. Particularly important is that they become completely transparent, with information flow unimpaired throughout the process of service delivery. Accordingly, as should be noted in the previous section, an organization and a community become thoroughly integrated when they are community-based.

At this juncture, a few concrete examples are introduced to illustrate this process. Questions are asked that attempt to illustrate how transparency and integration are achieved in community-based health organizations, such as hospitals or community clinics.

1. Is an organization hierarchical or flat? The goal of community-based organizations, of course, is to be as flat as possible. Can policy decisions and accompanying changes be led at any level of the organization? In this way, community sentiment can easily reach leaders, who are not ensconced in the world of administration. The organization, in other words, is not abstract and intimidating.
2. Are departments linked together, other than, perhaps, on the organizational chart? A real linkage should be in place that requires these groups to work together and share information. Rensis Likert (1967) called this a “linking-pin model.” Do persons in specific departments collaborate with others, as a regular practice of conducting business? Do they coordinate their needs and efforts? In community-based organizations, departments should be interacting, for example, as they track clients when they receive services and move through an organization. In this way, a client’s record is holistic, while the members of an organization gain a broad picture of service delivery.

3. Do local persons sit on departmental committees? Community members, for example, are often invited to be on hospital boards. But participating regularly in how these committees function represents something completely different. In their case, local knowledge is integrated into the everyday operation of an organization, rather than intermittently when a crisis may arise.
4. Is there active involvement with communities? Usually, most community contact is passive—locals may be consulted, for example, when a needs assessment is expected to be conducted. Community outreach is, likewise, passive, with attempts made to locate or contact persons. But the question remains: Do community members work regularly, for example, with clinicians or evaluators? Are they a normal part of these teams?
5. Is training available to local persons? The point is that local skill development is important, along with community participation. For example, learning how to navigate the administration of a hospital, become familiar with clinical nomenclature, and how to introduce significant input and make changes are important skills. Training should thus be extended to all those who are expected to shape an organization.
6. Are clinical practices—hospitals as well as neighborhood clinics—close to communities? Often these providers are spatially in or near to communities, but have the pathways been cleared to treatment? Is local knowledge used to define problems and accessibility, so that stigma is not attached to seeking care, for example, for mental health issues? Making sure that services are in a community must extend beyond logistical considerations. How a health organization interacts with a community should be a local determination.

Conclusion

The bottom line is that the delivery of health services is a group effort. But the nature of this group, or organization, is a key concern in the design of community-based interventions. By traditional standards, community-based organizations implode and dissolve into their respective communities. According to traditionalists, such organizations are insubstantial. But while these organizations may be unobtrusive, they are not flimsy.

An organizing principle certainly exists that is neither natural nor autonomous. A community-based organization is self-generating and represents collectively designed narratives about how health issues should be addressed. A community specifies what problems are important and how remedies should be applied. In fact, how these plans are executed constitutes a health-care organization. In terms of a community-based philosophy, this dispersed locus of organizing is vital.

In community-based work, a particular population becomes the organization. No facet of this process is treated as autonomous; nothing about service delivery is imposed. As a community becomes self-directed, and begins to focus on health care, an organization emerges that is dedicated to identifying and finding solutions to problems. In this regard, service delivery is thoroughly local.

At the root of this change is philosophy. Specifically important is that organizations must be imagined to exist without support from dualism. Within this new framework, at least initially, institutions may appear to be weak, even flighty. But without dualism, problems can be identified, plans made, and remedial strategies implemented in the absence of the usual formalized guidelines.

For this reason, community-based organizations are substantial but difficult to pin down. The community that invents these organizations knows the rules, has access, and recognizes transgressions, because local knowledge is operative. Outsiders, nonetheless, may declare in frustration that no organization exists, only a hodgepodge of persons and practices. Those who want to become community-based, however, should not fall prey to the stale imagery supplied by realism and settle for rigorous, clearly delineated but irrelevant health-care organizations, out of fear of not having a true organizational presence.

Community-based organizations hold a lot of promise. Health services can be provided in an effective way, thereby improving care. And somewhat related, communities can acquire skills and gain a sense of self-efficacy, so they can become agents of social change (Bandura, 1995). But these changes are not likely to occur unless service organizations are rethought. A new theory of organizing is needed, one that enhances local agency, knowledge, and, in the end, control. In this sense, philosophy is at the core of changing direction and becoming community-based.

References

Bandura, A. (1995). *Self-efficacy in changing societies*. Cambridge, UK: Cambridge University Press.

Behforouz, H. L., Farmer, P. E., & Mukherjee, J. S. (2004). From directly observed therapy to Accompagnateurs: Enhancing AIDS treatment outcomes in Haiti and in Boston. *Clinical Infectious Diseases, 38*, S429–S436.

Bordo, S. (1987). *The flight to objectivity*. Albany, NY: SUNY Press.

Bourdieu, P. (1990). *In other words*. Stanford, CA: Stanford University Press.

Burrell, G., & Morgan, G. (1979). *Sociological paradigms and organizational analysis*. London: Heinemann.

Campbell, C., & Kerry, S. (2011). Retreat from Alma-Ata? The who's report on task shifting to community health workers for AIDS care in poor countries. *Global Public health: An International Journal for Research, Policy, and Practice, 6*(2), 125–138.

Cueto, M. (2004). The origins of primary health care and SELECTIVE primary health care. *American Journal of Public Health, 94*(11), 1864–1874.

Dussel, E. (2008). *Ethics and community*. Eugene, OR: Wipf & Stock.

Fals Borda, O. (1988). *Knowledge and people's power*. New York: New Horizons Press.

Freidson, E. (1970). *The profession of medicine: A study of the sociology of applied knowledge*. Chicago: University of Chicago Press.

Fromm, E. (1959). *The sane society*. New York: Rinehart and Co.

Gadamer, H.-G. (1996). *The enigma of health*. Stanford, CA: Stanford University Press.

Geiger, H. J. (2016). The first Community Health Center in Mississippi: Communities empowering themselves. *American Journal of Public Health, 106*(10), 1738–1740.

Gergen, K. (1999). *An invitation to social construction*. Thousand Oakes, CA: Sage.

Greenhalgh, T. (2009). Chronic illness: Beyond the expert patient. *British Medical Journal, 338*, 629–631.

Howick, J. (2011). *The philosophy of evidence-based medicine*. West Sussex, UK: Wiley-Blackwell.

Kanter, R. M. (1983). *The change masters: Innovations in productivity in the American corporation*. New York: Simon & Schuster.

Kretzman, J. P., & McKnight, J. L. (1993). *Building communities from the inside out*. Chicago, IL: ACTA.

Lefkowitz, B. (2007). *Community health centers: A movement and the people who made it happen*. New Brunswick, NJ: Rutgers University Press.

Likert, R. (1967). *The human organization: Its management and value*. New York: McGraw-Hill.

Luhmann, N. (2017). *Trust and power*. Cambridge: Polity Press.

Lune, H. (2010). *Understanding organizations*. Cambridge, UK: Polity Press.

Murphy, J. W. (2014). *Community-based interventions: Philosophy and action*. New York: Springer.

Perrow, C. (1979). *Complex organizations*. Glenview, IL: Schott, Foresman, and Company.

Rifkin, S. B. (2009). Lessons from community participation in health programmes: A review of the post Alma-Ata experience. *International Health, 1*(1), 31–36.

Rothschild, J., & Whitt, J. A. (1986). *The cooperative workplace*. New York: Cambridge University Press.

Scott, R. W. (2002). *Organizations: Rational, natural, and open systems* (5th ed.). Englewood Cliffs, NJ: Prentice-Hall.

Selznick, P. (1948). Foundations of the theory of organizations. *American Sociological Review, 13*(1), 25–35.

Stufflebeam, D. L. (2001). The metaevaluation imperative. *American Journal of Evaluation, 22*(2), 183–209.

Ward Jr., T. J., & Geiger, H. J. (2017). *Out in the rural: A Mississippi health center and its war on poverty*. New York: Oxford University Press.

Weick, K. (1976). Educational organizations as loosely coupled systems. *Administrative Science Quarterly, 21*(1), 1–19.

Wu, C.-C. (2011). The impact of hospital brand image on service quality, patient satisfaction, and loyalty. *African Journal of Business Management, 5*(12), 4873–4882.

Chapter 3
Establishing Community-Based Primary Health Care

Karen A. Callaghan

Introduction

For many decades, global attention has focused on the need to deliver effective health care to all communities, including those that are impoverished and disenfranchised. Despite advancements in technology and medical science, disparities in health outcomes and access to care continue to persist (Weinstein, Geller, Negussie, & Baciu, 2017). In addition, the cost of providing health services continues to increase. These problems are particularly evident in the American health care system, where government resources are the only safety net for those who cannot acquire private insurance. This approach affects adversely lower income communities, since they are more likely to face financial, cultural, linguistic, and other barriers to accessing adequate health care. While this situation may seem dire, what is known as the primary health care movement may provide viable remedies.

According to the World Health Organization (WHO), primary health care requires reconceptualizing the very nature of health, illness, delivery modalities, and the status of medical professionals and patients. The WHO Alma-Ata Declaration (1978) stipulates that health refers to "complete mental, physical, and social well-being, and not merely the absence of disease or infirmity…" (section I). Focusing on "well-being" rather than the eradication of pathological conditions requires a thoroughly different approach to health services. Effective care must target a myriad of social, economic, and personal circumstances previously considered tangential to medical treatment and intervention. In addition, helping patients and communities achieve good health must involve an assessment of the quality of relationships, the environment, educational and employment opportunities, housing, finances, and

K. A. Callaghan (✉)
Barry University, Miami, FL, USA
e-mail: kcallaghan@barry.edu

© Springer Nature Switzerland AG 2019

S. L. Arxer, J. W. Murphy (eds.), *Community-Based Health Interventions in an Institutional Context*, International Perspectives on Social Policy, Administration, and Practice, https://doi.org/10.1007/978-3-030-24654-9_3

personal choices, as well as of the laws, policies, procedures, and social practices that affect access to relevant care and resources (Kickbusch, 2003).

The Alma-Ata Declaration went further, however, to ensure that health care would be tied closely to the concerns and circumstances of communities. One of the key tenets of the Declaration is "…maximum community and individual self-reliance and participation in the planning, organization, operation and control of primary health care…" (World Health Organization, 1978, section VII, 5). This statement reflects the endorsement by the Conference of authentic democratization of the health-care system. Such a maneuver requires that population health become a primary focus of government and nongovernment entities that control or influence related policies, planning, and the distribution of resources. The goal of this strategy is the coordination of health promotion and care across all sectors. When these efforts are accomplished with maximum community participation, relevant and effective services can be delivered more efficiently.

Subsequent WHO Conferences continued to emphasize this needed shift to health promotion, direct community participation, health focus in all policies, intersectoral coordination, and consideration of the social determinants of health. The Ottawa Charter for Health Promotion (1986), for example, states that:

> Health promotion works through concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health. At the heart of this process is the empowerment of communities, their ownership and control of their own endeavours and destinies. (Strengthen community action section)

This Charter (1986) also emphasizes that the health-care system must "embrace an expanded mandate" to go beyond clinical interventions, emphasize health promotion, and "open channels" to address social, economic, and environmental barriers to well-being (Reorient health services section). Likewise, the Rio Political Declaration on the Social Determinants of Health (2011) calls specifically for more intersectoral cooperation and coordination and for support "to empower the role of communities and strengthen civil society" (section 12.2). An emphasis on local empowerment, collective responsibility, coordinated efforts, and "harnessing the potential of digital technology" to enhance participation can be found also in the Shanghai Declaration (2016, Health literacy empowers and drives equity section).

The fundamental assumptions of these Declarations are clear: if the purpose of health care is to maintain the well-being of all persons, then *all* of the circumstances jeopardizing that well-being must be addressed in ways that are meaningful and effective. Providing care in a one-dimensional, reductionist framework is a stopgap and ultimately a waste of resources, since health exists within a complex of social, economic, environmental, and personal situations that are unique to local communities.

The WHO Declarations should be understood as the formal culmination of various global movements dedicated to reducing disparities in health and in access to meaningful services and care. Inequities in health represent a threat to individuals who are suffering but also to the strength of democratic civil society (Brown, Harrison, Burns, & Ziglio, 2013). An inclusive society where persons participate fully in multiple levels of governance is predicated on facilitating their well-being and full development. Excluding entire segments of a population from meaningful participation due to a lack of resources, information, or support undermines democracy.

These very concerns gave rise to several movements in the American health care system that were intended to expand access, provide more effective care, become patient-centered, include community participation, and integrate social determinates of health. In other words, each of these reforms attempted to introduce an aspect of primary health care into the existing system. Examples of these projects include community health centers, community-oriented primary care, patient-centered medical homes, and the use of social determinants of health in formal diagnoses (Geiger, 2002). While each approach has helped to expand services within the context of a more holistic view of health, the question remains as to whether these practices are guided by a community-based philosophy. This type of conceptual framework is crucial for facilitating maximum community participation in the planning, implementation, and control of a primary health-care system.

Primary Health Care as Community-Focused Projects

Implementation of the Affordable Care Act (ACA) signaled renewed interest in primary health care in the United States (Klink, 2015). This legislation mandated providing access to health care for millions of new recipients, as efficiently and effectively as possible. While some critics have cast this legislation as unprecedented, the ACA should be understood as part of a history of reforms intended to provide accessible *community-focused* care (Chowkwanyun, 2018). For example, the ACA provision to expand Medicare and Medicaid eligibility clearly ties this approach to the development of community health centers, which was a strategy of the 1960s War on Poverty. While political struggles over the right to adequate health care are a necessary part of this process, the primary health-care movement depends also on efforts to reconceptualize the nature and practice of medical treatment and intervention.

Although instituted originally as part of the Public Health Services Act of 1965, community health centers (CHCs) continue to serve as an important care provider in many low income and poor communities (Wright, 2013b). According to the National Association of Community Health Centers (2019), more than 1350 federally qualified health centers annually serve approximately 28 million people. Approximately, 90% of these patients live in or near poverty, over 60% are Black or Hispanic, and more than 50% receive Medicaid or Medicare health benefits. In order to retain eligibility to receive federal funds, CHCs must provide care in designated high medical need areas, offer comprehensive “enabling” services, be affordable to everyone, and maintain a 51% patient member governing board (National Association of Community Health Centers, 2019, pp. 2–3). CHCs are expected to address population health issues, since many of their clients experience chronic conditions associated with racial-ethnic and income disparities (Stevens, 2016). As proponents note, “CHCs pride themselves equally on providing community-accountable and culturally competent care aimed at reducing health disparities associated with poverty, race, language, and culture” (Adashi, Geiger, & Fine, 2010, p. 2049).

Community accountability is obviously an important theme in the governance of CHCs. Serving on the governing or advisory boards is the primary mechanism for the community to exercise influence or control over operational and policy decisions. CHC governance is described as “community-based leadership” (Sharma, Huang, Knox, Willard-Grace, & Potter, 2018, p. 1070), a “grass roots governing structure” (Fiscella & Geiger, 2014, p. 2044), and as a means to “engage and empower patients” (Wright, 2013a, p. 430). While this approach appears to be moving toward full participation, several crucial issues should be addressed regarding the scope and nature of community input. The goals of CHCs are to effect positive clinical outcomes for individual patients and to bring about changes in the social determinants that are effecting the whole community. Those aims require different levels of community participation and even control over health projects. The CHC movement has struggled to understand how community involvement might require fundamental changes in the traditional biomedical approach to clinical care.

H. Jack Geiger (2002), one of the pioneers of the CHC movement, addressed the issue of how a “health program … could be deliberately fashioned as an instrument of community development and as a lever for social change” through the community-oriented primary care (COPC) model made famous by Sidney and Emily Kark’s work in South Africa (pp. 1714–1715). The Karks’ approach used community development techniques to address population health issues, which, as the WHO Declarations stipulate, are linked clearly to the social, environmental, and economic circumstances of any community. This project illustrated that community empowerment should be understood as an important first step to creating sustainable changes in overall well-being.

Since the 1950s and 60s, however, the implementation of COPC and the notion of community empowerment have undergone various changes. Proponents of COPC point to several key principles and practices that constitute the community-based nature of this approach. COPC begins with “a defined community” and delivers services based on “its assessed health needs” (Mullan & Epstein, 2002, p. 1750). Importantly, this care is delivered “through the planned integration” of public health and primary care practices (Mullan & Epstein, 2002, p. 1750). Since COPC assumes that health promotion practices are as important as clinical interventions, community engagement is a principle feature, since this involvement is needed to assist in assessing and prioritizing health problems and selecting feasible interventions. Community members’ participation is usually accomplished via service on formal and informal advisory boards, on task forces or research groups, and as part of focus groups.

An additional influence of the ACA on primary health care models is the emphasis on delivering better quality services to patients through more efficient use of resources. In this context, the Patient-Centered Medical Home (PCMH) is considered a primary means to deliver high-value care to a wide range of clients. Through rigorous accreditation standards, PCMHs are required to provide services in a sensitive, responsive, relevant, and coordinated manner (Stange et al., 2010). Teams of professional and clinical staff provide care and treatment planning, which is supposed to ensure informed coordination of service. Patients and family members can expect to have direct continuous contact, via phone calls and electronic messages, with their care providers. In addition, group and home visits, drop-in services, same-day appointments, and referrals to non-clinical services are routine practices. Communication between service providers and patients is considered a key concern for services and relationships to be culturally informed, honest, and supportive.

PCMHs are expected also to be guided by Patient Advisory Councils that are composed of patients, family members, and caregivers. Typically, these Councils address issues related to "practice improvement," which can range from enhancing the physical comfort and look of the clinic waiting rooms to better quality communication about "bad news" regarding a patient's health status (Sharma et al., 2016, pp. 778–779). PCMHs are characterized also as employing a community-oriented approach. However, according to the US Agency for Healthcare Research and Quality, PCMH interventions are considered community-based when patients are referred to preventative services, located in their local neighborhoods, which typically involve screening and counseling (Dymek et al., 2013).

A final practice that should illustrate the community-based nature of these approaches to care and intervention is the recognition of the social determinants of health (SDH) in formal diagnoses and treatment planning. As illustrated in the WHO documents, addressing SDH is crucial for reducing health disparities and improving the well-being of communities. Many people are sick and suffering due to where they live, their social identities, whether they have a job, and their ability to pay for care. Effective interventions must include services to individual patients as well as comprehensive prevention and health promotion programs. New approaches to public health and social epidemiology have emerged in response to this shift (Awofeso, 2004). Public health models now call for the critical interrogation of the social and political changes that are needed to ensure better quality housing, food, water, sanitation, education, employment, and recreation, because these conditions are related directly to the health status of communities. Social epidemiologists have developed multidimensional eco-social frameworks to explain disease and health distribution. Krieger (2009), for example, recommends that epidemiological studies should routinely address salient factors such as stress related to living in lower income neighborhoods, structural and institutional privilege and oppression, and targeted marketing of unhealthy products and lifestyles.

The U.S. Centers for Disease Control (CDC) promotes a "place-based" framework for understanding and addressing SDH. Krieger's recommendations appear to be included as common issues that public health professionals should employ when designing health promotion activities. In addition, the CDC guidelines recommend that practitioners incorporate engagement strategies to "harness the skills and talents of a community" and "foster connectedness and trust" (Centers for Disease Control, 2013, p. 10). Examples of recommended community engagement methods include participation in interviews, focus groups, and forums; service on research teams and advisory boards; and employment in agencies or other community-based organizations.

Since community-oriented health projects are supposed to integrate public health and primary care practices, efforts are underway to use of SDH information in clinical care settings as well. The American College of Physicians recommends that medical professionals should become advocates for public policy and clinical interventions designed to ameliorate the negative effects of SDH (Daniel, Bornstein, & Kane, 2018). In addition, medical education should include training on the significance of SDH and on how to integrate this information into screening techniques and treatment planning.

As should be expected, CHCs have been at the forefront of the use of SDH in formal clinical intake and diagnoses. The widespread use of electronic health record (EHR) systems has presented new challenges for the focus on SDH. In order to ensure that patient-level SDH information is included in EHRs, the National Association of Community Health Centers and several other professional associations have launched national effort to adopt the Protocol for Responding to and Assessing Patient Assets, Risks, and Experiences (PRAPARE) (Gold et al., 2018). This assessment tool can be embedded in EHRs. After collecting information on 13 core SDH measures (for example, race-ethnicity, housing status, stress, employment status), clinical staff can use these data to determine if patients require referrals to additional services or need support to comply with treatment and care requirements (Gold et al., 2018, p. 403). According to the PRAPARE training manual, using this electronic assessment tool allows medical and other clinic staff to see the "increased complexity of patients," provide more targeted care, and "advocate for change at the community and national levels" (National Association of Community Health Centers, 2016).

These various attempts to develop a more responsive and holistic model of care seem to have embraced a community-based approach; however, significant barriers to full and authentic participation continue to exist. Even when the desire to offer effective primary care, prevention, and health promotion services is genuine, the task of connecting with and affording patients and communities maximum participation and control seems elusive. Giving patients direct access to medical professionals, providing care in pleasant surroundings, and taking into account the well-documented relationships between social indicators and health will result in providing services that are possibly more relevant and, therefore, effective. However, these practices do not support or reflect the exercise of sustained community participation, control, and self-reliance. Why then despite numerous attempts to allow more involvement and inclusion in the design, delivery, and control of health care services, do communities seem to remain on the periphery of important decision-making about their well-being?

Community-based approaches to research, planning, and intervention require not only the adoption of new practices, such as allowing patients to serve on an advisory board, but also, and more important, a dramatic re-thinking of certain philosophical assumptions. This conceptual shift requires a critical interrogation of the traditional biomedical, science-based approach to health and illness. The notion that everyday members of a community can play a significant role in the design and delivery of health projects makes little sense in this traditional framework. Nonetheless, from the biomedical standpoint, individuals and communities when supplied with the correct information can learn to make better choices about diet and exercise and they can help clinical staff understand how to make interactions less stressful. In addition, communities can create health-related support programs to help other residents. In this regard, communities can serve as important consultants for any medical practice. However, for communities to become the central driving force of primary health care systems, an important epistemological shift is imperative (Murphy, 2014).

The philosophical assumptions on which the biomedical model is based stress the importance of developing objective knowledge that is not tainted by subjective opinions or perspectives. In the medical context, this objectivity is expressed as “expert” knowledge that is developed through employing rigorous scientific methodology. Only persons with certain credentials can be authorized to interpret and use this knowledge, while they follow specific protocols for implementation. In this context, communities are incapable of producing or independently analyzing knowledge (Murphy, Franz, & Callaghan, 2015). In addition, intimate contact or engagement with those who may be the recipients of treatment or interventions is viewed as inappropriate or even harmful. Forming such relationships with communities is antithetical to the protocols that should be followed to produce the desired outcomes. Community input needs to be limited to those issues or aspects of care that are related to facilitating compliance with treatment regimens.

As with any paradigm based on dualism, only knowledge divorced from subjectivity should be used to make serious decisions. If any useful information exists within communities, certain methods must be used to extract what will become valid data. These empirical indicators can then be used by researchers and medical professionals to gain insights into individual and community needs, assets, and challenges. Community involvement with these data collection efforts is usually minimal. Persons may be asked to complete surveys or interviews, but in many cases, communities are often pre-defined by using zip codes and census tract data. The voices of actual persons are marginalized to preserve as much objectivity as possible.

Qualitative methodologies may appear to include more dynamic community participation; however, these approaches do not necessarily reject the dualistic scientific paradigm (Murphy et al., 2015). Common qualitative methods, such as key informant interviews and focus groups, do not preclude identifying the researchers and practitioners as the experts who must control the data collection, analysis, and interpretation. Focus groups, for example, are used typically to elicit feedback on specific questions or issues that have been identified as important by external parties. Often, the aim of this type of data collection is to determine how to generate community support or buy-in for projects. The personal viewpoints garnered through these techniques are often used as proxies for the community as a whole.

A more authentic democratic form of community participation requires a shift away from the biomedical-scientific paradigm and the underlying dualism of objectivity-subjectivity. When dualism is rejected, an alternative framework of how knowledge, community, and participation are constituted is possible. Within a community-based paradigm, full community participation not only makes sense but also is a necessary prerequisite for any primary health-care project (Murphy & Franz, 2017).

Participation, Dialogue, and Local Knowledge

An authentic community-based approach assumes that all knowledge is derived from particular interpretations and perspectives (Murphy, 2014). Professional experts may have knowledge and skills that are quite useful for many persons and communities. However, the true validity of that knowledge cannot be determined until close contact has been established with these persons. Developing such contact is not possible if a community is identified or understood through analysis of empirical referents or social indicators. For example, using zip code areas and census tracts to define communities creates a disembodied, abstract version of actual persons and the way they experience and interpret their lives. From a community-based perspective, a health project should begin with attempts to gain entrée to a new social world, rather than with plans for extracting data or objectively determining neighborhood boundaries.

When dualism is rejected, how communities are understood and approached is fundamentally changed. In order for community-based projects to be successful, what had been deemed previously as subjective, and therefore unreliable and unsubstantiated, viewpoints must be given full attention and consideration. As Berger and Luckman (1966) contend, a community is a life-world or a complex of meaning, which emerges as persons engage with others and try to make sense of their lives. Human agency or intentionality are evident in all aspect of community life (Berger & Luckman, 1966, pp. 20–21). How persons define or interpret health, well-being, and illness is revealed only through their narratives or stories, that is, through the meaning they have constructed about their lives.

Communities, then, have biographies, that is, complex narratives, that reveal persons' perspectives, values, and assumptions (Murphy, 2014, pp. 25–26). Any efforts to include community participation in research, planning, and interventions must allow these stories to be told. This assumption underscores the importance of gaining entrée and using dialogue as a primary means to developing sustained relationships with communities. Soliciting community feedback on an occasional basis to ensure that new projects have support will create relationships that are fragmented, unreliable, and not worthy of much attention or trust. Furthermore, community members need time to reflect on how the services of a clinic or the effects of an intervention might serve a meaningful purpose in their lives. Authentic dialogue requires, therefore, that the biographies of communities be taken seriously, that is, as legitimate knowledge that can not only inform but also direct the planning and delivery of primary health care and interventions (Fals Borda, 2013, p. 160; Fals Borda, 1988).

The ultimate aim of community-based approaches is to allow researchers, medical professionals, and local residents to co-constitute services, interventions, planning, and further investigations (Freire, 1992, p. 97). What has been considered "expert" knowledge must play a role in this process but only as one type of narrative, developed by professional communities as they construct interpretations of specific problems and remedies. This knowledge can be introduced to communities once trust and intimacy have been established. However, medical practitioners must enter communities with humility and respect and with a genuine interest in learning. Regardless of their credentials or experience, these professionals are novices in each unique community. They must be open to grasping and affirming the multiple layers of social reality that are revealed by the narratives of a community's history, conflicts, victories, defeats, alliances, and challenges. These stories can be dynamic, confusing, and contradictory but they must be understood to form sustained, productive relationships. Medical practitioners must learn to understand the world from the standpoint of the community. In other words, once dialogical relationships have been established, practitioners and residents can begin to explore democratically the feasibility of various interventions and services (Solomon, 1976).

Community-Based Primary Health Care

The global efforts to institute primary health care systems that allow maximum participation reflect the commitment to empower individuals and communities to become directly responsible for sustaining their own well-being. Empowerment, in this context, does not mean that communities are disorganized and helpless and must rely on more powerful outsiders to secure the information and resources needed to address their problems (Rappaport, 1987). An authentic community-based approach begins by forming dialogical relationships in order to reveal local knowledge, rather than merely asking residents to react to or "consume" the ideas and strategies of others (Freire, 1992, p. 100). Communities can be empowered when their histories, values, perspectives, and interpretations are taken seriously and not dismissed as trivial information that gets in the way of sound medical practice. This epistemological shift requires significant changes in the common strategies that have been used in the past to provide more community-accountability, grassroots leadership, and community development as key components in primary health care.

Primary care projects must begin with identifying a target community. In fact, one of the key processes for creating COPC involves "defining (geographically, members registered in a practice or as a sociological construct) and characterizing the community to determine health needs…" (Gofin, Gofin, & Stimpson, 2015, p. 128). Interestingly, COPC practitioners admit that the "idea of community" can be an “elusive concept” and that “simple geography” is not a sufficient means to identify a target community (Mullan & Epstein, 2002, p. 1750). However, the remedy proposed to resolve this dilemma is to make better use of electronic tools for mapping rates of chronic health problems, mortality and natality rates, and sociodemographic data to understand community boundaries and health concerns (Hayashi, Bazemore, & McIntyre, 2011, p. 62; Mullan & Epstein, 2002, p. 1752).

While the use of Geographic Information Systems and electronic databases can readily identify the spatial clustering of resources, services, and various social, economic, and health problems (Sampson, Morenoff, & Gannon-Rowley, 2002), a community cannot be defined through these methods. Reliance on empirical indicators creates a disembodied schematic of community life that may have little relevance for the persons actually living in these areas. While the data garnered through electronic means may have some utility for planning processes, the communities in question must first be identified through direct contact.

Participatory community-based mapping processes can be used to begin a dialogical process that allows residents to define the space, relationships, and commitments of their community life (Murphy et al., 2015). Gaining entrée to initiate this process may begin with local clubs, churches, and community-based agencies. However, the purpose of mapping is to become continuously more inclusive to avoid relying on the perspectives of select groups or leaders. Communities consist of multiple realities, and the particular connections, issues, and possibly contested interpretations of certain groups and associations cannot be considered the sole arbiter of local knowledge (Blumenthal, Hopkins III, & Yancy, 2013; Elwood, 2006). Participatory mapping allows the residents to take the lead, literally, on a project or discussion. In this context, residents are cast not as patients or research subjects but as co-investigators who provide direction and original thinking for the project.

COPC practitioners may feel that defining a community is a slippery task if they are expecting to discover a fixed, stable entity that readily conforms to objective referents. Communities’ identities are dynamic and reflect diverse viewpoints, conflicts, and disputes as well as solidarity and consensus. Participatory mapping processes can provide opportunities for residents to reflect critically on an identity and begin to consider the perspectives and aims of practitioners and researchers. Further, multiple maps can be created to represent the diversity and various dimensions of residents’ lived experiences. These different maps can be discussed and critiqued to reach a strategic consensus on how to define and prioritize health problems (International Fund for Agricultural Development, 2009). As part of this process, residents can consider how the resources and services available from a health center or medical interventions might be of use to the community.

Having patients and residents serve on advisory and governing boards is also a way that local knowledge can have a direct impact on decision-making about health services. However, in practice, the role of local representatives on these boards is usually marginalized in favor of those who can contribute more professional expertise, particularly in the areas of law and finance. Wright and Martin (2014) refer to this situation as the “expertise gap” that governing boards may face when trying to foster direct community involvement. As a result, local representatives are viewed as "non-professionals" and their input is construed often as a type of consumer feedback (p. 932). These dynamics reflect clearly the dire need for a community-based framework for health-care governance. Without this framework, local knowledge is understood as nothing more than feedback on personal experiences. However, CHC boards, for example, need information about the community they serve. As a result, local representatives are often criticized as "… being too particular in their perspectives and interests, and therefore unable to provide the breadth of insights about the needs and views of the wider community" (Wright & Martin, 2014, p. 943). This contradiction is tied directly to status of what is considered subjectivity in the traditional biomedical model. As a result, the role of patients in governance is undermined, since from an epistemological standpoint they have nothing to offer as board members.

If COPC projects and CHCs, in particular, are serious about fostering grassroots leadership, then community-based models of co-governance must be implemented. The nature of and need for "expertise" should be critically explored. The fact that community representatives may not already possess certain information should not diminish their status. Must all board members have the same depth of knowledge about finances, legal statutes, and accreditation issues? Community participants can be trained in these issues as they can learn to guide research projects and medical interventions. Participatory budgeting practices can be used to facilitate all board members' commitment to ensuring that community priorities are reflected in their work (Hagelskamp, Schleifer, Rinehart, & Silliman, 2018). In this regard, all board members should be trained on the use of authentic community-based techniques to develop sustained relationships with the community being served. Indeed, local representatives can serve as the facilitators for this process (Minkler, Garcia, Williams, LoPresti, & Lilly, 2010).

Obviously, building sustained and close relationships is key to ensuring that communities increasingly become more involved and eventually assume full responsibility for health-care planning and implementation. However, facilitating sustained community participation requires fundamentally rethinking and reorganizing the roles, processes, and even facilities associated with medical care. Creating and maintaining vibrant health committees and employing community health workers are practices that can facilitate the development and organizing that are important for expanded community control (Pérez & Martinez, 2008).

Local health committees can be organized as part of the mapping processes that should accompany the initial entrée to a community. As local residents discuss and debate their identity, aspirations, and challenges, these committees can begin to coordinate and communicate salient information to medical practitioners, planning and advisory boards, and government agencies. But communities should decide how health committees are composed and members are appointed or elected. Local activists and leaders play important roles in this process and local health practitioners should participate as well.

In addition, health committees can function most effectively when supported by community health workers (CHWs) (Murphy, Franz, & Callaghan, 2016).

Community members can be trained as CHWs and conduct health surveys and assessments, serve on health committees, and accompany local patients through the health system as advocates. The ACA includes provisions for expanding the role of CHWs, but with primary focus on their capacity to provide support and referral services to individual patients and their families (Malcarney, Pittman, Quigley, Horton, & Seiler, 2017; Shah, Heisler, & Davis, 2014). Although CHWs are viewed as important liaisons between the clinic staff and patients, their communication is often limited to addressing SDH issues as the "social barriers" that might limit the effectiveness of services (Thomas-Henkel & Shulman, 2017).

However, CHWs can also assume leadership roles in conducting community-based research and community development projects and ensuring that an ever-expanding number of residents are included as co-investigators in these endeavors (Murphy et al., 2016). Researchers and practitioners can assist with these processes by sharing their related knowledge and skills about how to collect and organize information and to interact effectively with decision-making authorities. Medical professionals and other clinic staff can ensure that CHWs are taken seriously, as recognized advocates for the community who can share information that is vital to providing effective care. Whenever possible, clinics and other facilities should be made available to health committees, CHWs, and other groups for meetings, training sessions, and similar gatherings. The clinic or heath center can become a hub for a wide range of community activities and as such become an embodied space for care, support, and meaningful action (Krieger, 2005).

As community residents become involved in co-designing and conducting research projects, collaborating on developing proposals for policy changes, and coordinating service delivery, what Kiefer (1984) calls their "participatory competence" is enhanced (p. 9). This development represents more than the acquisition of better technical skills. As communities engage in mapping processes, open debates and dialogues, and research projects, they reflect critically on their identity, self-efficacy, assets, aspirations, and challenges. Consequently, as Freire (1992, pp. 95–96) notes, persons can then "see and act differently toward the world," as they assess how certain personal and social changes and interventions may improve their well-being. Likewise, as medical professionals, researchers, and clinic staff appreciate the nature and importance of local knowledge, they should see and act differently toward communities. From a community-based perspective, practitioners do not enter a community simply to deliver ready-made health services. On the contrary, a community-based approach requires that health projects be initiated by finding opportunities for practitioners to share their knowledge and skills through close collaboration with communities.

Furthermore, practitioners should see their potential collaborators as not only as those (patients) who visit a medical facility but as all local residents who are in need of advocacy to promote their well-being. From a population health standpoint, for example, all residents who are effected by SDH should be viewed as the community served by a clinic or practice. SDH issues are typically addressed only on an individual patient level through referrals to support services. While those remedies are still needed, organizing and advocating for specific social and political changes might provide more sustainable solutions to chronic health problems. Prominent groups such as the National Association of Community Health Centers and the College of Physicians call for significant legal and policy changes at the local and national level. CHCs and medical practitioners should be at the forefront in supporting community activism to address SDH (Daniel et al., 2018; National Center for Community Health Centers, 2016). Practitioners and governing boards should be willing to work with health committees and CHWs to develop action plans to address these needs of communities. Working collaboratively with communities, they can help define the policy changes that would create more access, openness, and democracy in the planning and delivery of health care.

Conclusion

The primary health care movement, globally and in the United States, calls for reducing health disparities, including inequities in access to services. In addition, as advocated by the WHO, primary health care is effective only when the design and delivery of services has included the maximum participation of individuals and communities. The point is that the well-being of neglected and marginalized communities can be assured only when they are able to exercise direct control of their health care. In essence, primary health care should be derived from a community-based model.

In the American health care system, CHCs and other models of COPC have been implemented to ensure that services are culturally appropriate, accessible, affordable, and representative of the patient population. However, the strategies for achieving these goals have been well entrenched in the traditional biomedical model. The focus is still on individual patients and their immediate health needs. When patients serve on decision-making councils, they are treated more like consumers with limited knowledge of the real workings of the clinic or health center.

An authentic community-based model for health care requires practitioners to be ready to form close bonds with communities based on solidarity and respect. The community cannot be understood simply as a location from which to deploy services. Entering into a relationship with a community must begin with dialogue and openness. Practitioners must divest themselves of the notion that their medical knowledge and skills provide automatically insights into the life-world of a community. Only by listening carefully to the stories of local residents will the various perspective, values, interpretations, and commitments be revealed. Medical professionals must be willing to take local knowledge seriously, if interventions are to have any appeal or impact.

In addition, from a community-based approach, community empowerment and development are as important as any clinical interventions for creating well-being (Moore, 2018). Practitioners should be able and willing to facilitate enhancing community capacity for research, advocacy, and organizing by supporting health committees, CHWs, and sustained collaborations with activists and community-based organizations. In other words, practitioners must assume that communities, regardless of their challenges or lack of resources, are capable of sophisticated analysis of their circumstances, effective self-advocacy, and creative problem solving.

References

Adashi, E. Y., Geiger, H. J., & Fine, M. D. (2010). Health care reform and primary care - the growing importance of the community health center. *New England Journal of Medicine, 362*, 2047–2050. https://doi.org/10.1056/NEJMp1003729

Awofeso, N. (2004). What's new about the "new public health"? *American Journal of Public Health, 94*(5), 705–709.

Berger, P. L., & Luckman, T. (1966). *The social construction of reality: A treatise in the sociology of knowledge*. New York: Doubleday & Co.

Blumenthal, D. S., Hopkins III, Y., & Yancy, E. (2013). Community-based participatory research: An introduction. In D. S. Blumenthal, R. J. DiClemente, R. L. Brauthwaite, & S. S. Smith (Eds.), *Community-based participatory health research: Issues, methods, and translation to practice* (2nd ed., pp. 1–34). New York: Springer Publishing.

Brown, C., Harrison, D., Burns, H., & Ziglio, E. (2013). *Governance for health equity*. Copenhagen, Denmark: Regional Office of the World Health Organization.

Centers for Disease Control and Prevention – Division of Community Health. (2013). *A practitioner's guide for advancing health equity: Community strategies for preventing chronic disease*. Atlanta, GA: US Department of Health and Human Services.

Chowkwanyun, M. (2018). The war on poverty's health legacy: What it was and why it matters. *Health Affairs, 37*(1), 47–53. https://doi.org/10.1377/hlthaff.2017.1328

Daniel, H., Bornstein, S. S., & Kane, G. C. (2018). Addressing social determinants to improve patient care and promote health equity an American College of Physicians position paper. *Annals of Internal Medicine, 168*, 577–578. https://doi.org/10.7326/M17-2441

Dymek, C., Johnson Jr., M., Mardon, R., Hassell, S., Carpenter, D., McGinnis, P., et al. (2013). *Clinical-community relationships measures atlas*. Rockville, MD: Agency for Healthcare Research and Quality. Retrieved from https://pcmh.ahrq.gov

Elwood, S. (2006). Negotiating knowledge production: The everyday inclusions, exclusions, and contradictions of participatory GIS research. *The Professional Geographer, 58*(2), 197–208.

Fals Borda, O. (1988). *Knowledge and people's power*. New York: New Horizons Press.

Fals Borda, O. (2013). Action research in the convergence of disciplines. *International Journal of Action Research., 9*(2), 155–167.

Fiscella, K., & Geiger, H. J. (2014). Caring for the poor in the 21st century: Enabling community health centers for a new era. *Journal of Health Care for the Poor and Underserved, 25*(4), 2044–2052.

Freire, P. (1992). *Pedagogy of the oppressed*. New York: Continuum.

Geiger, H. J. (2002). Community-oriented primary care: A path to community development. *American Journal of Public Health, 92*(11), 1713–1716.

Gofin, J., Gofin, R., & Stimpson, J. P. (2015). Community-oriented primary care (COPC) and the affordable care act: An opportunity to meet the demands of an evolving health care system. *Journal of Primary Care & Community Health, 6*(2), 128–133.

Gold, R., Bunce, A., Cowburn, S., Dambrun, K., Dearing, M., Middendorf, M., et al. (2018). Adoption of social determinants of health EHR tools by community health centers. *Annals of Family Medicine, 16*, 399–407. Retrieved from https://doi.org/10.1370/afm

Hagelskamp, C., Schleifer, D., Rinehart, C., & Silliman, R. (2018). Participatory budgeting: Could it diminish health disparities in the United States? *Journal of Urban Health, 95*, 766–771. Retrieved from https://doi.org/10.1007/s11524-018-0249-3

Hayashi, A. S., Bazemore, A., & McIntyre, J. (2011). Transforming community health and primary care education using clinical and administrative data and geographic information systems. *Journal of Map and Geography Libraries, 7*, 61–70.

International Fund for Agricultural Development. (2009). *Good practices in participatory mapping, a review prepared for IFAD*. Rome: IFAD.

Kickbusch, I. (2003). The contribution of the World Health Organization to the new public health and health promotion. *American Journal of Public Health, 93*(3), 383–388.

Kieffer, C. (1984). Citizen empowerment: A developmental perspective. In J. Rappaport & R. Hess (Eds.), *Studies in empowerment: Steps toward understanding and action* (pp. 9–36). New York: Haworth Press.

Klink, K. (2015). Incentives for physicians to pursue primary care in the ACA era. *American Medical Association Journal of Ethics, 17*(7), 637–646.

Krieger, N. (2005). Embodiment: A conceptual glossary for epidemiology. *Journal of Epidemiology and Community Health, 59*, 350–355.

Krieger, N. (2009). Putting health inequities on the map: Social epidemiology meets medical/health geography—An ecosocial perspective. *GeoJournal, 74*(2), 87–97.

Malcarney, M.-B., Pittman, P., Quigley, L., Horton, K., & Seiler, N. (2017). The changing roles of community health workers. *Health Services Research, 52*(1), 360–382.

Minkler, M., Garcia, A. P., Williams, J., LoPresti, T., & Lilly, J. (2010). Sí se puede: Using participatory research to promote environmental justice in a latino community in San Diego, California. *Journal of Urban Health, 87*(5), 796–812. https://doi.org/10.1007/s11524-010-9490-0

Moore, A. (2018). *Partnerships for health equity and opportunity: A healthcare playbook for community developers*. Build Healthy Places Network. Retrieved from https://www.buildhealthyplaces.org/resources/partnerships-for-health-equity-and-opportunity-a-healthcare-playbook-for-community-developers//

Mullan, F., & Epstein, L. (2002). Community-oriented primary care: New relevance in a changing world. *American Journal of Public Health, 92*(11), 1748–1755.

Murphy, J. W. (2014). *Community-based interventions: Philosophy and action*. New York: Springer.

Murphy, J. W., & Franz, B. (2017). The patient-centered medical home as a community-based strategy. *The Permanente Journal, 21*, 17–002. Retrieved from https://doi.org/10.7812/TPP/17-002

Murphy, J. W., Franz, B. A., & Callaghan, K. A. (2015). Is community-based work compatible with data collection? *Journal of Sociology and Social Welfare, XLII*(4), 9–21.

Murphy, J. W., Franz, B. A., & Callaghan, K. A. (2016). Group maturity in a community-based project. *Social Work in Public Health, 31*(5), 341–347. https://doi.org/10.1080/19371918.2015.1125320

National Association of Community Health Centers. (2016). *Understand the PRAPARE project*. Retrieved from http://www.nacha.org/PRAPARE

National Association of Community Health Centers. (2019). *Community health center chartbook*. Retrieved from http://www.nachc.org/wp-content/uploads/2019/01/Community-Health-Center-Chartbook-FINAL-1.28.19.pdf

Pérez, L. M., & Martinez, J. (2008). Community health workers: Social justice and policy advocates for community health and well-being. *American Journal of Health, 98*(1), 11–14.

Rappaport, J. (1987). Terms of empowerment/exemplars of prevention: Toward a theory of community psychology. *American Journal of Community Psychology, 15*(2), 121.

Sampson, R. J., Morenoff, J. D., & Gannon-Rowley, T. (2002). Assessing "neighborhood effects": Social processes and new directions in research. *Annual Review of Sociology, 28*, 443–478.

Shah, M., Heisler, M., & Davis, M. (2014). Community health workers and the Patient Protection and Affordable Care Act: An opportunity for a research, advocacy, and policy agenda. *Journal of Health Care for the Poor and Underserved, 25*(1), 17–24. https://doi.org/10.1353/hpu.2014.0019

Sharma, A. E., Huang, B., Knox, M., Willard-Grace, R., & Potter, M. B. (2018). Patient engagement in community health center leadership: How does it happen? *Journal of Community Health, 43*, 1069–1074.

Sharma, A. E., Willard-Grace, R., Willis, A., Zieve, O., Dubé, K., Parker, C., et al. (2016). How can we talk about patient-centered care without patients at the table? Lessons learned from patient advisory councils. *Journal of the American Board of Family Medicine, 29*(6), 775–784. https://doi.org/10.3122/jabfm.2016.06.150380

Solomon, B. B. (1976). *Black empowerment: Social work in oppressed communities*. New York: Columbia University Press.

Stange, K. C., Nutting, P. A., Miller, W. I., Jaén, C. R., Crabtree, B. F., Flocke, S. A., et al. (2010). Defining and measuring the patient-centered medical home. *Journal of General Internal Medicine, 25*(6), 601–612.

Stevens, D. (2016). Health centers after 50 years: Lessons from the health disparities collaboratives. *Journal of Health Care for the Poor and Underserved, 27*, 1621–1631.

Thomas-Henkel, C., & Shulman, M. (2017). *Screening for social determinants of health in populations with complex needs: Implementation considerations*. Center for Health Care Strategies, Inc. Retrieved from https://communityactionpartnership.com/external_resources/screening-for-social-determinants-of-health-in-populations-with-complex-needs-implementation-considerations/

Weinstein, J. N., Geller, A., Negussie, Y., & Baciu, A. (2017). *Communities in action: Pathways to health equity*. The National Academies of Science, Engineering, and Medicine: The National Academies Press.

World Health Organization. (1978). *Declaration of Alma-Ata*. International Conference on Primary Health Care, Alma-Ata, USSR. Geneva, Switzerland: World Health Organization.

World Health Organization. (1986). *Ottawa charter for health promotion*. Geneva, Switzerland: World Health Organization.

World Health Organization. (2011). *Rio declaration on social determinants of health*. Geneva, Switzerland: World Health Organization.

World Health Organization. (2016). *Shanghai declaration on promoting health in the 2030 agenda for sustainable development*. Geneva, Switzerland: World Health Organization.

Wright, B. (2013a). Do patients have a voice? The social stratification of health centers governing boards. *Health Expectations, 18*, 430–437.

Wright, B. (2013b). Who governs federally qualified health centers? *Journal of Health Politics, Policy, and Law, 38*(1), 27–55. https://doi.org/10.1215/03616878-1898794

Wright, B., & Martin, G. P. (2014). Mission, margin, and the role of consumer governance in decision-making at community health centers. *Journal of Health Care for the Poor and Underserved, 25*, 930–947.

Chapter 4
Community-Based Funding and Budgeting: Participatory Budgeting as a Transformative Act

Jung Min Choi, John W. Murphy, Ramsey Dahab, and Charlene Holkenbrink-Monk

Why Community-Based Budgeting?

Since the 1980s, when Ronald Reagan aggressively rolled back the gains made by the various civil rights groups in the 1950s and 1960s, many people have been disillusioned about the state of our democracy (Katznelson, 2005). Citizens are often dissatisfied and frustrated at the dysfunction of the government shrouded in an oversized bureaucratic machine. And for years, everyday citizens have felt disconnected from the neoliberal government that caters mostly to millionaires and multinational corporations who lobby solely for personal profit (Chomsky, 1999).

Partly in response to an unresponsive government, people in different cities across the country have engaged in, and supported, participatory policy reforms. Borrowing from the general framework found in community-based work (CBW), people are experimenting with direct democracy to improve their communities through policy (Lerner, 2014). An aspect of CBW that is drawing the bulk of attention recently is called Participatory Budgeting (PB). While PB has its roots in Porto Alegre, Brazil, it is a growing trend throughout the world, including the United States. In some cities, like New York and Chicago, citizens engaging in participatory budgeting where community members have a direct say and control over the budget for community improvement is becoming commonplace. In fact, the

J. M. Choi (✉)
Department Sociology, San Diego State University, San Diego, CA, USA
e-mail: jchoi@sdsu.edu

J. W. Murphy · R. Dahab
Department of Sociology, University of Miami, Coral Gables, FL, USA

C. Holkenbrink-Monk
Department of Sociology, California State University, San Marcos, CA, USA

© Springer Nature Switzerland AG 2019

S. L. Arxer, J. W. Murphy (eds.), *Community-Based Health Interventions in an Institutional Context*, International Perspectives on Social Policy, Administration, and Practice, https://doi.org/10.1007/978-3-030-24654-9_4

New York Times has recently called participatory budgeting "revolutionary civics in action," noting that Participatory Budgeting in New York City (PBNYC) is the fastest growing participatory budgeting process in the United States. According to the Ash Center for Democratic Governance and Innovation at the Harvard Kennedy School, over 51,000 local residents voted on implementing and overseeing projects to improve their neighborhoods to the tune of 32 million dollars in 2014–2015 through the Participatory Budgeting in New York City.

A Community-Based Philosophy

Quite often, community projects encourage participation and involvement of people in producing an outcome. Along the way, strangers may become acquaintances and acquaintances may become friends. The point is that intimacy among community members is nurtured and cultivated. A variety of persons and groups can participate in a community project as stakeholders or partners. While this sentiment seems to portray a positive trajectory toward democratic planning, on closer examination, traditional community projects continue to operate under atomistic philosophy with altruism as the default mechanism that supposedly ties its members as a collective.

Unlike traditional community projects, the philosophy of community-based work rests on two major principles that are very important. The first is that local knowledge should guide any project (Fals-Borda, 1988). Second, *full* participation by community members is a prerequisite to any community-based work. Accordingly, a crucial epistemological shift is made by true community-based initiatives.

Traditionally, community projects have been based on dualism (Bordo, 1987). Specifically, the assumption is made that subjectivity can be divorced from objectivity. In fact, this separation is necessary to acquire reliable data. After all, objective information is the accepted standard. Within this dualistic framework, methods are designed to overcome subjectivity. With this source of error transcended, sound data can be gathered and reliable decisions made. In effect, subjectivity is a distraction that must be left behind if a project is to be based on real evidence. In the absence of subjectivity, facts are available for scrutiny.

Community-based projects, on the other hand, eschew this dualism; this separation is thought to be impossible to justify. What actually occurs, instead, is that persons are intimately connected with everything that is known. Specifically, they interact and give meaning to their lives and act on the basis of these interpretations. In this sense, interpretation and other modes of human agency are impossible to sidestep.

Communities are thus comprised of what Kleinman (2010) calls "moral worlds," that is, norms and expectations that are constructed and modified as those persons see fit. The implication is that rather than objective, facts are invented and tied intimately to language use and the narratives communities create to make sense of their history and prospects. Hence, as some critics say, facts are "biographical" (Berger & Luckmann, 1967).

What this rejection of dualism suggests is that local knowledge is essential to the success of any project. The values, beliefs, and commitments of a community's members are not illusory but provide insight into how they define themselves, important issues, and a successful intervention. Local knowledge, in short, reveals how a project should be designed to fit neatly and effectively into a community.

The second big principle is participation (Murphy, 2014). Clearly, community projects rely on local volunteers. But most often, these persons are mainly consulted or invited periodically to meetings. In reality, they are manipulated to gain their approval or access to resources, such as funds or land. A community-based project moves far beyond this minimal level of involvement.

Advocates of community-based projects, accordingly, argue that local persons should participate intimately in every phase of the project. Some go so far as to argue that they should control these endeavors. Given the importance accorded to local knowledge, this degree of participation only makes sense. Every opportunity, in short, should be available for this reliable information to be utilized.

But equally important is that this participation enhances the sustainability of a project. The research in social psychology demonstrates that real inclusion increases a community's commitment to an activity (Lune, 2010). For example, such "buy-in" helps to guarantee the longevity and quality of a project (Kaplan, 1973). Because of their continuous input, neighbors will take pride in their work, demand to make suggestions, and assume key responsibilities.

Most community projects do not address the issue of dualism. This epistemology often labors silently, however, to marginalize local input and lessen participation. Most community projects, after all, are very practical rather than philosophical affairs. Nonetheless, despite this initial conception, a significant theoretical shift is at the core of community-based work.

What Is a Community?

Almost none of the discussions of traditional community projects begin with the question: what is a community? This omission seems to indicate that the answer is obvious. In fact, they adopt the two usual options. But both of these versions, due to the influence of dualism, treat communities in a very superficial manner. Most projects are thus integrated into a community haphazardly.

A community is envisioned typically to be either a group or a collection of individuals (Murphy, 2014). And because of dualism, both identities are specified by objective traits that link these persons to a particular location. For example, racial, ethnic, and other markers are understood to identify persons from a particular locale. In most cases, a community is associated with demographic features and a location.

Recent research, on the other hand, reveals that this perspective is shortsighted. What is missed by the traditional objective indicators is the process whereby persons become connected and form a community (Land, 1983). Persons, stated simply, are united through their commitments. They define themselves as existing together, as sharing key elements or experiences, and gradually establish bonds that reflect these beliefs. At times, conventional identity markers may refer to a community that mimics these traits, but at others, these characteristics may have little or nothing in common.

A community is thus fairly elusive but not impossible to discover. From a community-based perspective, however, this finding is very important. No longer can a project be predicated on merely making contact with a community and trying to establish workable and cordial relationships. Something more profound is necessary, since a community is not an object but a domain of commitment (Chavis & Newbrough, 1986). A community-based viewpoint takes into account that persons constructed and continue to construct this association.

The point now is not simply to find or enter but engage a community. This process can begin with the standard "walk about," in order to become visible, interact with residents, and understand the environment. But the goal of these efforts goes beyond familiarity or friendship.

Eventually, discussions, meetings, maps, and any other means must lead to a dialogue that reveals why certain persons formed a community. From the inception of a community-based project, the world created by persons is the focus of attention (Minkler & Wallerstein, 2011). Access to this domain, or a true meeting, is necessary to understand why a community exists and how to engage these persons in meaningful relationships. Clearly without local knowledge, this style of engagement will not likely occur. Indeed, the basic premise of participatory budgeting is to best capture the elusive local knowledge of different communities (often forgotten or underserved) so that the needs of that community are met according to the priorities set by its community members.

Participatory Budgeting (PB): Beyond Traditional Budgeting

Traditionally budgets have been out of the hands of the public and made behind closed doors. The standard practice of budget making usually involves publicly elected officials consulting experts or bureaucrats in the allocation of tax dollars. The dualistic nature of traditional budgeting is quite clear: the demarcation of managers of money (politicians) and recipients (the public) of money. This benefactor/beneficiary relationship is sustained and legitimized through what Durkheim calls "rituals" where things are categorized distinctly between the sacred (experts) and the profane (lay community members) (Durkheim, 2001).

Nevertheless, due to many years of dysfunction and misuse of the tax money, the public is now clamoring for increased transparency. Due to economic fluctuations, and poor budget decisions, local needs have been overlooked. Select segments of cities, for example, have been ignored, while money is readily available in other parts for neighborhood improvements (Lerner, 2014). Such inequities have begun to erode confidence in governmental planning. Many surveys report government dysfunction as one of the most serious problems faced by the American public.

The outcry for a new budget process is not merely a technical issue. The point is not merely the elimination of corruption or bias, or to streamline matters, but to democratize the budget process. Only a "thin democracy" is in place if communities cannot play a role in determining how tax money is allocated (Barber, 1984). Given that the economy is central to social life, anything less than full participation of the citizenry poses serious questions about whether democracy exists at all. And a democratic polity seems to have widespread appeal.

Participatory budgeting burst on the scene in Porto Alegre, Brazil (Abers, 1998, 2000). As part of the worldwide movement to create a more equitable and sustainable world, a revolutionary way of creating, implementing, and evaluating city budgets was initiated. Through their local councils, persons who were formerly excluded from this process—including the poor and marginalized—were suddenly thrust into the forefront of formulating budgets. A strategy for allocating funds, accordingly, began to percolate up from neighborhoods, including specific projects that were identified as having priority. And because of this change, services were greatly improved in underserved areas (Pape & Lerner, 2016).

Once this process began, local persons felt empowered and demanded more inclusion (Rappaport, 1981; Wampler, 2007b). Simply put, they began to understand the connection between the economy and their freedom. If they could control city spending, many of the barriers to personal and collective growth could be eliminated.

The benefits of participatory budgeting began to be recognized beyond Brazil (Abers, 1998, 2000). Although a radical idea, many cities examined the process. One of the more famous examples in the United States is Chicago. Although tried seriously in only one ward, the concept began gradually to spread. Many citizens throughout the city, accordingly, began to raise questions about how government spending could be made more pertinent and equitable.

But many fears plagued this process. Specifically noteworthy is that persons will be selfish and only look out for themselves. Those who are most powerful, furthermore, will likely dominate this activity (Lerner, 2011). Hence, the budget process will no longer be rational but a free-for-all, whereby persons and communities battle one another to secure advantages.

While such dire scenes were never witnessed, why budget participants should collaborate was never made clear. At times, appeals were made to altruism and community spirit (Sousa, 1998). But another rationale is available that has not received much attention, although this idea is central to community work. This principle is solidarity, and can offer an appropriate moral framework for participatory budgeting.

While altruism and community spirit are sometimes effective in supporting participatory budget formation, these notions are notoriously vague. Solidarity, likewise, can be misunderstood, unless the philosophical maneuver presupposed by this notion is explained, along with the practical implications. In other words, simple appeals for solidarity will not likely advance the cause of participatory budgeting.

The aim of this chapter, accordingly, is to address solidarity to supply participatory budgeting with a necessary moral framework (Pateman, 1970; Jordan, 2016). Of course, there is never a guarantee that persons or communities will adhere to moral guidelines, but having a framework is certainly better than not. Additionally, one that is attuned to the participatory nature of budget formation would be especially important.

Participatory Budgeting Must Do More than Simply Reform

Clearly, there are many benefits to participatory budgeting. In addition to improved transparency, proponents claim that relations are improved within and between communities, not to mention with governmental representatives (Lerner, 2014). Democracy seems to spread, in other words, as persons learn about the needs and ambitions of their neighbors and engage them in dialogue about budget priorities. In this regard, even the World Bank has identified participatory budgeting as a valuable best practice (Lerner, 2017).

In democratic societies, local participation in institutions is encouraged. Town meetings and involvement on school boards, for example, are part of the mythology, along with grassroots activism. Nonetheless, budgets have been almost sacrosanct and developed mostly by professionals. The assumption is that when carried out in this way, the process will be reasonable, follow set guidelines, and be value-free. In short, rationality will prevail.

For the most part, the formation of budgets remained out of sight. But even when reviewed publicly, the process seems vague, mysterious, and mostly incomprehensible. After all, for the most part, the public has had little or no experience in these affairs. Only a select group has had access to these deliberations and grasps the technicalities of assembling a budget.

Critics, accordingly, began to call for increased accountability, and local participation seemed to be a logical solution. In different places, the theories and motivations varied, but in the end, grassroots guidance was considered to be necessary and viable. The required budget information is thus disseminated throughout a community, along with the requisite skills, so that local persons can act as experts and direct the budgeting process (Wampler, 2007a). Over time, these persons acquire the confidence and skills necessary to be in complete charge of this activity.

Most often, a community group is formed that guides this activity. Following this step, meetings are called where budget information is discussed, projects are proposed and evaluated, and votes are taken. Like most community discussions, this process is not necessarily neat and can be tedious. Constructing a local budget, accordingly, can take up to 6 months. But communities seem to enjoy the process and like the outcomes (Cabannes, 2004).

The anticipated result is that due to this participation, money will be spent wisely and that communities will be satisfied with the results. Local projects, in other words, will be supported in the long term, due to the commitment of community members. Simply put, participation confers a sense of ownership that culminates regularly in increased sustainability (Souze, 2001). In the literature on this topic, this support is referred to as "buy-in," and is recognized as vital to the success of a project.

While communities do not have access to the entire budgets of cities, even in Brazil, a lot of money is available—usually up to 15% of a city's budget. Most important, however, is that this amount has been sufficient to foster significant change (Kasdan & Markman, 2017). Indeed, the cumulative effect has been impressive. But can these non-professionals perform such a task, even with the necessary training? The general fear is that they are undisciplined, untested, and likely to make either stupid or self-serving decisions. What must guide this process, therefore, to avert disaster?

Cultural Challenges of Participatory Budgeting

In many respects, participatory budgeting resembles a utopian project. That is, given how persons usually behave, how can this process ever succeed? Local participation may be a nice, and even a captivating idea, but the likelihood of average persons dedicating themselves to a long-term, voluntary endeavor and cooperating is slim. In fact, this idea contradicts the cultural norms that are currently in place (Harvey, 2005).

The standard expectation is that most persons or communities will focus on their personal interests. For the most part, they are encouraged to follow this path and believe that such behavior is entirely warranted. After all, in the United States, they are taught to look out for themselves first, and if inclined to engage later in charity. Concern for the collective good, however, is optional. Any other policy is simply irresponsible.

For participatory budgeting to succeed, therefore, neighbors must be forced or enticed to cooperate. Pressure must be applied so that they see the wisdom of working together. This socialization may take the form, for example, of moral appeals or something more stringent, such as legal mandates. The problem is that these and similar enticements result often in resentment, and even spawn additional conflict.

Why does this situation appear to be so entrenched? The simple answer is that America is a capitalist society. Even though democracy is touted, and the common good applauded, persons are consumers first and then citizens. What this distinction means in everyday affairs is that they succeed or fail through their own efforts and owe little to others. Persons are expected to make sound decisions that advance their own aims, and perhaps those of their families, while according others the freedom to pursue their goals.

Although capitalism certainly contributes to minimizing the communal character of daily life, there is another, more profound philosophy that contributes to this condition. Specifically, the Western tradition is replete with atomism (Mathews, 1991). The basic idea is that reality, including society, is comprised of isolated units, or atoms, that may combine under certain conditions. Their traditional behavior, however, is that they adhere to individual trajectories and, at times, crash into one another. Any association, and resulting configuration, is tenuous.

Clearly, capitalism is consistent with this outlook, since relationships are mostly strategic to secure advantages at the market place. But what about participatory budgeting? In this case, persons can be expected to behave like self-interested egos, who calculate and strategize to protect their individual interests.

A neighborhood, accordingly, will likely act like a composite of interest groups, who focus on their immediate concerns (Herrnson, Deering, & Wilcox, 2013). Any suggestion that they should cooperate is not appealing, due to the sacrifice that may be involved. As interest groups, almost by definition, they have unique agendas that must be given priority. In fact, within this framework, cooperation may even be treated as unnatural, or at least an unwarranted intrusion or burden.

With this atomistic imagery in place, participatory budgeting will be difficult to implement. Persons can be presumed to bicker constantly and become easily frustrated with the dedicated interaction required by the process. When people believe that they must be brought together, and view these appeals as coercive, any collective action is going to be resisted and breed resentment. Participatory budgeting, accordingly, will likely be approached as an idealistic scheme, with little chance of success.

The Philosophical Thrust of Participatory Budgeting

The problem is that atomism conveys an illusion. In effect, persons are not, and never have been, atoms. They are not fundamentally cut off from one another, and only by chance come into contact. Social existence, in other words, does not consist of mostly accidental encounters, interspersed with chance alliances (Taylor, 1985). At the basis of social existence is a bond.

Basically, atomism is sustained by faulty imagery, and, most recently, a particular economic ideology. In reality, persons are open to others and share a common space. In many ways, accordingly, their fates are joined, even when the communal nature of social life is denied. Even when persons or communities strive to assert their individuality, and stress their unique virtues and successes, they cannot escape the influence of others.

But given this connection, how is the illusion of atomism maintained? Stated simply, this imagery persists because of dualism. Although fundamental to Western philosophy, dualism came to the forefront with Rene Descartes (Bordo, 1987). To supply a sound, unequivocal foundation for truth, he claimed that the mind and objects occupy categorically distinct realms. In more contemporary terms, subjectivity is separated from objectivity, along with facts from values. As a result, reliable knowledge is available that is uncontaminated by personal flaws or opinions.

Although dualism is treated by various contemporary philosophers as defunct, this viewpoint prevails in many areas, including descriptions of social life. In this specific case, persons are subjects while others are objects and vice versa. The result is solipsism, whereby each person is presumed to occupy a unique bubble (Strauss, 2008). A lot of ink has been spilt by philosophers, accordingly, trying to explain whether the minds of others can be known. Any authentic solidarity is thus difficult to imagine.

Bringing persons together is fraught with difficulty. Various schemes have been proposed, such as the state or contract, which assume a gap exists between persons. But also presumed, for example, is that persons are bound together sufficiently to form a state or establish a contract. That is, even before persons are saved from chaos by these schemes, they are open to others and able to cooperate.

What these newer writers are saying is that social philosophy traditionally has begun in the wrong place (Levinas, 1998). In other words, persons were never separate and unable to establish relationships, without the aid of governmental or legal frameworks. For this reason, the term intersubjective is used regularly nowadays to describe the basic human condition. Persons are not subjects severed from others, or objects, but instead are always intertwined with others and able to interact.

A more holistic image is thus appropriate for describing a community (Bauman, 2008). A new way of thinking about moral order is also implied, one that supports participatory budgeting. An entirely different message about motivation and goals is possible than is associated with atomism. Most important is that the ideology of the "individual first" loses credibility, with the ascendance of communitarian viewpoint. Starting from intersubjectivity, instead of the individual, inaugurates a new approach to understanding social responsibility (Mijuskovic, 1992). Instead of rare, simply put, cooperation is the norm. Solidarity, accordingly, is not beyond the pale.

Communal Budgetary Discourse: A New Moral Framework

Simply because persons or communities are open to others, and have impact on one another, does not mean that they have similar priorities. In contrast, the assumption is that they have different perspectives and ambitions. Conflict is thus likely. Nonetheless, even in view of these differences, a discussion about budgets diverges significantly from past discourse. The key realization is that persons are in this budget process together.

As a result, the first important change in their initial response is not self-enhancement. The traditional view that persons are on the prowl constantly to seek advantages and hoard opportunities no longer makes sense, given the communitarian character of social life (Cohen & Arato, 1992). Such avariciousness would be a scandal and hardly normative. Those who exhibit such behavior would no longer be cheered but criticized.

On the most basic level, the morals of society would change. The usual rip-off ethic would be viewed as leading to chaos. How could everyone looking out mostly for themselves, and taking advantage of others, have a positive outcome? Society would consist of barking dogs who exhibit only the most superficial concern for others, such as avoiding direct confrontations. All the time, however, they scheme against their adversaries (Lewis & Weigert, 1985).

But contrary to this unfortunate situation, the second change is that compromise is not treated as defeat. When in their adversarial mode, interactions are tactical and disingenuous. Persons or communities listen to others simply to circumvent their positions and gain the upper hand. Taking the views of others into consideration in a more genuine way is treated as naïve and, in general, unproductive (Harvey, 2005).

In a more communal situation, a different outlook and outcomes are expected. Rather than a loss of freedom or autonomy, compromise is logical. Because behavior has impact far beyond the individual in the absence of atomism, divergent views should be equitably reconciled. After all, who has the unlimited freedom required to usurp the positions of others? Persons are now expected to act in concert, because of their fundamental connection.

As a result, and third, a moral budget emerges from honest negotiation that recognizes possibly different aims. The basic view of this process is that everyone’s view counts and should never be violated (Sen, 1999). A realistic budget, therefore, resembles a mosaic rather than a consensus. The aim, in other words, is not to distill positions until a bottom line is achieved, but to incorporate as many proposals as possible. Basically, a different logic of negotiation is operative than is usually the case. Instead of imposing a framework a priori that restricts, and thus eliminates proposals, persons strive to adjust their respective positions until the largest range of possible projects is included. Multiple interests are thus encouraged, rather than mergers that may reflect power or a mythical imperative and require the marginalization of many proposals.

During this process, for example, some persons may realize that, at this time, the proposals of others are more important for the commonweal. Such deferment is not a personal loss, but a gain that everyone will realize. Remember that the basic point, from the beginning, is not personal enhancement but a more expansive project, that is, the promotion of all participants. The representation of diverse positions in the final budget product entails a new logic, as opposed to a zero-sum game (Thurow, 1981). Such a restrictive game, in fact, represents the old imagery of separate competitors who strive to control the budget process.

In the end, the participants make a budget. And indeed, this process is only nominally economic but social, since budget restrictions depend on how persons or communities want to treat one another and use their collectively generated resources. With persons negotiating within the confines of the common good, and the accompanying diversity, they can make any adjustments they see fit to fulfill their goals (Dussel, 1988). Budgetary *a prioris*, in other words, are passé in a truly participatory or communal environment (Baiocchi & Ganuza, 2013).

Conclusion

Clearly, budgeting is a very practical activity to determine how money will be spent. Nonetheless, the participants should not be lulled to sleep by the apparent mundane nature of this process. A change of philosophy is advanced that is crucial to the success of participatory budgeting. If this shift is not appreciated, this approach to forming a budget is in jeopardy.

Particularly noteworthy is that past imagery has been antagonistic to this mode of budgeting, not to mention misrepresenting social life. Persons are not atoms, thereby invalidating the “me-first” reaction to opportunities for gain. As atoms, the collective response necessary for participatory budgeting to succeed is difficult to envision. The personal gains of persons or communities take precedence over everything else.

But a different imagery, and accompanying philosophy, is available that is more supportive of this novel economic process and solidarity. In the absence of atomism, persons and communities must now negotiate in a framework that encourages collective action, and even sees such a response as perfectly rational. A new moral outlook is thus possible, in contrast to adversarial relationships.

Rather than focusing on personal gain that may translate into the common good, a more direct approach is suggested to dispensing funds (Baiocchi, 2005). That is, through dialogue, a fair and representative budget can be developed. Through a fully participatory process, each proposal can be treated with dignity. The result is a budget mosaic that includes a range of proposals, without pre-conceived mandates (Lerner, 2014). The end product can thus be representative, rather than a distillation of input.

But as mentioned earlier, this new imagery requires a serious discussion of philosophy. At first, such an assessment maybe resisted. After all, in the traditional context of framing budgets, such an analysis is a distraction. In participatory budgeting, on the other hand, a reassessment of philosophy is essential. Participants must understand, for example, why atomism is unworkable, inaccurate, and generally silly. An opposing position, based on intersubjectivity, must make sense and be applied appropriately. Participatory budgeting, in fact, depends on the moral position that accompanies this change in philosophy. Participatory budgeting without this philosophy will not likely come to full realization.

References

Abers, R. (2000). *Inventing local democracy: Grassroots politics in Brazil*. Boulder, CO: Lynne Rienner.

Abers, R. (1998). From clientelism to cooperation: Local government, participatory policy, and civic organizing in Porto Alegre, Brazil. *Politics and Society, 26*(4), 511–523.

Baiocchi, G. (2005). *Militants and citizens*. Palo Alto, CA: Stanford University Press.

Baiocchi, G., & Ganuza, E. (2013). Participatory budgeting as if emancipation mattered. *Politics and Society, 42*(1), 29–50.

Barber, B. R. (1984). *Strong democracy: Participatory politics in a new age*. Berkeley, CA: University of California Press.

Berger, P., & Luckmann, T. (1967). *The social construction of reality*. Garden City, NY: Doubleday.

Bordo, S. (1987). *The flight to objectivity*. Albany, NY: SUNY Press.

Bauman, Z. (2008). *Does ethics have a chance in a world of consumers?* Cambridge, MA: Harvard University Press.

Cabannes, Y. (2004). Participatory budgeting: A significant contribution to participatory democracy. *Environment and Urbanization, 16*(1), 27–46.

Chavis, D. M., & Newbrough, J. R. (1986). The meaning of community in social psychology. *Journal of Community Psychology, 14*(4), 335–340.

Chomsky, N. (1999). *Profit over people: Neoliberalism and global order*. New York, NY: Seven Stories Press.

Cohen, J. L., & Arato, A. (1992). *Civil society and political theory*. Cambridge, MA: MIT Press.

Durkheim, E. (2001). *The elementary forms of religious life*. Oxford, UK: Oxford University Press.

Dussel, E. (1988). *Ethics and community*. Eugene, OR: Wipf and Stark.

Fals-Borda, O. (1988). *Knowledge and people's power*. New York, NY: New Horizons.

Harvey, D. (2005). *A brief history of neo-liberalism*. Oxford, UK: Oxford University Press.

Herrnson, P. S., Deering, C. J., & Wilcox, C. (2013). *Interest groups unleashed*. Thousand Oaks, CA: Sage.

Jordan, B. (2016). Building student power through participatory budgeting. https://www.thenation.com/article/building-student-power-through-participatory-budgeting/

Kaplan, R. (1973). Some psychological benefits of gardening. *Environment and Behavior, 5*, 145–161.

Kasdan, A., & Markman, E. (2017). Participatory budgeting and community-based research: principles, practices, and implications for impact validity. *New Political Science, 39*(1), 143–155.

Katznelson, I. (2005). *When affirmative action was white*. New York, NY: W.W. Norton and Company.

Kleinman, A. (2010). Four social theories for global health. *The Lancet, 375*(9725), 1518–1519.

Land, K. C. (1983). Social indicators. *Annual Review of Sociology, 9*, 1–26.

Lerner, J. (2017). Conclusion: Time for participatory budgeting to grow up. *New Political Science, 39*(1), 156–160.

Lerner, J. (2014). *Everyone counts: Could participatory budgeting change democracy?* Ithaca, NY: Cornell University Press.

Lerner, J. (2011). Participatory budgeting: Building community agreement around tough budget Decisions. *National Civic Review, 100*(2), 30–35.

Levinas, E. (1998). *Entre nous: On thinking-of-the-other*. New York, NY: Columbia University Press.

Lewis, J. D., & Weigert, A. J. (1985). Social atomism, holism, and trust. *The Sociological Quarterly, 26*(4), 455–471.

Lune, H. (2010). *Understanding organizations*. Cambridge, UK: Polity Press.

Mathews, F. (1991). *The ecological self*. London, UK: Routledge.

Mijuskovic, B. (1992). Organic communities, atomistic societies, and loneliness. *The Journal of Sociology and Social Welfare, 19*(2), 147–164.

Minkler, M., & Wallerstein, N. (2011). *Community-based participatory research: From processes to outcome*. San Francisco, CA: Jossey-Bass.

Murphy, J. W. (2014). *Community-based interventions: Philosophy and action*. New York, NY: Springer.

Pape, M., & Lerner, J. (2016). Budgeting for equity: How can participatory budgeting advance equity in the United States? *Journal of Public Deliberation, 12*(2), 9. https://www.publicdeliberation.net/jpd/vol12/iss2/art9

Pateman, C. (1970). *Participation and democratic theory*. Cambridge, MA: Cambridge University Press.

Rappaport, J. (1981). In praise of paradox: A social policy of empowerment over prevention. *American Journal of Community Psychology, 9*(1), 1–15.

Sen, A. (1999). Democracy as a universal value. *Journal of Democracy, 10*(3), 3–17.

Sousa, B. (1998). Participatory budgeting in Porto Alegre: Toward a redistributive democracy. *Politics and Society, 26*(4), 461–509.

Souze, C. (2001). Participatory budgeting in Brazilian cities: Limits and possibilities in building democratic institutions. *Environment and Urbanization, 13*(1), 159–184.

Strauss, D. F. M. (2008). Atomism and holism in the understanding of society and social systems. *Koers, 23*(2), 187–205.

Taylor, C. (1985). Atomism. In *Philosophical papers* (pp. 187–210). Cambridge, UK: Cambridge University Press.

Thurow, L. C. (1981). *Zero-sum Society*. New York, NY: Penguin Books.

Wampler, B. (2007a). A guide to participatory budgeting. In A. Shah (Ed.), *Participatory budgeting* (pp. 21–54). Washington, DC: The World Bank.

Wampler, B. (2007b). *Participatory budgeting in Brazil: Contestation, cooperation and accountability*. University Park, PA: Penn State University Press.

Chapter 5
Aims of a Community-Based Research Program

Steven L. Arxer

Introduction

The theoretical considerations related to community-based planning and organization discussed so far in this volume extend to community research. A new community-based philosophy suggests a different methodology and approach to conducting research. In some ways, community-based research is defined by the shift away from positivism. Rather than adopting the assumptions and tactics of the natural sciences, community-based researchers often prefer the tactics advanced by the cultural sciences. And while a movement away from positivist science is notable, community-based research presents new aims that are broader than conventional methodological debates.

The debate between positivism and cultural sciences has been a prominent issue in the Western intellectual tradition. At the center of this controversy is a question about the nature of reliable knowledge. To the extent that human perception is filled with values, assumptions, and commitments, then particular methodologies should be used to acquire the facts leading to truth. Reminiscent of early Greek thinkers such as Plato, *doxa* must be overcome if information is not to remain muddled by opinion. A more certain basis of knowledge is needed, at least with respect to a scientific world-view.

In this way, Western philosophy has been identified with a realistic view of nature that leads to positive science. This realism means that an ahistorical ground, separate from bias and quotidian issues, should be the source of knowledge. Hughes and Sharrock (1997, pp. 97–100) describe this discussion in Western philosophy as the *Natur- Geisteswissenschaften* debate. While experience is the root of knowledge,

S. L. Arxer (✉)
Department of Sociology and Psychology, University of North Texas at Dallas,
Dallas, TX, USA
e-mail: steven.arxer@untdallas.edu

© Springer Nature Switzerland AG 2019

S. L. Arxer, J. W. Murphy (eds.), *Community-Based Health Interventions in an Institutional Context*, International Perspectives on Social Policy, Administration, and Practice, https://doi.org/10.1007/978-3-030-24654-9_5

the focus of research is on nature and not cognition, interpretation, or other human sources (de Man, 1983, pp. 2–35). To borrow from Stanley Fish (1989, p. 30), the aim of science is to "anchor the universe and thought from a point above history and culture." Positivism asserts that valid knowledge must be severed from everyday subjectivity so that the true nature of things can be illuminated. Moreover, researchers should adopt specific methodologies to guarantee valid judgments about facts. In practice, this strategy entails using data collection techniques that are primarily empirical and capture the quantifiable characteristics of objects. With respect to the social sciences, an empirical methodology fosters certitude about the structure of society, institutions, and communities.

To be sure, the central tenants of positivism have not gone unscrutinized. Social scientists have grown skeptical of positivism, particularly following the "linguistic turn" in philosophy (Tucker, 1994, p. 13). Simply put, access to a primordial foundation, such as nature, is precluded given the symbolic texture of reality. Humans cannot be disinterested observers, since all information is derived from assumptions that guide the perception of reality. Michel Foucault (1989, p. 42) refers to this symbolic domain as "epistēmē" while drawing attention to the cultural presuppositions that are endemic in any outlook. Through language and communication, persons cultivate meaning for themselves and their environment. Basically, persons intervene in their world and are active participants in the creation of knowledge.

Some see this methodological debate as culminating in quantitative and qualitative researchers occupying different camps. As Fred Kerlinger once noted, "There is no such thing as qualitative data. Everything is either 1 or 0" (quoted in Miles & Huberman, 2002, p. 40). On the other side, for instance, D. T. Campbell has stated that "All research ultimately has a qualitative grounding" (Miles & Huberman, 2002, p. 40). Community-based philosophy has generally been characterized as more compatible with a "qualitative version," which focuses on community participation and community biographies (Murphy, 2014 p. 77). Describing communities as places where persons enact their values and behavioral modalities seems to be an appropriate lens to understand communities, as opposed to as empirical locations. In this vein, community-based participatory research (CBPR) has emerged as the methodology of community-based researchers (Minkler, 2005). As McTaggert (1991) notes, CBPR attempts to center the voices and actions of community members, thereby avoiding a reductionist empirical view of social life.

This chapter explores the ways in which CBPR moves community-based research beyond the quantitative and qualitative debate. In particular, quantitative and qualitative approaches still share a preoccupation with successful strategies for collecting data. As Dabbs Jr. (1982, 31–63) writes, "Qualitative and quantitative are not distinct." Dabbs Jr. (1982, p. 31–63) differentiates between qualitative and quantitative investigations noting that qualitative research refers to the collection of "meanings, concepts, definitions, characteristics, metaphors, symbols and descriptions of things…" while arguing that quantitative research generates "counts and measures of things." In both cases, the focus is on a data collection strategy and in refining the tools of this process. Although the issue of accurate data acquisition is important to CBPR, a community-based research agenda pays attention to research activism among community members to gather information and effect social change. Accordingly, Minkler (2005, p. ii3) defines CBPR as “participation, research, and action.”

So as to better appreciate the unique methodological orientation proposed by CBPR, some historical roots to this practice are presented and compared to positivist and qualitative methods. Given that the aim of CBPR is to involve community members in research projects, as a way to better plan and deploy healthcare projects, the way that participation is conceptualized by quantitative and qualitative methods must be explored. The goal is to address how a preoccupation with data collection techniques and rigor marginalizes persons not identified as experts in methods. In this way, both approaches miss the important step of promoting community-directed plans because they adhere to traditional views on knowledge production that center professional experts in the research process.

Against Positivism and Realism: Roots of Community-Based Participatory Research in Health

The difficulties associated with health problems in marginalized communities, such as the urban poor, helped to give rise to a community-based approach to solving healthcare issues. The complexity of these problems and the need for more “authentic” community partnerships meant that traditional approaches, driven by “outside experts,” were viewed as insufficient to address healthcare needs in locally relevant ways (Minkler & Wallerstein, 2003). The historical roots of CBPR can be found in the action research of social psychologist Kurt Lewin in the 1940s (Lewin, 1946). He emphasized the cyclical process of data collection, participant action, and investigative reflection. Perhaps to a greater extent, CBPR is tied to the revolutionary intellectual approaches put forth in countries in South America, Asia, and Africa in the 1970s (Hall, 1992). For example, the ideas of Brazilian adult educator Paulo Freire (1970) and of Fals-Borda (1987) focused on co-learning and action-based inquiry. These scholars developed their approaches to inquiry in light of, and as a way to counter, the colonial experience of oppressed communities. Within this broad intellectual and geo-political context, new research approaches grew to address community development problems in areas of health and inequality, among others (Minkler & Wallerstein, 2003).

At the core of participatory action methods is a rejection of positivistic logic and method. While participatory action research is identified as a “political process,” driven by the commitments and social practices of community participants (McTaggert, 1997), positivism seeks to distinguish facts from values. Knowledge for positivists exists “outside the mind” and is related most closely to physical events (Durkheim, 1965, p. xiii). Unhampered direct experience, accordingly, is of paramount importance in discovering truth.

Because nature is the source of facts, knowledge is only available to those who can perceive nature accurately. The degree to which physical properties contain knowledge suggests that careful observation and perception are necessary. For this reason, positivists view knowledge and the acquisition of information to be a rigorous affair. As Reid (1994) notes, positivists view legitimate knowledge to be derived from serious experimentation. Most commonly, this viewpoint means that research should adopt the scientific method as a way to temper the mind and minimize perceptual errors. Only after rigorous training is perception trusted, since the human element is always a liability. Consequently, the mind is given a passive role in this methodology, in that knowledge is both objective and only obtainable through the use of specific techniques and steps.

Once in the hands of expert practitioners, data collection can be considered sound and result in information treated as objective. Information that is empirical in nature and highlights objective properties is thought to be valid. Methodology that narrows the mind through instrumentation and natural observation helps persons discard their biases (Lake, 1993). A key assumption of positivism is that methodological techniques are value-free. Lyotard (1984) claims that these tools are treated as "prosthetic aids" that enable researchers to better contact the world. Simply put, interpretation is presumed to be overcome through strict pursuit of standardized techniques. Research proceeds in a rigorous stepwise manner, because judgments are replaced by methodological rubrics, operations, and calculation. Data are transformed into autonomous, objective *things*. All that is needed to obtain facts are skilled researchers who can follow methodological guidelines that are neutral. (Hughes & Sharrock, 1997, p. 28).

Positivism's focus on standardized protocols is significant in community work. When this approach is applied to studying communities, a hierarchy can easily develop between researcher practitioners and community members. An emphasis on specialized skills—such as identifying research questions, methodological design, and statistical analysis—raises the stature of trained professionals who gain control of local projects. The implied training deemed necessary for research inquiry defines professionals as the "experts" and indispensable to social planning (Gilgun, 2005). A type of surrogate vision on behalf of communities is encouraged, for otherwise data may be sullied by the beliefs and values of the everyday observer.

The end product of this situation is twofold. First, in order to avoid being guided by unsubstantiated ideas, expert researchers must be at the center of the research process. After all, what training does the layperson possess that is sufficient to encounter the real world in a dispassionate manner? Often enough, interpretive judgments and personal experiences are presumed to be the starting point of community members' understanding. However, a key tenant of CBPR is that community inquiry should be a "'co-learning process' to which community members and outside researchers contribute equally" (Minkler, 2005, p. ii4).

Second, an abstract or realistic view of the social world is created. Specifically, the social world is associated with empirical properties, such as demographic factors, social networks, and capacity levels, that characterize a community. However, researchers become disconnected from the social world they study. Their role as practitioners is merely to gather and analyze data, because methodology has been overly formalized. A community is thus imagined to be a complex of variables that can be collected in a mechanistic way.

In contrast, community-based research assumes that expert knowledge is not a priori superior to that of community members and their worldviews. Rather than dispassionate, researchers must be deeply involved, as opposed to taking a passive stance, when encountering communities and tap into local knowledge. Researchers should, as Minkler (2005, p. ii4) states, show “a lifelong commitment to self-evaluation and self-critique” in relation to assumptions about community life. After all, communities are not obtrusive things to be observed but rather a political terrain shaped by local and external discourses. In a way, expert knowledge may be a hindrance to local projects to the extent that their presumed superiority marginalizes community viewpoints.

Qualitative Approaches and the Rejection of Grand Designs

A number of different intellectual traditions, such as phenomenology, ethnography, symbolic interactionism, and postmodernism, claim that the philosophical basis of positivism is simply untenable. Specifically, the Western philosophy of dualism that has separated truth from opinion and has sought to identify select methodological approaches as superior is passé. As Derrida (1978, p. 282) argued, the positivist grand design of knowledge and method is “forced to stop considering itself as the culture of reverence.” This incredulity toward the scientific enterprise is due to what some call the “linguistic turn,” which reimagines the way the human presence relates to facts, truth, method, and reality.

Central to this new epistemology is that reality is symbolic, that is, represents a constellation of “language games” that mediate perception (Lyotard, 1984, pp. 9–11). The upshot of this argument is that reality is linguistically constituted by the way persons interpret themselves and their surroundings. It is worth mentioning that this thesis on language replaces the “indexical view” used by positivists. Indexicality refers to the idea that language basically “points to” or “indicates” what is real in the world. A natural reference still exists, distinct from speech acts; the role of language is simply to express the way an empirical world is already organized. This portrayal of language is still dualistic, because reality retains a distinct status outside of symbolic interpretation (Rorty, 1991). Put differently, language merely puts reality on display for researchers.

Qualitative approaches contend that discourse does not stand for reality, but rather shapes the nature of human perception. As Derrida (1976, p. 156) once stated, “nothing exists outside of the text.” Reality and discourse are intertwined in a fundamental way that requires what is meant by reality and truth to be rethought. The schism between facts and values is extremely difficult to retain, because linguistic interpretation precludes a neutral standpoint. As Roland Barthes (1977, p. 30) writes, there is "no other side" to language, no autonomous reference point to anchor truth.

Because reality is a discursive practice, the traditional methods used by positivists to acquire knowledge are jettisoned by qualitative researchers. In this respect, the use of structural metaphors to describe the arrangement of the social world and the instrumentation used to access facts are abandoned. Indeed, the mechanistic imagery that suggests standardized techniques neatly separate judgments from facts is not suitable in a linguistically constituted world. As Lyotard (1984, p. 36) notes, "knowledge has no final legitimacy outside of serving the goals envisioned by the practical subject." Because reality is mediated by language and no longer exists a priori, all knowledge emerges from the locally conceived rules of language. Scientific and other models of reality are thus the result of different language games that draw the boundaries of reality. To borrow from Kuhn, science is a "paradigm" that represents one model of reality. Truth, therefore, is tied to the rules of speech that sustain a particular community.

In this context, technical competence is not sufficient to procure knowledge. Positivists understand technical rigor to be the antidote to the biases imposed by subjectivity and assume that with methodical tools in hand, facts can be revealed as a detached reality. However, qualitative researchers view this methodology as counterproductive to the discovery of truth, because of the abstract portrayal of knowledge (Lacan, 1977, p. 282). Language subtends reality; thus, the assumptions that frame discourse become the focus point of inquiry. Rather than obscuring values through instrumentation, the goal of research is to apprehend the symbolic dimensions of reality. Derrida (1980, p. 48) makes this point when he claims that researchers need to consult the epistemological interests that accompany data. The concern is that researchers who prioritize scientific refinement in the name of objectivity may distort data. At worst, researchers marginalize the persons they study when the assumptions that accompany a particular linguistic community are overshadowed by a structural rendition of community identity.

The New Language of Qualitative Research: Cultural Competence

Rather than technical competence, qualitative researchers often strive to develop their communicative competence instead. This "new language of qualitative method" becomes the focal point of analysis (Gubrium & Holstein, 1997). At the center of a qualitative research is an appreciation that facts are not things, but rather "accomplishments" reached through social interpretation (Pollner, 1991). Values and beliefs, therefore, imbue facts. Qualitative methods thus introduce a new element in knowledge acquisition. Gubrium (2009), for example, notes that communication is the focus of data collection. Through various methods, such as interviewing and participant observations, qualitative researchers try to gain access to how communities build their social worlds through collaborative speech.

This shift is important for community-based research. The empirical character of a community (e.g., demographics, geography, levels of capital, etc.) should not be taken as the sole cause of behavior and experience. Put differently, variables have primarily a social significance for a community. Reminiscent of the symbolic interactionist Herbert Blumer (1969), behavior is viewed by qualitative researchers to be the result of how persons give meaning to their worlds. Community assessments, for instance, are evaluated in terms of the intentions, beliefs, and commitments of community members. Claims related to community needs are validated from within the constellation of priorities established by these persons. This is to say that the knowledge production of a community should not be ignored in favor of expert insights. The patina of scientific objectivity does not carry the status required to obscure other sources of knowledge, given that a "disinterested logic of inquiry" is impossible (Foucault, 1975, p. 8).

The problem with positivism, according to qualitative researchers, is that simply having numerical data collection does not guarantee that the meaning of a phenomenon will be obtained. Instead, a qualitative approach asks researchers to exhibit sensitivity to the "domain assumptions" (Gouldner, 1970, p. 46) that contextualize a community. In some circles, this practice has come to be known as "intercultural competence" or cultural sensitivity (Deardorff, 2009). Either way, this practice implies that the researchers understand a person's or community's actions by exploring the presuppositions they make about reality. Murphy (1986) describes this activity as "epistemological participation" and distinguishes this activity from the procedural issues that are the hallmark of positive science.

In the field of health care, the idea of cultural competence has gained widespread attention as a possible way to improve the quality of care, as well as reduce social inequalities (Betancourt, Green, Carrillo, & Park, 2005). But to the extent that professionals still control research and services, local knowledge may be marginalized, even though emphasis is placed on communication (Betancourt et al., 2005). Nonetheless, exhibiting some awareness of the value of local input may improve planning, although a community may not play a large role in this process.

Beyond Cultural Sensitivity and Toward Praxis

While qualitative methodologies are most closely tied to community-based research, there are reasons why this strategy is not necessarily suggestive of a community-based approach. As Minkler (2005, p. ii5) cautions, there are "dangers of co-optation" related to certain research and intervention proposals. Of concern here is the reintroduction of traditional top-down research approaches that obscure the real intent of community-based planning and CBPR in particular.

McTaggert (1997, p. 79) identifies several core principles of CBPR. One is the notion of "self-critical communities." In practice, community-based research requires that community participants be engaged in inquiry and reflection, and not just professional researchers. In short, everyday persons should be deeply involved in the research process, or in what some call "theory-making" (Minkler, 2005, p, ii5). The issue for CBPR is the status of laypersons in the research process and not just the nature of knowledge.

While qualitative research emphasize the symbolic side of reality and encourages exploration of how communities frame issues, this aim does not guarantee that a community-based model will be adopted in the research process. After all, community members may be solicited to share their stories through interviews and focus groups, but a qualitative project may still be driven primarily by professionals. A community project may still be designed and managed by the researcher who develops the study question, conducts interviews and observation, codes and analyzes data, and produces findings (Heron & Reason, 1997).

The issue is that promoting cultural sensitivity does not address the assimilation of laypersons into the scientific enterprise. As opposed to such assimilation, CBPR seeks to develop a "partnership synergy" between community and researcher (McTaggert, 1997). Moreover, this relationship is not superficial and based merely on the transference of information from subject to researcher. As explained by Lasker et al. (2001, pp. 1799–205),

> [T]he synergy that partners seek to achieve through collaboration is more than a mere exchange of resources. By combining the individual perspectives, resources, and skills of the partners, the group creates something new and valuable together—something that is greater than the sum of its parts.

The challenge with both quantitative and qualitative methods is that they do not directly address the issue of inequality in the dialogue between researchers and community members. Qualitative investigations may remain led by professional researchers and thus communication is limited. Since the researcher directs what is asked, who is asked, and how to interpret community stories, certain viewpoints may be missed. In the end, the community is asked to adjust to the structure of the research process, because professionals are assumed to be best trained to collect the narratives of communities and distill pertinent information through elaborate coding schemes.

Although in-depth observations and narrative data can provide some context to a community, the values and perspectives of these persons may remain hidden without their thorough participation in a project. Cornwall and Jewkes (1995, pp. 1667–1676) highlight this concern by noting that community-based research should be alert to the "the attitudes of researchers, which in turn determine how, by and for whom research is conceptualized and conducted and the corresponding location of power at every stage of the research process." For this reason, CBPR argues for a participatory methodology that more fully centers community members' praxis, as authentic and full participants in the research process.

Conclusion

This chapter examines the epistemological and methodological backdrop to developing community-based research. The philosophical shift away from positivism toward more qualitative approaches highlights the trends within healthcare research to adopt methods that are attuned to local communities and their needs. In particular, methods that sensitize researchers to the communities they study and serve have become de rigueur in some circles, as professionals begin to see the value of local input. In many ways, health planners have begun to recognize that communication with communities is vital to successful health plans.

At the same time, these efforts to sensitize health professionals have a long way to go. To borrow from Stanley Fish (1989), cultural sensitivity does not "go all the way down," in that this strategy may not necessarily promote local control of health research. In particular, rejecting the epistemological hierarchy between local and expert knowledge is only part of the solution. Also needed is a shift that places local persons at the center of how and why knowledge is produced, managed, and used. CBPR suggests that professional researchers should no longer be presumed centerpieces of research projects; instead, community members should be given fuller participation in this knowledge economy.

References

Barthes, R. (1977). *Image, music, text*. New York, NY: Hill and Wang.

Betancourt, J. R., Green, A. R., Carrillo, J. E., & Park, E. R. (2005). Cultural competence and health care disparities: Key perspectives and trends. *Health Affairs, 24*(2), 499–505.

Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Englewood Cliffs, NJ: Prentice-Hall.

Cornwall, A., & Jewkes, R. (1995). What is participatory research? *Social Science & Medicine, 41*, 1667–1676.

Dabbs Jr., J. M. (1982). Making things visible. In J. Van Maanen (Ed.), *Varieties of qualitative Research* (pp. 31–66). Beverly Hills, CA: Sage.

de Man, P. (1983). *Blindness and insight*. Minneapolis, MN: University of Minnesota Press.

Deardorff, D. K. (2009). *The SAGE handbook of intercultural competence*. California, USA: Sage Publications.

Derrida, J. (1976). *Of grammatology*. Baltimore, MD: Johns Hopkins University Press.

Derrida, J. (1978). *Writing and difference*. Chicago, IL: University of Chicago Press.

Derrida, J. (1980). *The archeology of the frivolous: Reading Condillac*. Pittsburgh, PA: Duquesne University Press.

Durkheim, E. (1965). *The rules of sociological method*. New York, NY: The Free Press.

Fals-Borda, O. (1987). The application of participatory action-research in Latin America. *International Sociology, 2*, 329–347.

Fish, S. (1989). *Doing what comes naturally*. Durham, NC: Duke University Press.

Foucault, M. (1975). *The birth of the clinic*. New York, NY: Vintage Books.

Foucault, M. (1989). *The archaeology of knowledge*. London, UK: Routledge.

Freire, P. (1970). *Pedagogy of the oppressed*. New York, NY: Seabury Press.

Gilgun, J. F. (2005). The four cornerstones of evidence-based practice in social work. *Research on Social Work Practice, 15*(1), 52–61.

Gouldner, A. W. (1970). The coming crisis of Western sociology. New York: Basic Books.

Gubrium, J. F., & Holstein, J. A. (1997). *The new language of qualitative method*. New York, NY: Oxford University Press.

Gubrium, J. F. (2009). *Analyzing narrative reality*. Thousand Oaks, CA: Sage.

Hall, B. L. (1992). From margins to center: The development and purpose of participatory action research. *The American Sociologist, 22*, 15–28.

Heron, J., & Reason, P. (1997). A participatory inquiry paradigm. *Qualitative Inquiry, 3*(3), 274–294.

Hughes, J., & Sharrock, W. (1997). *The philosophy of social research*. New York, NY: Longman.

Lacan, J. (1977). *Ecrits*. New York, NY: Norton.

Lake, R. W. (1993). Planning and applied geography: Positivism, ethics, and geographic information systems. *Profess in Human Geography, 17*(3), 404–413.

Lasker, R. D., Weis, E. S., & Miller, R. (2001). Partnership synergy: A practical framework for studying and strengthening the collaborative advantage. *Milbank Quarterly, 79*, 179–205, III–IV.

Lewin, K. (1946). Action research and minority problems. *Journal of Social Issues, 2*, 34–46.

Lyotard, J. F. (1984). *The postmodern condition: A report on knowledge*. Minneapolis, MN: University of Minnesota Press.

McTaggert, R. (1991). Principles for participatory action research. *Adult Education Quarterly, 41*(3), 168–187.

McTaggert, R. (1997). Sixteen tenants of participatory action-research. In Y. Wadsworth (Ed.), *Everyday evaluation on the run*. Sydney, Australia: Allen & Unwin.

Miles, M. B., & Huberman, M. A. (2002). *The qualitative researcher's companion*. Thousand Oaks, CA: Sage.

Minkler, M. (2005). Community-based research partnerships: Challenges and opportunities. *Journal of Urban Health, 82*(2), ii3–ii12.

Minkler, M., & Wallerstein, N. (2003). *Community based participatory research for health*. San Francisco, CA: Jossey-Bass.

Murphy, J. W. (1986). Phenomenological social science: Researcher in the public interest. *Social Science Journal, 23*(3), 327–343.

Murphy, J. W. (2014). *Community-based interventions*. New York, NY: Springer.

Pollner, M. (1991). Left of ethnomethodology: The rise and decline of radical reflexivity. *American Sociological Review, 56*(3), 370–380.

Reid, W. J. (1994). The empirical practice movement. *Social Service Review, 68*(2), 165–184.

Rorty, R. (1991). *Objectivism, relativism, and truth*. Cambridge, MA: Cambridge University Press.

Tucker, W. (1994). *The science and politics of racial research*. Urbana, IL: University of Illinois Press.

Chapter 6
Training Community-Based Health Workers

Tashina J. Vavuris

Introduction

Community-based work (CBW) has the potential to transform the scope of research, which is an aspect of CBW that needs to be addressed and reflected to include non-traditional perspectives and different forms of knowledge (Smith, 2012, p. 1). But this potential transformation takes time and energy to deconstruct ways of knowing that stem from histories where research has been hierarchical and one-dimensional—where the experts contact and unleash their own knowledge to transfuse what they presume to be problematic. Moving beyond this type of engagement, community-based practitioners (researchers, students, professors, and those alike) must undergo a philosophical shift, one that redirects their understanding of knowing. Further, allowing practitioners to disengage from traditional knowledge to embrace the ways of understanding operative in a given community is central to any community-based initiative.

The training and educational shift that is needed to foster community engagement in a genuine manner incorporates dialogue, respect, empathy, collaboration, commitment, and solidarity and allows *critical praxis* to form (Ferreira, 2017; Freire, 1970, 2000; Murphy, 2014). Placing the community at the center of a project allows for community members to self-identify their needs and engage every facet from start to finish. This specific aspect of training cannot be overlooked, since community members are not just participants, but are intertwined in all aspects of a project. This type of practice is essential for community engagement to be self-sustaining and the goals of a project to be continuously re-worked. Accordingly, training for genuine community engagement to take place is crucial from the beginning of a project and cannot be a mere afterthought.

T. J. Vavuris (✉)
Department of Environmental Studies, University of California, Santa Cruz,
Santa Cruz, CA, USA

© Springer Nature Switzerland AG 2019

S. L. Arxer, J. W. Murphy (eds.), *Community-Based Health Interventions in an Institutional Context*, International Perspectives on Social Policy, Administration, and Practice, https://doi.org/10.1007/978-3-030-24654-9_6

Additionally, there is an important ethical commitment to embrace communities, one where practitioners move beyond the dominant status quo and embrace ethics where "passionate solidarity and informed empathy" can take precedence (Lykes, 2013). Thus, practitioners must adopt a *new vantage point* through vital epistemological shifts (Tuck, 2009, p. 55). A new paradigm thus enables and incorporates personal histories to understand individual biases and reimagine a future that encompasses a *deeper awareness* and understanding of the everyday lived experiences of people in their communities (Torre & Ayala, 2009). This *deeper* awareness must encourage the critique necessary for local knowledge to support a project.

Given the assumption that current social programs do not meet the needs of most people, they can feel alienated and, at first, be reluctant to participate in local community affairs (Murphy, 2014). Alienation is not an abstract term, but sheds light on the modes of disconnect between persons and their daily experiences. In this regard, María Elena Torre and Jennifer Ayala examine the importance in acknowledging the role of the researcher by stating:

> Participation, action, and research are not neutral, value-free terms…with the recognition that knowledge production is a political activity and that researchers come from particular communities with their own historically rooted relationships to research and power. (Torre & Ayala, 2009, p. 388)

Indeed, Torre and Ayala (2009) state that there is a "liberatory potential" in community engagement practices. In addition, the ethical role of the practitioner/researcher is essential in community work, with the aim of reinventing the current situation and promoting social change (Cahill, 2007). Hence, when community engagement is carried out with the ideals described above, personal and collective agency can be nurtured to bring about transformative and collective praxis (Murphy, 2014, p. 3).

In this chapter, several concepts will be explored. First, the idea of traditional community-based practices, where pragmatic training methodologies are endorsed, will be introduced. Second, a brief overview of community-based philosophy will be examined to illustrate the need to move beyond the traditional ways of training CBW practitioners. Third, community knowledge will be examined and explored to reveal how this information can reinforce the shift to prioritizing local knowledge. And finally, the chapter will end with a summary of how the essential components of CBW can be interwoven in the training of health workers.

Overall, there are many fields that speaks to varying degrees of community engagement (CBW, Y-PAR, PAR, Community-initiated PAR, Student-led community-engaged research, Community-initiated student research, Community-based design research, and so on). Nonetheless, there are similarities between community engagement practices, but there are also distinct ways in which community work is conceptualized and practiced. This discussion in no way is an end to community engagement pedagogy, but rather a continuation of conversation that has already taken place within various fields and by many authors (Murphy, 2014; Tuck, 2009; Tuck & Guishard, 2013; Torre & Ayala, 2009; Munck,2014; Medin & Bang, 2014; Kretzman & McKnight, 1993). Community engagement draws from various disciplines such as sociology, psychology, and community well-being, in addition to various histories of activism that embrace topics such as liberatory pedagogy, decolonial methods, feminism, black liberation, and so on. All that said, this chapter is limited due to space and will not be able to address all the necessary dimensions for community-based involvement, but will summarize basic aspects of engaging in ethical and liberating community work.

Traditional Community-Based Pedagogy

Traditional training education is mostly pragmatic, that is, focused on how to conduct needs assessments, evaluate interventions, or implement accreditation standards. Of course, these tasks are important, but must be expanded to include a critical epistemological dimension. This shift in orientation is not often the centerpiece of training; hence, the goal of this chapter is to expand on how training can support community-engaged practices.

Specifically important is that the traditional style of training and education is not in line with community-based philosophy. While pragmatism is important when engaging in community-based practices, especially when the overarching topic is community health, there is a shift that needs to be at the forefront for CBW to undergo a philosophical alignment. Practitioners should not only learn about a range of research and organizational tasks but also acknowledge the new outlook that accompanies community-based projects. In fact, training must go beyond technical and practical preparation to address some key philosophical themes.

The education regularly received often lacks concern for community members and their needs, more so, their dreams and desires. The ideal community education breaks down the traditional hierarchy and focuses on the members that are being served with a given project. This task does not follow a straight line, but rather is fluid and adheres to a community's views and aspirations. As a result, training is not about teaching the community, but more about recognizing how understanding the perspective operative in a community is a resource to more fully engaging the community. Once this change is understood, the goals of a community can come into focus. Accordingly, the community must be treated in a manner that allows each member to have the potential to contribute to a project. The point is to inaugurate a reflexive process where community members become the new experts who solve problems. But the traditional approach adopts a methodology that attempts to make a given community more like a researcher or practitioner, and thus projects are disconnected from these persons and fail inevitably to be community-based.

Pedagogical approaches in community-based interventions must understand the theoretical implications behind the work. To bring about change that community members see fit, the pedagogical practices need to be rethought. One of the facets of training that needs to be stressed is how learning is situated and includes various levels of knowledge. Most often, the researchers' questions and ways of knowing dominated an inquiry, as well as the classroom (Gutiérrez & Vossoughi, 2010,

p. 101). In this regard, education can be a “tool to produce and dispossess the other,” which for obvious reasons has the potential to further alienate communities (Tuck, Smith, Guess, Benjamin, & Jones, 2014, p. 53). To avoid this problem, Gutiérrez and Vossoughi (2010) state how the process they employ in community work is one

> in which *experiment* is reclaimed and reframed as open and creative, in ways that creates spaces to experiment pedagogically, to design collective Third Spaces that heighten the potential for deep learning to occur and for the development of powerful literacies that facilitate social change (p. 102).

Liberating pedagogy (among other names) and ways of critical thinking, as outlined by many, but mostly credited to Paulo Freire, are interwoven into critical frameworks and pedagogical practices that embrace the idea of recreating worlds based on the needs and perspectives of communities (Freire, 1970). While there are limitations to Freire’s critical pedagogical thought, his strategy has influenced pedagogical practices and social research methods, including participatory community engagement approaches. Freire’s aim is to question the production of knowledge and who benefits from this activity (Fals Borda, 1979, 1987). Interweaving liberating pedagogy with the training of community workers has benefits, especially for researchers who want to engage local knowledge. Specifically, this engagement can act as a form of resistance by revealing any hierarchies of knowledge. For example, Caitlin Cahill (2007) states, “As an ethic of inclusion, participatory research potentially represents a challenge to white privilege’s [white supremacist] investment in maintaining and producing racial hierarchies in the normative production of knowledge” (p. 363). As many activists have claimed, community engagement, when genuinely embraced, can begin to celebrate diverse knowledge bases and widespread inclusion.

In this fashion, there has been an extensive history that tends to favor elites’ knowledge within education, with a range of others marginalized in both research and planning (Darder, 1994). As a remedy, CBW can be used to reveal some of these historical patterns and unearth how the world and society do not function on their own, but rather are socially created. The upshot of this reorientation is that there is potential to bolster the needs and imaginaries of communities. Consequently, as outlined by Antonia Darder (1994):

> Educational conditions promoting inequality have been made possible by the underlying philosophical assumptions that inform traditional research methodology, namely, the acceptance of a dualistic, objective, value-free, hierarchical, and instrumental perspective regarding knowledge. It is a view that sees human beings as separate from nature, and thus, as objectifiable, observable, quantifiable, predictable, and controllable. Through objectifying human beings into “things,” human behavior can be treated as if it existed according to a predetermined set of universal rules, independent of the contexts in which the behavior takes place. (p. 23)

Moving beyond this trap needs to be at the forefront of community-engaged training and practice. Training should pursue the demystification of knowledge hierarchies and question the origins and implications of knowledge histories to bring communities into planning routines. CBW should embrace pedagogy practices that facilitate community members actively participating in their own production of their knowledge, by elevating in importance the meaning of their lived experiences and how they construct their situations (Darder, 1994; Murphy, 2014).

The Need for Community-Based Philosophy

A nondualistic framework is needed in order to shift into a new paradigm (Krieger, 2011). Understanding the separation of objectivity and subjectivity is a necessary part of training to act appropriately. When communities are viewed within this binary, the idea that community members use subjective information identifies a community's perspectives as false information. In academia, especially in regards to research-focused institutions, the emphasis falls on "value neutrality and a positivist objectivity as prerequisites for 'serious science'" (Fals Borda, 1987, p. 330). Thus, a reorientation is required to alter the traditional scope of research. Specifically important, community members should not be dismissed because their perspectives of the world are needed to promote change. True community practitioners peruse local narratives in order to understand how a given issue is locally constructed. Nonetheless, for this shift to take place, practitioners must learn to treat knowledge as biographical, that is, as a product of local discourse and related commitments (Berger & Luckmann, 1967; Schutz, 1967). This adventure of understanding how a community constructs their lived experiences and reality is part of a community-engaged philosophy.

Understanding the philosophical importance of community-based work is imperative when engaging in communities that have been historically marginalized for various reasons. Especially important is the idea of dismantling the normative ethos about the nature of a community. In CBW, the concept of *community* should be a key starting point. Further, being able to redefine the meaning of *community*, which should be defined by the community, lays the groundwork for developing an *authentic commitment* to a project (Fals Borda, 1987; Murphy, 2014). And, the community has the opportunity to interact through meaningful dialogue and genuine collaboration.

In this case, dialogue is not merely reduced to communication or an intimate relationship, although, these notions are also important. As Hans-Georg Gadamer (1996) states, dialogue requires taking a risk and entering the worlds of other persons, and thus presumes that people enter into a truly living relationship. This activity is realized by persons reflecting on their own stories, that is, placing them at risk, and thereby recognizing their boundaries. As a result, they can begin to entertain others' narratives and read them as their authors intend. In other words, practitioners can overcome their own stories and enter the world created by the narratives enacted by communities. Dialogue, however, is not value-neutral, but represents the ability to shift from one world to another through reflection.

The identity of a community moves beyond geographical location or a common trait, but reflects a commitment to a particular new order. This idea is revolutionary in the sense of how communities have been constructed over the years and within the realm of community work (Murphy, 2014). In the traditional understanding of communities, people are grouped together by geographical location, skin color, cultural identity, language, economic status, and so on. While these identifiers are potential unifiers, community members should not be limited to these “qualifying” markers without consulting how a sense of solidarity is created through dialogue and agreement. With this new way to understand communities, entrée occurs when certain signs or indicators are read in the manner intended by the participants. In a manner or speaking, communities are authors.

The idea is to reimagine a space where local knowledge aligns with research goals and that critique becomes a regular part of community training practices. Radical and liberating strategies have been utilized throughout time, but have not been given priority in community engagement practices (Fals Borda, 1988). Indeed, the goal is not to reinforce an existing system, but to open the opportunity for communities to establish their own agendas. Thus, CBW requires training that incorporates local experts into planning, and thus rethinking the concept of “expert status.” But this task is done not by leading, but rather learning and assisting when needed (Murphy & Casanova, 2018, p. 18). When thinking of community interventions, there are many ways that this expectation can be implemented to provide a project with an appropriate framework (Gutiérrez & Vossoughi, 2010; Murphy, 2014). Especially important, the necessity is that these practices are continuous throughout a project and guided by community members (Gutiérrez & Vossoughi, 2010; Murphy, 2014).

To understand this change further, there are basic principles that sustain CBW to nourish a community’s transformation. Throughout the philosophical shift, there are two distinct components that are vital for a community project to be genuine and sustainable. The first is that community or local knowledge is valid and already exists prior to a project taking form (Murphy, 2014). Frequently, community engagement uses terms such as *empowerment* to explain that the project will allow community members to have a voice. The assumption, however, is that community members did not have power prior to the project, and were merely granted this power based on the researchers’ largess. The term empowerment, according to Wallerstein and Bernstein (1994), is defined as: “a social action process in which individuals and groups act to gain mastery over their lives in the context of changing their social and political environment” (p. 142). Furthermore, this concept is extended not only to individuals but communities to uproot oppressive situations (Wallerstein & Bernstein, 1994). But the issue remains: with their ability to define themselves, communities do not need outsiders to acknowledge their skills or power to (re)create their futures.

Hence, communities need to be viewed as assets rather than deficits that need to be fixed, overcome, or empowered (Chambers, 1997; Kretzman & McKnight, 1993). Through community engagement practices, these assets can be activated as expanded. The basic idea is that community-based philosophy illustrates a community’s agency and encourages further involvement in the planning process. Furthermore, through collaboration and critical praxis, community-based projects can bolster community members to be active agents of change within their own communities. Here praxis is not just theory and action as discussed by Freire (1970), but political action and community organizing (Fals Borda, 1979).

The second principle is the importance of community members being engaged in every aspect of the project (Murphy, 2014). The key to authentic participation is an intimate connection to a project, rather than token, periodic consultation. Taking this a step further is insuring that a project is truly dictated by community members, rather than seeing persons as simply the focus of a project. Community members, for example, should establish a project design, how this undertaking is evaluated, and formulate any policies that may be deemed important. The more the community is connected to and leading a project, sustainability is increased and the prospects for positive outcomes improved.

Engaging a Community

As mentioned in the previous section, local knowledge needs to be infused into a project from the start to hold true to community-based practice (Murphy, 2014). Learning from the community and the *already present knowledge* is essential for a project to be properly situated (Medin & Bang, 2014; Murphy, 2014). As Gutiérrez and Vossoughi state, "it is important to highlight the principles that orient and help organize the work, always mindful of the need to situate the project in ways that privilege the standpoint of nondominant communities to whom the learning project is oriented" (2010, p. 102). Thus, and as mentioned in previous sections, standard notions of expertise need to be confronted with the recognition that "everyday people carry deep knowledge and analysis about conditions of their lives and should lead in determining meaningful research questions, designs, methods, analyses and products" (Torre & Ayala, 2009, p. 388).

In this context, the concept of participation needs to be explored further, given the power dynamics present and who should dictate the flow of a project (Munck, 2014). Many projects claim to be participatory, but challenges remain (Murphy, 2014). What is distinct here is that participation means more than increasing numbers of participants. True collaboration and co-generation of a project should incorporate the values, beliefs, and commitments of a community into a project (Murphy, 2014).

For example, a community-based project should embrace personal narratives as teaching tools, helping to produce a model of "meaningful, complex, and sometimes disrupted" lived experiences, rather than focusing on deficits that encourage the "painful stories" to be re-lived for the sake of research (Tuck et al., 2014, p. 60). Therefore, to engage a community in an authentic way self-reflection must be ongoing. Once personal and communal biases are acknowledged, interaction can proceed in an honest and genuine way. As Murphy (2014) reminds us:

> Prejudices must be addressed, for example, that portray certain persons as unintelligent or unmotivated, so that participation is widespread and ideas that were formerly unknown may receive serious attention. Planning can thus begin to reflect a community. (p. 10)

Without an honest reflection, the harm that can be done by social projects, and well-intentioned practitioners, will go unnoticed. Accordingly, reflection on existing injustices is an aspect of CBW that needs to be prioritized, along with communities and their ambitions (Long, Ballard, Fisher, & Belsky, 2016). But respect should not be reduced to superficial treatment, such as decorum, but rather suggest a deeper commitment to others (Buber, 1958). Moving in a similar direction is the idea of social reflexivity, which allows for community collaborators to reflect through and with one another. By engaging one another in this way, participants can come together despite biases and personal narratives that are potentially fixed in history and rooted in many forms of discrimination (Cahill, Sultana, & Pain, 2007).

Community knowledge is a way to move beyond social relationships that continue to oppress communities, especially poor and minority communities. As mentioned by Eileen R. Carlton Parsons (2017) and Richard Delgado (1989), *counterstories* are a way for people who have been marginalized to reflect on obstacles to self-development, regain their integrity, and move in a new direction. Therefore, the goal of a project should not be to measure the community, but rather embrace dialogue and communicate effectively (Murphy, 2014). The difference here is the epistemological framing of how communities are defined and how the community knowledge is used in a project. The important question at this juncture is: whose reality is important? A community-based project, simply put, celebrates local participants and the agenda that emerges.

Conclusion

Valid knowledge, communities, and norms are some of the key items that will need to be rethought in the training process to engender effectiveness in community-based interventions. Community practitioners need to be sensitive and self-reflective to have success in these projects. In addition, being able to understand and incorporate a philosophical shift that allows community knowledge to be imbedded into every facet of a project is as crucial, but is often an overlooked aspect of training. Education of practitioners should include reflection on the struggle of communities to maintain their integrity in the face of attempts at marginalization and insults.

In terms of CBW, a reflective question is *who is benefiting from the research*? (Whitman, Pain, & Milledge, 2015). Bringing together narratives that have undergone meaningful connections to bring about change in a community is a vial facet of CBW. Thus, through "sovereignty, contention, balance, and relationship" a move can be made to a new vantage point to engage in new ways of understanding (Tuck, 2009, p. 47).

In sum, there needs to be a shift in understanding of community-based work and interventions. To truly connect with a community in a non-oppressive manner, a philosophical change in the training of practitioners is critical. By engaging in dialogue and continual praxis, communities can be approached in a more honest way, thereby celebrating community knowledge and projects. Training should reflect these aims and become transformative.

References

Berger, P., & Luckmann, T. (1967). *The social construction of reality*. New York, NY: Anchor Books.

Buber, M. (1958). *I and thou*. New York, NY: Scribner.

Cahill, C. (2007). Repositioning ethical commitments: Participatory action research as a relational praxis of social change. *ACME: An International E-Journal for Critical Geographies, 6*(3), 360–373.

Cahill, C., Sultana, F., & Pain, R. (2007). Participatory ethics: Politics, practices, institutions. *ACME: An International E-Journal for Critical Geographies, 6*(3), 304–318.

Chambers, R. (1997). *Whose reality counts? Putting the first last*. London,UK: Intermediate Technology Publications.

Darder, A. (1994). Institutional research as a tool for cultural democracy. *New Directions for Institutional Research, 1994*(81), 21–34.

Delgado, R. (1989). Storytelling for oppositionists and others: A plea for narrative. *Michigan Law Review, 87*(8), 2411–2441.

Fals Borda, O. (1979). Investigation reality in order to transform it: The Colombian experience. *Dialectical Anthropology, 4*(1), 33–55.

Fals Borda, O. (1987). The application of participatory action research in Latin America. *International Sociology, 2*(4), 329–347.

Fals Borda, O. (1988). *Knowledge and people's power*. New York, NY: New Horizons.

Ferreira, F. (2017). Critical sustainability studies: A holistic and visionary conception of socioecological conscientization. *Journal of Sustainability Education*, 13.

Freire, P. (1970). *Pedagogy of the oppressed*. New York, NY: Continuum.

Freire, P. (2000). *Pedagogy of freedom: Ethics, democracy, and civic courage*. Lanham, MD: Rowman & Littlefield Publishers.

Gadamer, H.-G. (1996). *The enigma of health: The art of healing in a scientific age*. Stanford, CA: Stanford University Press.

Gutiérrez, K., & Vossoughi, S. (2010). Lifting off the ground to return anew: Mediated praxis, transformative learning, and social design experiments. *Journal of Teacher Education, 61*(1–2), 100–117.

Kretzman, J., & McKnight, J. (1993). *Building communities from the inside out*. Chicago, IL: Acta Publications.

Krieger, N. (2011). *Epidemiology and the people's health*. New York, NY: Oxford University Press.

Long, J., Ballard, H., Fisher, L., & Belsky, J. (2016). Questions that won't go away in participatory research. *Society and Natural Resources, 29*(2), 250–263.

Lykes, M. B. (2013). Participatory and action research as a transformative praxis: Responding to humanitarian crises from the margins. *American Psychologist, 68*(8), 774–783.

Medin, D. L., & Bang, M. (2014). The cultural side of science communication. *Proceedings of the National Academy of Sciences of the United States of America, 111*(Supplement 4), 13621–13626.

Munck, R. (2014). Community-based research: Genealogy and prospects. In R. Munck, L. McIlrath, B. Hall, & R. Tandon (Eds.), *Higher education and community-based research* (pp. 11–26). New York, NY: Palgrave Macmillan.

Murphy, J. W., & Casanova, F. (2018). *Community-based work and the accompanying changes in sociology*. Unpublished Manuscript, Department of Sociology, Miami University.

Murphy, J. W. (2014). *Community based interventions: Philosophy and action*. New York, NY: Springer.

Parsons, E. R. C. (2017). Interfaces between critical race theory and sociocultural perspectives. In I. Esmonde & A. Booker (Eds.), *Power and privilege in the learning sciences: Critical and sociocultural theories of learning sciences* (pp. 24–46). New York, NY: Routledge.

Schutz, A. (1967). *The phenomenology of the social world*. Evanston, IL: Northwestern University Press.

Smith, L. T. (2012). *Decolonizing methodologies: Research and indigenous peoples*. New York, NY: Zed Books.

Torre, M. E., & Ayala, J. (2009). Envisioning participatory action research entremundos. *Feminism and Psychology, 19*(3), 387–393.

Tuck, E. (2009). Re-visioning action: Participatory action research and indigenous theories of change. *The Urban Review, 41*(1), 47–65.

Tuck, E., & Guishard, M. (2013). Uncollapsing ethics: Racialized sciencism, settler coloniality, and an ethical framework of decolonial participatory action research. In T. M. Kress, C. S. Malott, & B. J. Portfilio (Eds.), *Challenging status quo retrenchment: New directions in critical qualitative research* (pp. 3–27). Charlotte, NC: Information Age Publishing.

Tuck, E., Smith, M., Guess, A. M., Benjamin, T., & Jones, B. K. (2014). Geo-theorizing Black/Land: Contestations and contingent collaborations. *Departures in Critical Qualitative Research, 3*(1), 52–74.

Wallerstein, N., & Bernstein, E. (1994). Introduction to community empowerment, participatory education, and health. *Health Education Quarterly, 21*(3), 141–148.

Whitman, G. P., Pain, R., & Milledge, D. G. (2015). Going with the flow? Using participatory action research in physical geography. *Progress in Physical Geography, 39*(5), 622–639.

Chapter 7
Creating a Community Health Worker Training Program

Dawn Graham, Kerri Shaw, and Lesli Johnson

CHW Importance in the Region

The role of Community Health Workers (CHWs) cannot be understated. Their roles include outreach, programming, prevention, and linkages to healthcare access for the wider population. This emerging occupation is critical as noncommunicable, chronic, and preventable disease rates continue to rise. For a successful implementation, community organizations and university partnerships must work efficiently and in tandem in order to enhance service delivery. CHWs serve a key role in facilitating access to services in rural areas. By developing a certified CHW training program, healthcare providers are creating a strong workforce that aims to improve overall health outcomes in the region. Promotion of health and wellness combined with preventing the adverse effects of noncommunicable disease states prove an important advancement in the health and well-being of the Southeastern Ohio region. In partnership with the Athens City-County Health Department and colleges from across Ohio University, we promote and extend the CHW efforts within the region. In this chapter, we discuss the implementation, challenges, and resilience that contribute to a successful CHW program.

D. Graham (✉)
Social Medicine, Heritage College of Osteopathic Mediicne, Athens, OH, USA
e-mail: grahamd@ohio.edu

K. Shaw
Social Work, Ohio University, Athens, OH, USA

L. Johnson
Voinovich, Ohio University, Athens, OH, USA

© Springer Nature Switzerland AG 2019

S. L. Arxer, J. W. Murphy (eds.), *Community-Based Health Interventions in an Institutional Context*, International Perspectives on Social Policy, Administration, and Practice, https://doi.org/10.1007/978-3-030-24654-9_7

Community Health Worker (CHW) trainings are offered throughout the Appalachian region of Ohio, which suffers from at-risk and distressed economies, high poverty rates, declining population demographic trends, and a workforce that often lacks the skills needed in emerging business sectors. Additionally, these counties have low levels of educational attainment, relative lack of access to healthcare services, and sparse health-promoting community infrastructure. A key social determinant that influences health outcomes is the level of economic distress. Athens County is the poorest county in Ohio according to data from the 2010 US Census, and neighboring counties experience similar levels of economic distress. Adjacent to Athens County, Vinton County is the second poorest in the State of Ohio. In Vinton County, approximately 1 out of 5 (20.6%) residents is living in poverty and in nearby Meigs County, 22.4% of residents are living in poverty (quickfacts.census.gov). Perry County ranks 78th out of Ohio's 88 counties; Washington County ranks 34th out of the 88 counties. The healthcare needs of this population are greatly impacted by its poverty (Kliegman, 1992). Lack of access to care combined with high rates of uninsured contribute to overall acute and chronic health concerns.

The Appalachian Region

The distinct needs of Appalachian Ohio and the unique cultural elements of our service area provide a key context for the training design. This uniqueness of culture is highlighted at a state level, as the Ohio Development Services Agency partners with the Governor's Office of Appalachia to enhance strategic initiatives to promote health, wellness, and strengthen both the health and economic development of this underserved region of Ohio (Ohio Development Services Agency, 2019). Specifically, the focus areas include increasing job opportunities, reducing isolation, and most important, strengthening the capacity of regional infrastructure and the ability of people to be competitive in the global economy. The proposed community health worker program enhances these strategic principals by augmenting social support networks (decreasing social isolation) and connecting our population with access to healthcare.

Access to healthcare services is a critical need throughout Perry, Meigs, and Vinton Counties and specifically in the rural areas of Athens and Washington Counties. Vinton, Washington, and Perry are designated as federally underserved areas for primary care, dental care, and mental healthcare, while Athens County is underserved for dental and mental health. Perry and Vinton Counties also lack adequate hospitals, urgent care facilities, and emergency departments. The targeted counties also rank poorly in the Robert Wood Johnson 2016 County Health Rankings. Among the 88 Ohio counties, Athens (68th), Perry (54th), Meigs (79th), Muskingum (71st), and Vinton (85th) all rate in the lower half in terms of measured health outcomes.

Developing a New Curriculum

One of the major challenges in developing a new curriculum was to first explore what other training programs were doing successfully, and then develop a plan to integrate these ideas into our existing organization in an efficient way. The CHW program was an interprofessional, university-community collaboration joining the Athens City-County Health Department, the Ohio University College of Health Professions, and the Heritage College of Osteopathic Medicine. The community health work is at an intersection of social work and health professions, and we recognized the need to work across disciplines to meet the training needs of our community. Additionally, the Athens City-County Health Department was already involved in community health work and was a willing partner thanks, in part, to successful past collaborations Logistically, the three organizations held regular face-to-face meetings to develop a curriculum that aligned with the Ohio Board of Nursing's competencies and our own community needs. We created a shared electronic depository for the creation of e-materials.

The Northeast Ohio Medical University (NEOMED) granted us access to the materials they had developed. In addition, as the planning team collected and amended materials found throughout the curriculum "road trip," we took to assess other community health worker programs and inform our own. Working within the university system, the curriculum is technically university property. Our colleagues at NEOMED were gracious in granting access to the documents and materials they used in order to implement their own training program. In fact, throughout the State of Ohio, there is a formalized library cloud into which various organizations can download and disseminate research and materials to one another for increased efficiency in programming.

Currently, there are 15 certified community health worker training programs throughout the State of Ohio (Ohio Board of Nursing, 2019). Certification is a challenge, since the Ohio Board of Nursing has the duty to accommodate the needs of healthcare organizations throughout the state, while still adhering to strict standards of competency. Since the educational level of CHW trainees ranges from GED-level students to individuals with college degrees, the curriculum must be set up to make CHW training didactics understandable and portable across various agencies and regions within the state. As we talked to colleagues around the state, the most basic lesson learned was that there was no standardized curriculum that existed due to CHW as an emerging profession.

The OU CHW Training Program received certification by the Ohio Board of Nursing in January 2017. The curriculum content focuses on culturally competent care within a patient-centered, rural Appalachian Ohio community. Participants learn how to provide relational-based care to patients as generalists, while learning about chronic care issues prevalent in the rural community such as Type 2 Diabetes, and COPD. Participants also develop a knowledge base of the resources available to community members to help them meet basic needs and tackle social determinants of health. Due to the high poverty rate, ingrained behavioral health patterns, and isolated population, the program's development leadership specifically recruits participants with a deep commitment to serve and understand the distinct population.

The Appalachian Region and Stakeholders

There are three key stakeholder groups and two related groups within the Appalachian region related to CHW programming. Primary stakeholders include the programs and organizations that utilize or seek to utilize CHWs to increase access and improve health outcomes, including health departments and Federally Qualified Health Centers. Others include individuals who could potentially become certified and employed as CHWs and those who are part of a vulnerable population who could benefit from the effective use of CHW services. Secondary stakeholders include the OU CHW certification, providers, and Medicaid/managed care organizations. In order to address these critical health outcomes, we offered a training and master training program throughout the region. The master training program was delivered to us by Northeastern Ohio Medical University. As master trainers are developed in each region, they are able to sustain programming efforts by working collectively and offering low or no cost training to other healthcare sites interested in the curriculum.

History of the Program

In the fall of 2015, faculty across Ohio University were invited to discuss a potential grant that would allow greater access to healthcare agencies and services to local community members. The authors have years of experience in the healthcare system and have experience in this Appalachian region. The main charge was to begin setting up the infrastructure that would later become Ohio University's more standardized and formal curriculum. Eventually, we were able to develop, train, and disseminate both a standardized community health worker curriculum and a master training program for long-term sustainability of CHWs across the area. The purpose of this critical grant funding opportunity (Ohio Medicaid and Technical Assistance and Policy Program) is to help train healthcare professionals to work with the large population of Medicaid-assisted patients in order to improve the overall health metrics in the State of Ohio.

The Ohio University Community Health Worker Program is well-received throughout the region to date and, has developed a strong working partnership with the Athens City-County Health Department and its Director of Community Health Worker Development, who serves as a primary trainer for the OU CHW Program. In 2016, the Athens City-County Health Department conducted a Communities

Preventing Chronic Disease Assessment (CPCDA), which identified if and how local healthcare providers utilize CHWs in their practices to link patients to community resources that promote the self-management of blood pressure. As a result of this assessment, participants in Year 2 identified evidence-based lifestyle change programs (42.9% Yes) and prevention of type 2 diabetes (28.6% Yes). Holzer Clinic, Ohio University Community Health Program Free Clinic, OhioHealth O'Bleness Athens Medical Associates OB/Gyn, University Medical Associates, Inc., O'Bleness Ohio Health Residency Clinic, and Hopewell Health Center (FQHC) were included in the CPCD Assessment. This information was used toward setting the goals of creating CHW field placements and workforce development opportunities moving forward.

In August 2016, nine professionals completed Community Health Worker and Master Trainer programs. These trainers are community members serving their home communities in public health and are committed to offering CHW training programs in their counties, as well as supporting efforts in other identified counties. These nine professionals represented:

- Ohio University College of Health Sciences and Professions
- Ohio University Heritage College of Osteopathic Medicine Department of Social Medicine
- Athens City-County Health Department
- Muskingum County Health Department
- Washington County Health Department
- Unique Services Logistics Career Academy, LLC (Columbus)

In addition to the professional organizations listed above, additional agencies are coordinating efforts. The Athens City-County Health Department and Washington and Meigs County Health Departments were recipients of a POWER (Partnerships for Opportunity and Workforce and Economic Revitalization) grant through Marshall University. Through this opportunity, the CHW trainers focused on creating healthcare professionals who specifically target clients with chronic health concerns including decreasing A1C levels in patients with diabetes. Although training will continue to expand, we currently have CHWs working in a regional Mennonite community, a local FQHC, and a WIC office.

CHW Regional Training and Utilization

In March 2016, *State Reform*, an online resource sponsored by the Robert Wood Johnson Foundation, provides up-to-date information about how different states are addressing the use of community health workers (State Community Health Worker Models 2016). Ohio has a certification process in place through the Board of Nursing, as well as a number of certified training programs. However, compared to other states, Ohio has not yet identified a funding mechanism or appropriate CHW roles. Currently, there are a number of efforts throughout Ohio University and

Southeast Ohio to utilize CHWs. Several local health departments, some physician practices, and The Diabetes Institute among others have requested or received funding to support CHWs within their organizations. Since the CHW Program was initiated in 2015, opportunities for research collaboration, workforce development, and community partnerships have arisen. For example, the Diabetes Institute submitted a HRSA expansion grant, *A New Approach to Diabetes Navigation in Rural Appalachia*, to train and employ community health workers in tandem with Diabetes Navigators to expand the reach of services in the region to include children with diabetes while also providing a sustainable source of employment for community members.

Additionally, Marietta Senior High School is offering a year-long course to graduating seniors, taught by a CHW Master Trainer. The training program serves as a pipeline for workforce development in this poverty-stricken region. This course allows graduating students to be eligible for the Ohio Board of Nursing certificate, thereby making them more competitive in the job market. The training offers them experience and practice in the healthcare field while serving as a pathway to higher education in healthcare professions. The course falls under the administrative auspice of Ohio University.

Stakeholder Needs

The primary stakeholder groups benefit from shared information, role clarification, education, and potential collaboration. As the CHW pipeline progresses, the stakeholders could use a common marketing platform to spread word to the public. The OU CHW certification provider could use information for continuous program improvement and to support the clinical training requirement, while managed care organizations benefit from more cost-effective services. Further, some exploration of opportunities to network and potentially collaborate could be beneficial to the various stakeholder groups. Finally, exploring strategies for sustainability is key to the continued development of this effort. Otherwise, current efforts will be fragmented and time-limited. We utilize a multipronged approach, beginning with contacts with organizations, currently or potentially employing CHWs, to identify the following: what current programming efforts are in place, challenges, successes, evaluation activities, and current needs, otherwise known as an environmental scan. After this initial step, we propose a facilitated stakeholder meeting to explore opportunities, needs, and barriers to collaboration.

We explored the feasibility of creating a regional network that would include organizations that are using or plan to utilize CHWs and identify potential opportunities for collaboration and the creation of community health improvement strategies. Another objective is to standardize the curriculum already approved by the Ohio Board of Nursing to create user-friendly, replicable lesson plans and training manual for the CHW training program. To date, we have completed a comprehensive training manual, and e-based trainings continue around the region. Experimental courses were offered to Ohio University students beginning in fall 2018.

Diversity of Programs

We discovered that CHW training programs were as diverse as the communities in which they were implemented. In an urban, northern Ohio, CHW trainings were offered to high school students as a way to help promote community advocacy, as well as give these students a skill set upon graduation. With graduation rates in Ohio currently at 84% (nces.ed.gov), the implementation of new certification upon graduation would serve to set up high school seniors for success.

From an organizational perspective, this program is also a strong workforce development pipeline. As the national rhetoric focuses on affordability and accessibility, the timing of our local implementation could not be more perfect. In a sense, we are training people to implement access to healthcare services at a lower cost at the same time insurance companies and managed care organizations are ramping up ways to cover the cost of preventative services. One of our first steps in information gathering was to visit existing programs around the state to see how they were training and implementing their CHW curriculums. Two sites within Ohio included Cleveland State University and the University of Cincinnati Nursing programs. Of note, the Cincinnati program focuses on decreasing infant mortality rates. Our purpose is to create a generalist program that allows each student to specialize on a target population (maternal/child health, developmental disabilities, diabetes management, etc.) These two institutions were gracious in helping us to develop ideas that could work in our rural, Appalachian region.

Logistical Challenges

One of the main challenges of managing the ongoing training program is to find a graduate assistant who is passionate and available to provide support with the certification process, literature review, and curriculum development. Throughout the life of the program, we have been fortunate to hire graduate assistants who have been instrumental in helping with day-to-day duties and moving the project forward. The College of Health Sciences houses a series of graduate students from health professions to help us organize and document the developing curriculum. They have also conducted and transcribed interviews as part of the regional assessment process.

Another challenge of implementing our community health work has been learning how to market the service. In the early days, we received feedback from other health professionals worried about “turf” issues. More specifically, public health professionals were worried that community health workers would target the same communities that receive services from the local health departments (i.e., immunizations). But, through cultivating relationships and building trust, we were able to understand how to best market the value of community health workers. In fact, that marketing is still in process. We had to learn to explain to our colleagues that the role of CHWs is to serve as a liaison to connect community members to services. Oftentimes, the role of the CHW can be seen as overlapping with public health and nursing professionals. Time was needed to help CHW trainees understand how to market themselves as a help to other service providers while making the case that the CHW serves as a pipeline for patient populations that would otherwise have not accessed these health services. This understanding was critical to developing a meaningful relationship that emphasized the outcome of services while strengthening the healthcare workforce. In addition, we had to recruit community partners who would help us train with minimal recompense due to limited resources.

The concept of community health workers as culturally competent conduits of health information and access to care, is especially useful in rural areas where people may be reluctant to trust outsiders and tend to rely on family and friends for health information. Oftentimes, especially in rural areas, people are reluctant to trust outsiders. In addition, if someone has what is perceived to be a bad experience in a healthcare setting, that person is likely to avoid the organization and spread this information to their friends and family members.

Scope of Work/Timeline

The chart below outlines the timeline and scope of work as the program continues to evolve throughout Ohio University and the larger Southeastern Appalachian region of Ohio.

Year 1 Fall July–Dec 2017	Year 1 Spring Jan–Jun 2018	Year 2 Fall July–Dec 2018	Year 2 Spring Jan–June 2019
Training #1 (2 simultaneous cohorts)	Curriculum Implementation (cohorts 1 and 2)	Training #2 (2 simultaneous cohorts)	Curriculum implementation (cohorts 3 and 4)
Student recruitment for year 1 spring	Student recruitment for year 2 fall	Student recruitment for year 2 spring	Focus group interviews for student experience
Community site recruitment	Community/student match (cohorts 1 and 2)	Community/student match (cohort 2)	Community/student match (cohorts 3 and 4)
Evaluation data setup and planning	Pre-evaluation for cohorts 1 and 2	Post-evaluation for cohorts 1 and 2	Pre-evaluation for cohorts 3 and 4 (post upon completion)

Year 1 Fall July–Dec 2017	Year 1 Spring Jan–Jun 2018	Year 2 Fall July–Dec 2018	Year 2 Spring Jan–June 2019
Identifying content experts to provide specialized training across years (cultural competency, etc.)	Motivational interviewing training and cultural competence training for cohorts 1 and 2	Motivational interviewing training and cultural competence training for cohorts 3 and 4	Post-evaluation for cohort 2
CHW site travel and discussions	Active recruitment of cohorts 3 and 4 for year 2	Preliminary data gathering and assessment	Dissemination and write up of data research to academic journals/conferences

CHWs Addressing Health Disparities

The community health worker can fulfill multiple roles in helping clients to access services. According to Snyder (2016), the roles of a CHW include the following: addressing social determinants of health affecting care, increasing care access, providing educational services, assisting in care coordination, and sharing cultural and economic characteristics with community members. The CHWs can provide and share access to screenings, focus on chronic disease management such as Diabetes, and promote maternal and child health.

An important component of the responsibilities of a community health worker include helping clients educate themselves on the importance of preventative health. Most insurance companies, including Medicaid, cover basic health screenings such as colon cancer screens and pap smears. Many community members do not realize that these prevention services are fully covered by Medicaid and private insurance. A large number of local community health workers promote screenings as critical prevention tools to help diagnose and treat problems before they result in a serious and chronic health condition or illness.

Program Metrics

Program outcome measures allow us to continue to monitor quality improvement processes and make sure that the program is having an impact on patients. Outcome measures are also key to sustainability for financial purposes. By talking with colleagues around the state and contracting with the Ohio University Voinovich School for Leadership and Public Affairs, we were able to come up with key program metrics. They include the following below:

Patient demographics	Process measures	Patient behaviors	Intervention outcome measures
Age	# receiving education	Program education process	Specific health outcomes (i.e., blood pressure, A1C levels)
Gender	# outside referrals to local agencies	Changes in daily activities	Consumer satisfaction
Specific health problems (i.e., type 2 diabetes, asthma)	# patients screened	Presence of compliance and self-management	Increase in health issue awareness as evidenced by survey data
Physical activity	# educational programs facilitated by CHWs	Office visits to primary care/ preventative medicine	Cost savings metrics (i.e., lower ED visit utilization)

In addition to program metrics, conducting continuous quality improvement processes is crucial to increasing sustainability efforts and efficiency in program delivery. In coordination with local agencies, we determined the key strengths, weaknesses, opportunities, and threats to program sustainability. The strengths identified included:

- Ohio University's CHW Program is now certified by the Ohio Board of Nursing and remains a platform for sustainable workforce development within the Southeastern Ohio region.
- An already existing master trainer program allows for expansion of services wherever demand is greatest.
- Local media and word of mouth has expanded the knowledge of our programming efforts in surrounding counties outside of Athens.
- Community partnerships and support for the CHW program have expanded in the form of providing participants, sites, and resources for training.
- The relationship with Athens City/County Health Department continues to grow and strengthen, thus extending financial resources and in-kind capacity to expand the CHW work throughout the region.

Weaknesses identified are as follows**:**

- This is an intensive training program with a significant time commitment; scheduling is challenging for trainers and trainees.
- Uncertainty in local and federal funding makes it difficult to plan for sustainability of programming efforts.
- The inability to have a full-time worker devoted to CHW training and development causes logistical difficulties in coordinating training efforts.
- The application turnaround was very quick for the first cohort, which might explain small cohort number.

New partnerships with health departments in neighboring counties are emerging:

- New Washington County partnerships extend programming across the region.

- Ongoing relationships with CHWs in Franklin County provide greater opportunity for training in urban areas.

Threats:

- Ambiguity of sustainable funding sources causes greater uncertainty in planning future training opportunities.
- Political climate around Medicaid funding and other organizations and impact on rural service providers makes it difficult to plan future programming.

The Curriculum

As the curriculum continues to refine individual modules and flexibility in course delivery, the original program goals stay consistent. Namely, the objectives are fivefold:

1. Increase enrollment and completion of community health worker programming for community members who may not otherwise have access to professional development opportunities that are offered in population dense areas.
2. Expand enrollment and completion of community health worker programming for community members who may not otherwise have access to professional development opportunities that are offered in population dense areas.
3. Increase, sustain, and maintain a community population in line with the community strategic initiative for economic development, patient recruitment, and overall public health prevention services.
4. Promote educational activities across multiple healthcare serving agencies.
5. Enhance community members' opportunities for professional development along the adult developmental spectrum.

Community-Based and Experiential Learning Curriculum

The existing CHW program emphasizes adult learning strategies that engage learners with community organizations in a systematic and engaging way. The Ohio University CHW Training Program emphasizes cultural competence throughout its curriculum, including a training session facilitated by FQHC Hopewell Health Center, *Appalachian Culture and Poverty,* which utilizes author Ruby Payne's materials from *Bridges Out of Poverty* (2001) to frame socioeconomic issues, social determinants of health, and communication styles in Appalachia to develop empathy and understanding in care providers. Twenty of the 100 hours of in-class didactic content focus on cultural competence implementing a curriculum developed by a faculty member of the Ohio University Social Work Program with an additional 130 hours completed while immersed in community-based field placements.

Students also complete a module of motivational interviewing training. The theory of motivational interviewing is a unique addition to the community health worker program in Appalachian Ohio. Motivational interviewing is an evidence-based practice that promotes behavior change with a patient-driven perspective that originated in the treatment of patients with substance abuse issues (Carroll et al., 2006). The practice employs an "OARS" approach to promote healthy behaviors and will be actively learned and implemented by all community health workers. The "OARS" approach allows for Open-ended questions; utilizes Affirming statements to promote patient empowerment; utilizes Reflective listening to confirm beliefs and challenges that prevent clients from making healthy choices; and Summarize concerns and feeling about healthcare in general (Berthold, Avila, & Miller, 2009). Motivational Interviewing is a systematic, learner-friendly approach to empowering patients for long-term, positive impact.

The Ohio University CHW Training Program is a model of interprofessional participation that utilizes trainers from diverse backgrounds, including public health, social work, psychology, and nursing with a focus on experiential learning practices. Ohio University has a unique approach of interprofessional learning, since it holds a yearly interprofessional education (IPE) forum for students and healthcare workers alike. Community health workers will have ready access to programming efforts and educational opportunities offered by Ohio University. Examples of IPE learning opportunities for community health workers include access to Global Health programming, interdisciplinary research symposiums, and practicum placement in integrated community health settings. In addition, the certified CHW curriculum has IPE examples and readings embedded into the training.

Identification of Students and Community Partners

Over the past 2 years, relationships have been cultivated with over 20 organizations in the region, and the CHW Program has been received with success and enthusiasm. Members of the recruitment team include a Social Work Field Liaison and the Director of Campus and Community Relations, both of whom have strong ties and histories with agencies and organizations in the region. These relationships have facilitated conversations and commitments from potential field placements and employers.

For example, students will be recruited through Ohio University, Hocking College, local social service agencies, healthcare institutions, and the AmeriCorps/COMCorps program. COMCorps is housed in the Ohio University Heritage College of Medicine Community Health Program and has a mission to increase access to:

- Evidence-based nutrition education
- Healthy fresh food

- Physical activity
- Preventative and primary healthcare services

The first training cohort began in February 2017 in Athens with six participants. These persons were recruited from local partner agencies that are supportive of the Community Health Worker training program. Participants represent the following organizations that serve Athens, Vinton, and Hocking counties:

- AmeriCorps/COMCorps – Athens City/County Health Department & Live Healthy Appalachia
- Vinton County Help Me Grow
- Ohio University College of Family Medicine
- Hopewell Health Center (FQHC)
- HAVAR, an agency that provides in-home daily living support to individuals with disabilities

Evaluation Plan

Students complete knowledge-based assessment surveys pre- and post- the training period. Demographic data are also collected, including employment history and the significance of obtaining the CHW certificate. Data are regularly compiled and analyzed into a longitudinal dataset via statistical analysis and through qualitative data coding. Participant feedback is collected after the completion of each training module and during field visits to enhance programming and continuous quality improvement practices. The Voinovich School of Leadership and Public Affairs is managing the evaluation plan and providing annual reports. Employment status and benefits of obtaining the CHW certificate will be tracked across time by the Voinovich School.

In addition, change in social empathy is assessed using a Social Empathy scale. The purpose of this study is to understand the level and dimensions of social empathy in community health worker trainees. Using the Social Empathy Index (Segal, 2011), information will be gathered when participants enter and complete the program. Participants will complete the SEI in the first class of the program and then again in the final class. The pre and post-assessments will be examined for changes generally in social empathy and specifically in areas of strength and weakness for the student group at entrance and completion. This analysis will contribute to understanding of community health worker education, social empathy in participants, and the concept of social empathy generally.

Social empathy adds dimensions of understanding system-level barriers and broader self-other knowledge to interpersonal empathy: “interpersonal and social empathy [are] tools for us to improve our own lives and other people’s lives, as well as to promote social well-being” (Segal, 2011). The community health worker program is focused on improving access to care and increasing education related to all aspects of health—physical, mental, and social. Cultural competence is required to provide quality, effective service and is a key element of the program.

Proposed Partnerships

The community health worker program that has been established through MEDTAPP currently has over 21 linkages within the Southeastern region of Ohio. These referral networks will be enhanced by each cohort trained throughout the next 2 years (approximately 8 additional training sites). By utilizing existing trained community health workers, we will continue to utilize and expand our reach for engaging providers. In addition, former MEDTAPP partnerships established in the local trauma informed care initiative have allowed us to expand outreach opportunities for local providers. For example, current training at Hopewell Health Centers, a local Federally Qualified Healthcare Center that also serves as a Community Mental Health Center, has been working with our local team and has access to providers in over 19 Ohio counties throughout the region. Our plan to expand partnerships includes the following steps:

1. Ask known established entities (i.e., Hopewell) about potential providers who are apt to utilize and/or communicate the usefulness and effectiveness of community health worker services.
2. Reach out to existing providers and providing brief education about the CHW program.
3. Utilize the marketing/communication toolkit to inform existing patients about the benefits and services existing within the community.
4. Track referral sources by existing community health workers through an already existing shared documentation platform through Ohio University's MEDTAPP programs.

Placement Sites

To date, over eight local rural agencies have agreed to be a secure placement site for regional trained community health workers, including a drug/alcohol addiction center, a geriatric nursing facility, two health departments, a local WIC agency, and a local Primary Care and dental clinic. As current community health workers continue to be certified in the region, part of their charge will be to identify additional site placements (including current employment sites). In addition, the current community health worker program through the Athens Health Department will utilize additional existing funding streams to help place CHWs in the surrounding rural areas.

In tandem, we will continue to enhance and develop community partnerships with managed care plans. Current leadership maintains existing partnerships with several of the local managed care plans through the work of former maternal and child health grants throughout the region. These existing linkages include Molina, Paramount, Caresource, and United. As CHWs are placed within the region, existing linkages with these managed care outreach workers will be called on for ongoing communication and potential employment opportunities to serve in the rural regional healthcare sites. In addition, managed care plans are invited to regional collaboration meetings for updates and information sharing between university and community partnerships.

Addressing Social Determinants of Health

Helping students understand the nuances of a community and community needs plays an integral role in the success of this program. The students need to understand the social determinants that affect the community members' decisions to seek or not to seek medical attention. The core instructors, given their extensive experience working in these communities, along with exposure through supervised practicums, will help develop these skills. Understanding the social determinants surrounding the healthcare of a community is paramount in the success of the CHW and the overall outcomes of the curriculum.

The social determinants of health that the CHW training program will utilize are taken from the evidence-based practice contributed by the Office of Disease Prevention and Health Promotion (HealthyPeople.gov). Leading health indicators such as poverty, local graduation rates, statistics on violence, and unemployment are emphasized and highlighted throughout the already approved curriculum through the Ohio Board of Nursing. Multiple pre-/post-outcome measures that include social empathy, concrete health knowledge, and developmental warning signs are measured on a quarterly basis to help track knowledge, attitudes, and outcomes. Culturally sensitive education involving the complexities of health disparities in this rural, Appalachian region is of the highest priority when training local CHWs. One CHW training participant shared that she is asked at every home visit where she is from and who her relatives are. Because of her cultural training, she understands that this is a way her patients build rapport and identify her as an "insider."

CHWs are embedded automatically into interprofessional experiences at each placement site. A unique aspect of the rural healthcare systems within Appalachian Ohio includes the ongoing coordination and programming between health professionals from several disciplines. Utilizing the existing infrastructure within Ohio University's College of Health Sciences and Professions, CHW cohorts are exposed to ongoing efforts across the region to make interprofessional experiences available. A specific example will be the inclusion of speakers from Hopewell

Health Centers, Inc. Hopewell Health Centers is a regional Federally Qualified Healthcare Center that also serves as a certified Community Mental Health Agency with 15 separate locations within the Southeastern Ohio. Hopewell is an established partner and has been providing integration and cultural competence training for our agencies throughout the past decade.

Implementation Timeline

Year 1 fall July–Dec 2017	Year 1 spring Jan–Jun 2018	Year 2 fall July–Dec 2018	Year 2 spring Jan–June 2019
Training #1 (2 simultaneous cohorts)	Curriculum implementation (cohorts 1 and 2)	Training #2 (2 simultaneous cohorts)	Curriculum implementation (cohorts 3 and 4)
Student recruitment for year 1 spring	Student recruitment for year 2 fall	Student recruitment for year 2 spring	Focus group interviews for student experience
Community site recruitment	Community/student match (cohorts 1 and 2)	Community/student match (cohort 2)	Community/student match (cohorts 3 and 4)
Evaluation data setup and planning	Pre-evaluation for cohorts 1 and 2	Post-evaluation for cohorts 1 and 2	Pre-evaluation for cohorts 3 and 4 (post upon completion)
Identifying content experts to provide specialized training across years (cultural competency, etc.)	Motivational interviewing training and cultural competence training for cohorts 1 and 2	Motivational interviewing training and cultural competence training for cohorts 3 and 4	Post-evaluation for cohort 2
CHW site travel and discussions	Active recruitment of cohorts 3 and 4 for year 2	Preliminary data gathering and assessment	Dissemination and write up of data research to academic journals/conferences

Future of the Training Program in Southeast Ohio

In 2017, funding priorities for MEDTAPP shifted and the Ohio University Community Health Worker Training Program went from being grant-funded to support a university endowment fund through the College of Health Sciences and Professions. This change has allowed the program director to focus on information gathering and visioning during 2018–2019. In collaboration with the Voinovich

School, an environmental scan of the work being done by community health workers in the region has been completed and analyzed in preparation for a Stakeholders Convening to be held in June 2019. The CHW Program is supported strongly by the University leadership and is included in several community-university grant proposals. As more data are collected and shared about the benefits and efficacy of community health workers in our region, we are hopeful that a consistent funding stream for employment will be identified; that the workforce will continue to grow and flourish; and that our communities will become more engaged in healthier lifestyle choices through access to resources and information as a result of their relationships with community health workers.

Acknowledgments Athens City-County Health Department: Ruth Dudding, Josh Scakacs, Jack Pepper
Cari Hollenbeck
Gemini Wright
Ohio Medicaid and Technical Assistance and Policy Program (MEDTAPP)
Marietta High School: Kim Depue and Mary Ella Bauer
Dr. Sarah Garlington
Dr. Jeff DiGiovani
Dr. John McCarthy
Dr. Randy Leite

References

Berthold, T., Avila, A., & Miller, J. (Eds.). (2009). *Core competencies in community health*. Oakland, CA: Jossey Bass.

Carroll, K., Ball, A., Nich, S., Martino, C., Frankforter, S., Farentinos, T., et al. (2006). Motivational interviewing to improve treatment engagement and outcome in individuals seeking treatment for substance abuse: A multisite effectiveness study. *Drug and Alcohol Dependence, 81*, 301–312.

Kliegman, R. (1992). Perpetual poverty: Child health and the underclass. *Pediatrics, 89*(4), 585–588.

Ohio Board of Nursing. (2019, March). *Community health workers.* Retrieved from URL http://www.nursing.ohio.gov/CommunityHealthWorkers.htm

Ohio Development Services Agency: Governor's Office of Appalachia. (2019, March). *Appalachian Regional Commission.* Retrieved from URL https://development.ohio.gov/cs/cs_goa_rc.htm

Payne, R., DeVol, P., & Smith, D. (2001). *Bridges out of poverty: Strategies for professionals and communities*. Highland, TX: Aha! Process.

Segal, E. (2011). Social empathy: A model built on empathy, contextual understanding, and social responsibility that promotes social justice. *Journal of Social Service Research, 37*(3), 266–277.

Chapter 8
Is the Affordable Care Act Encouraging Hospitals to Engage their Communities? Experiences from Appalachian Ohio

Berkeley Franz, Daniel Skinner, and Danielle Dukes

Scholars often describe hospitals as contained and unified social institutions. In fact, some of the most prominent social theorists of medical institutions, from Erving Goffman to Michel Foucault to Paul Starr, have chronicled the Western hospital as though it is a mostly homogenous institution governed by an internal logic (Foucault, 1973; Goffman, 1961; Starr, 1982). Although there is much that unites traditional inpatient hospitals in terms of their mission of providing acute patient care and organizational structure, they exhibit diversity as well. Variation owes to differences in hospitals' financial arrangements, organizational environments, regional locations, and unique histories.

The need to bring analytic nuance to the study of hospitals has gained renewed importance in an era of American health care defined in large part by passage of the Affordable Care Act (ACA) in 2010 (Jacobs & Skocpol, 2012; Starr, 2013). Yet, while the political landscape has been shaped by attempts to repeal the bill since early 2017 – with each repeal followed closely in media coverage – the bill's provisions concerning hospitals are rarely discussed. The extent to which they are understood among the general public is unknown. Among the more important and promising of these provisions are those requiring that nonprofit hospitals, roughly 56% of all hospitals in the United States (AHA, 2019), increase and more rigorously structure their "community benefit" activities as a condition of maintaining their 501(c)(3) nonprofit tax exempt status.

Although all nonprofit hospitals have been required by the IRS since the 1960s to document the ways in which they benefit their communities, over 85% of this benefit has traditionally been provided in various forms of charity patient care,

---

B. Franz (✉)
Heritage College of Osteopathic Medicine, Ohio University, Athens, OH, USA
e-mail: franzb@ohio.edu

D. Skinner · D. Dukes
Heritage College of Osteopathic Medicine, Ohio University, Dublin, OH, USA

© Springer Nature Switzerland AG 2019

S. L. Arxer, J. W. Murphy (eds.), *Community-Based Health Interventions in an Institutional Context*, International Perspectives on Social Policy, Administration, and Practice, https://doi.org/10.1007/978-3-030-24654-9_8

including the subsidization of costs associated with the care for patients covered by Medicaid and over government insurance programs (Folkemer et al., 2011; Young, Chou, Alexander, Lee, & Raver, 2013). The ACA nudges – even pushes – hospitals outward in stating that they must reach beyond their typical patient population and engage the communities beyond hospital walls. This move uses community benefit requirements to expand the hospital's role into traditional public health activities and beyond direct patient care.

Specifically, the ACA requires that nonprofit hospitals, in consultation with the communities they serve, undertake Community Health Needs Assessments (CHNAs) every 3 years to understand their communities' most pressing health needs and then publicly disseminate their findings (Evashwick, 2013). In response to these identified health needs, hospitals must develop an implementation strategy (Internal Revenue Service, 2013). The results of new programs and initiatives formed from the strategy are to be reported annually to produce accountability in community benefit programming. In mandating this process, the ACA is part of a broader trend that is encouraging hospitals to take on local population health needs in addition to providing patient-level care. For those that lack a commitment to the process, the ACA, through Section 4959 of the Internal Revenue Code, authorizes an excise tax of up to $50,000 per year (Rosenbaum, 2015) in addition to the possible revocation of their federal tax exemption status. In 2018, the IRS demonstrated that it actively audits nonprofit hospitals for CHNA compliance in the private letter ruling that revoked a hospital organization's section 501(c)(3) status for failing to comply with requirements (Internal Revenue Service, 2018).

Beginning in 2012, the first 3-year cycle of CHNAs and subsequent community investments created new opportunities for expanding the reach of hospitals' community benefit activities. Although preliminary reports suggest that hospitals are using a variety of different approaches to meet these new requirements such as collecting primary data and utilizing secondary data sources (Burke et al., 2014), less is known about the experiences of hospitals as they take on new community benefit activities, especially when addressing underserved and rural populations. As a result, our study aims to provide a thorough analysis of the community benefit and CHNA efforts of hospitals across the Appalachian region of Ohio. This sample includes a diverse subset of hospitals including small county hospitals, large urban hospitals, and hospitals within health systems of varying sizes.

Although preliminary reports indicate that US hospitals are responding to the new ACA requirements by developing various community partnerships and programs in response to CHNA findings and using multiple methodologies (e.g., collaborations between hospital facilities and public health agencies or consultant-led CHNA processes) to complete reports (Beatty, Wilson, Ciecior, & Stringer, 2015; Pennel, McLeroy, Burdine, & Mataritta-Cascante, 2015; Wilson, Mohr, Beatty, & Ciecior, 2014), few studies have documented the experiences of rural hospitals or, more specifically, hospitals within the Appalachian region of the USA. This region is particularly notable for distressed socioeconomic conditions, but more recently significant health disparities have been documented as a result of widespread unemployment and low income households, a prevalence of risky health behaviors, environmental factors, and lack of access to medical care (Borak, Salipante-Zaidel, Slade, & Fields, 2012; Halverson & Bischak, 2008; Hendryx, 2009; Hendryx & Ahern, 2009; Ludke & Obermiller, 2012; Morrone, Kruse, & Chadwick, 2014; Smith & Hollorman, 2011; Wewers, Katz, Fickle, & Paskett, 2006). As such, this region particularly stands to gain from increased population health activity if hospitals are able to implement new programs in underserved communities.

To understand hospital experiences with CHNAs in this underserved region, the first two authors conducted interviews with hospital staff, administrators, and consultants, and evaluated formal documents associated with the CHNA and implementation process. Specifically, we sought to understand how these new activities are informing community health engagement in surrounding communities. These findings make clear that the ACA has formalized community-benefit requirements; accordingly, we outlined how those tasked with taking on CHNAs have experienced the subsequent changes. As we explain, our interviews revealed a complex set of challenges, as well as muted optimism, regarding the possibility that ACA-mandated CHNAs will positively impact population health in a region that lacks material resources and faces a myriad of other challenges. Our results provide insight into the process of community-benefit activities and how such requirements might be improved in future health policy debates in order to successfully engage local communities in improving population health outcomes.

Methods

Overview of Study

The purpose of our study was to understand how hospitals in Appalachian Ohio have adjusted to new ACA requirements to conduct CHNAs and develop programming to respond to local needs. Using grounded theory methodology, we conducted in-depth interviews with hospital personnel and outside consultants who worked on CHNAs in either 2013 or 2016 in this region. In accordance with grounded theory principles, we did not begin with specific hypotheses, but rather guiding research questions that informed our interview guide (Charmaz, 2006). Specifically our questions were:

1. What steps have been taken and methods employed to carry out CHNAs in the years since the ACA was implemented?
2. How do hospitals evaluate the effectiveness of these new community benefit activities?
3. What are the significant challenges to improving health outcomes in rural, Appalachian communities?

The goal of this methodology is to begin with general questions that allow findings to emerge from participants' perspectives. After submitting a protocol outlining this study, we were cleared by the Ohio University Institutional Review Board on May 9, 2015.

Recruitment and Sampling

Appalachian Ohio's 32 counties include 26 nonprofit hospitals. We made initial contact with hospitals either by email or phone. Although hospitals are required to make their CHNA results public, often the persons responsible for these activities are not identified. Therefore, at times we had to initiate contact by calling the hospital's general number or by filling out comment forms on hospital web pages. Determining who was responsible for CHNAs was thus challenging given the fact that few of the hospitals in this region had dedicated full-time staff to these activities. Despite the challenges associated with making initial connections, consent was ultimately received from 17 research participants who had either worked or were currently working on post-ACA CHNAs. Fifteen participants were hospital employees while working on CHNAs, and two were external consultants. Participants represented 21 different hospitals, some of which were independent and others which were part of large, often multistate health systems. Of the 21 hospitals included in our sample, 12 were affiliated with nine health systems.

Data Collection and Analysis

Interviews occurred by phone and lasted between 30 and 60 minutes. After each interview was completed, the audio files were transcribed by a professional transcriptionist. In line with grounded theory methodology, preliminary coding began after each interview was transcribed and the results were used to inform future recruiting. Because there was a fixed sample size due to the region chosen for the study, preliminary coding was used to identify hospitals in the region who may be different or offer divergent perspectives than the existing hospitals who had not yet agreed to participate. Five additional hospitals were added to the sample through follow-up contact after theoretical sampling occurred (Charmaz, 2006). We continued to interview and analyze data until no new categories emerged. This stage, dubbed "theoretical saturation" by grounded theory experts, was reached after 17 interviews, spanning 21 hospitals. This sample size is within the normal range for grounded theory research (Charmaz, 2006).

Interviews were coded by the authors using the web-based data analysis software Dedoose. Following grounded theory procedures, coding was undertaken in three phases (Walker & Myrick, 2006). The first stage, open coding, requires line by line descriptors be applied throughout the transcript. The next step is for the researchers to complete “axial coding” where initial line by line descriptors are grouped into similar clusters. Finally, theoretical coding occurs and involves identifying overall emerging themes and describing a causal structure of relationships between these themes. Certain procedures are often employed at each stage of coding to ensure that data analysis is rigorous and consistent between researchers. In this project, the researchers engaged in cross-coding to improve reliability, in addition to the collaborative questioning of categories, memo-writing, and word-analysis (Strauss & Corbin, 1998). This method of coding was used to foster creativity and reduce bias while generating themes in a systematic approach.

Findings

Our findings concern the specific challenges of undertaking CHNAs for hospitals serving rural, underserved, and vulnerable populations, as well as the degree of optimism that interviewees displayed regarding the capacity of post-ACA CHNAs to positively effectuate change in their communities. Our interviews revealed significant challenges in studying and working with rural populations, notably demographic and geographic diversity, resources in both hospitals and communities, and other barriers to implementing the kind of programming required to address problems impacting these populations. In our analysis of the attitudinal dispositions held by interviewees regarding the CHNA process and future of community benefit, we consider participant perspectives on whether local health outcomes can be improved by hospital community benefit work, which range from the somewhat negative to muted, qualified optimism. The barriers described were relevant both in producing the official CHNA reports which are due every 3 years and also in developing the required implementation programs from the needs identified through the CHNA process. In order to ensure the anonymity of participants, we deploy pseudonyms for all data presented.

Challenges

Low-Resource Communities

In many ways, the successful undertaking of a CHNA requires cooperation not only with community organizations and health institutions, but community members themselves who are able to engage despite structural disadvantages they may face. Donna explained that the large county in which her hospital is located “is almost an entirely different world” than areas just on the other side of a major highway, adding:

> we have pockets of the county that don't have cell service. We have pockets of the county that don't really have access to broadband to have access to the internet. Seems unreal in 2016, but it's true. There were households that didn't have great running water, those are things that you've got people who, again, our unemployment rated always higher than the state/national average, which means people don't have the disposable income to really take control of their own health. Running advocates for themselves, because they're deciding whether or not I can eat today, or whether I can go to the doctor.

As Sharon noted:

> reaching…some of the population that we need to in this market is tough. You know, you really have to be out into the communities and where the people are that you need to reach… Reaching that population with the messages that we need to and helping them through, we do a lot of nutrition education and we have cooking classes at the library, things like that. But really getting the message to the people that we need to is a challenge for us.

In many cases, difficulty in reaching and working with local populations was cast as a communication issue. As Stacy noted, "access is always a challenge because our patients have access issues and communication sometimes can be an issue."

Jackie added:

> I would say that…the health needs are different. I mean, there's a huge problem with smoking…and of course, where there's a large proportion of smoking, you've got great incidence of lung cancer. In fact, lung cancer is the number one cause of death in those counties. So then what we have to do is we have to look at, you know, how can we motivate people to be tested, to do smoking cessation, how do we deal with some of the social determinants? You know, they don't have transportation, they don't have this, they don't have that. So there's a lot more extenuating resources that have to be provided if we really want to be successful.

Here Jackie is pointing out that while finding a relevant population health problem to address might be simple, finding the range of resources needed to provide effective intervention is not.

Rural Geography

Geography, for several reasons, creates additional barriers to working with local populations. Most of these ways, moreover, tend to be drawn in comparison with the contexts posed by urban populations. As Amy noted:

> I think it's much easier if you've got a concentrated population, to know how to do a few things and be able to get to people. When people are spread out all over the place, it's much more difficult to go into areas and to be able to provide services. It's more costly, it's less efficient to serve a rural community as opposed to urban.

In some cases, geographic challenges manifested in problems accessing data. Jennifer, for example, who oversaw a CHNA that spanned multiple states, notes:

> …when you would talk to people at the state level…Kentucky had decent data, but it wasn't as current as Ohio. But Indiana, we often just had trouble even figuring out what data had rolled up…So I think in a small town, there's a few places, not too many, but there are a few

> places that they were so small that the numbers were suppressed because you'd be able to figure out who was the person who had Hep-C.

The expansiveness of rural populations also presented challenges when developing implementation plans to respond to identified health needs. As Nancy noted:

> delivering the programming is always a challenge when you're serving a rural community because you don't have condensed areas of population, they have to be able to travel to get to it. There's also a lot more difficulty getting into the schools to do health programming, we have that. We try to get creative, like, we do a lot of summer programming at the public library…Those programs have like feeding programs during the summer, they serve lunches and that type of thing, so we can get upwards of 40 or 50 kids in a spot to do stuff. So that's an example of just trying to reach the population when it's spread out and not able to travel to what you're trying to do. So delivering the programming, that part of it, that's always a challenge. Budgeting for it to make sure that you're able to provide the services, particularly for us when you're talking about a health system that serves [multiple] counties. In those counties, for example, we have 31 school districts, over 100 schools. How do we provide equitable programming to all those places? We're not doing it. And it's not because we won't, it's because we can't. Trying to get the resources, the human resources and the monetary resources to do all of that is, it's not easy.

CHNAs directed at areas with large numbers of traditionally underserved populations, framed the experience for many of our interviewees. While most hospital personnel we interviewed reported difficulties in data collection, often because of what they saw as challenges with reaching distant populations. Lauren, however, reported the opposite, noting:

> we had great response, like I said, other than us not being probably as aware of some of our populations like we talked about with the Guatemalans and the Amish. I think we had great response, sometimes I think maybe being a smaller county may have worked to our advantage.

A minority of respondents, therefore, emphasized the unique advantage that Appalachian hospitals may have in that they often are an important institution in their county with existing community relationships in place which may facilitate successful CHNAs – something that urban hospitals might have to put more effort into.

Hospital Resources

These geographic and demographic factors result in clear challenges in carrying out CHNAs. Because most of the hospitals whose employees we interviewed tended to be undercapitalized when compared to their urban counterparts, many employees tasked with doing CHNAs must balance multiple duties, making focus on the CHNAs difficult. For example, Nancy estimated that working on CHNAs accounts for only a third of her time: "I am also the grant writer and grants manager for the health system, I am the government relations officer, I am also their community outreach person." Nancy added that this is probably unique to the Appalachian setting of her hospital. In other hospitals, "Those are all full-time jobs. These are all full-time jobs, even here. But we don't have the resources…." Patricia added:

> You know, going into this, that's something that we didn't necessarily anticipate. Having these new requirements, while they could be positive, they also are a new requirement that is a lot of work. So that's been quite striking. And you're right, it really does vary among the hospitals; some hospitals can afford to pay consultants to produce big reports.

Donna identified staffing as a problem, noting that while "obviously we staff to extremely safe levels and that sort of thing," she also lacked:

> a staff that is just then dedicated to doing community outreach, community benefits, community health. So it was difficult for us to implement some of the programs that we took a look at. For example, we have a problem with women who smoke in their first trimester. Part of it is…getting people to take advantage of the programs that we offered was a struggle….

Sharon added to this theme of problems associated with staffing, noting "you know, it's a mandate that we're required to provide that, we really just don't have the staffing."

Melanie agreed and explained how her institution had been creative to meet these new requirements with limited resources. Her solution was to leverage community partnerships to complete the CHNA and develop an implementation strategy:

> You know, we agreed for example, last community needs assessment, we agreed that obesity prevention was gonna be our one common strategy that we all tried to address over a 3-year period of time. It was based on how each organization would tackle the issues, but we did agree that it would be a common, top-of-mind strategy to improve population health. Again, there's a common purpose, a common theme for all of the activities if that makes sense.

Implementing Programs

For many interviewees, the social context of their hospitals also posed challenges for implementing strategies for addressing those needs. For example, Stacy noted, "that where we need the support is after the assessment is done, what are we gonna do about it? That's where the support needs to come in." Nancy added:

> They want us to be effective in impacting the health, but if there's not a lot of good models for us to follow to do it…I don't know. At the end of the day, I don't know how effective many of us are going to be. I spent a lot of time researching programming that we think will work and trying to develop community programs around clinical stuff we do that we know works, but how can we make it so it reaches the broader community?

For Sarah,

> Carrying out the assessment is not an issue, it's coming up with programs and getting people to participate and be interested in making lifestyle changes. And that may be, I would say some of that is maybe a personal bias in that I've lived and worked in a large metropolitan area as well as living and working here and, you know, the difference is dramatic. As far

> as, you know, the barriers that you're working with here in the Appalachian counties as opposed to some of the others are significant.

Sarah sees problems, as well, in the fact:

> …that there's requirements to do the assessment and then requirements involved in that with determining actions to help improve the health of the community that you serve. And then, as were defined later as many things as can be objectively measured in regards to the types of things that you're doing to help improve the health of the community, but there's no real funding in essence for that.

Cautious Optimism About CHNA Process and Effects

Doubting that CHNA Process Will Positively Affect Communities

Because of the significant challenges many participants faced in carrying out CHNAs and implementation programs to address needs, our interviews revealed a fairly wide spectrum concerning the degree to which those carrying out CHNAs were optimistic about the impact the new CHNA process was likely to have on local health outcomes. Nancy, when asked whether the CHNA process might improve health outcomes, let out an audible sigh before speaking. She responded:

> if I had to rate it on a scale, I probably would be right in the middle but just slightly to the left on the 'I don't think so'. And again, it has to do with the fact that, you know, what community programs, what types of outreach can you do that is going to be effective to the community that you serve? I find great examples, but many of them are in urban areas. The rural culture and Appalachian culture is something that you have to take into consideration here. You know, health literacy…. I'm not optimistic, not because I don't think people care and don't want to do the work; I'm not optimistic because I don't know that there's evidence-based models out there that are gonna be effective for us and our population.

Her mixed assessment was in large part a reaction to the particular challenges in programming that rural hospitals face, as well as a perceived lack of an evidence base to help them overcome those challenges.

Patricia was also not optimistic, and viewed the process largely as a burden that was likely to have few positive effects. Her view is:

> it's just a lot of paperwork for us to do. I really don't know that the people that really need it, you know, the low-educated people, the people that are in the system on welfare, I don't think they're getting anything out of it…. Yeah, the issues are out there and whether they're getting rectified or not I think we're all trying to take steps towards them, but they're tough. Especially with no funding available for them.

Hillary also exhibited mixed feelings about the process, explaining "I'm not saying that we wouldn't get information back from this that we couldn't use, but I don't know that it's really gonna shape how we are delivering our services." In Hillary's view, converting CHNA findings into tangible change in hospital services is perhaps more challenging than the CHNA process itself.

Describing Change as Slow in Community Health

Though not necessarily a pessimistic view, Amy emphasized the difficult, and at times imperceptibly slow, process of changing health outcomes and behaviors. Addressing smoking and tobacco use, for example, she asked:

> how many years has it taken us to really start seeing a decline? You know, it's like 20, 25, 30 years ago they started that process and you're seeing the benefits today. And I think it's the same thing with doing these community health needs assessments and working to impact communities. I think it's gonna be a slow process but, you know, I think it'll get there in time…Long-term, yes. With anything, you have so much ingrained and embedded issues, so many issues help determine the lifestyle. And it really takes a long time, long-term work in order to make impact. I think that, you know, re-doing this every three years, you're really not gonna see dramatic changes in what those community needs are or what direction you're going. But I think, you know, when you start going and looking 20 years back, when we reach that point I think yes, you will see that.

Chantelle similarly expressed optimism attenuated by what she perceived as socioeconomic realities. At the same time, there were worse consequences to not attempting to take on these challenges now, however difficult change would be. She explained:

> I think when you deal with the magnitude of the problems that have been identified, like substance abuse, for us to even move the needle even if everybody is fully resourced, is going to be really hard. But I think it gives us direction and I think if we can collaborate on an ongoing basis with our community partners, maybe we can be more strategic in the way we address some of these massive needs. And these are just such huge problems that honestly, if we don't get worse, that would be progress in some ways.

Believing CHNAs will Improve Local Health Outcomes

Sarah, whose institution had a more complicated view of the CHNA process, was more optimistic, but, like others in our sample, that optimism was muted by her perceptions of socioeconomic conditions. She noted, for example:

> I would like to think that it, you know, I think that we believe that it will have some impact. Again, I'm not sure if we're 100% convinced that we have enough resources and enough funding, particularly in Appalachia given the fact that if you look at most of the counties in Ohio that fall into that category, we tend to have lower income, more uninsured and then higher rates of poor lifestyle choices and higher rates of chronic disease. Again, cultures that are, you know, have maybe been rooted for a while that are more rooted in unhealthier lifestyle. Um, so I think that we hope that it'll do that, I don't know if we have enough resources to be able to counteract some of the things we have working against us. That's certainly our hope and our intention, but I can't, I don't think any of us could say with certainty…you know, that we could ultimately, compared to again other areas of the state that may not be, there's non-Appalachian areas of the state that may not have quite the same level of issues.

Stacy, however, is optimistic that the work invested in health education in the community will pay off over time. She explains:

> I think certainly the efforts that we've put out there have been beneficial. You know, we also know that our region is, you know, less healthy. And regions around us, movement on

> patient behavior is slow. So us having to do these guidelines are not gonna change people's desire to change their health, but you know, our hope is that having resources and education…you know, we've been doing it for years and we keep plugging away and over time that's gonna have an impact.

Susan's optimism is rooted in her institution's comparatively high level of capitalization and commitment to the CHNA process. Though she finds some aspects of the process to be "burdensome," her institution responded by hiring additional staff to support this work. She explained: "it's burdensome for only a short time and then when you see the impact that it makes, you realize that it was the right thing to do and that it was worth it."

Lauren recast the question of the effects that the CHNA she led was poised to make on her community as, "do we think this has been worth it?" which she posed to her colleagues. She reports, "And really the consensus from that group was yes."

Discussion

Given that socioeconomic and geographic challenges are very much part of the Appalachian context, the fact that barriers to improving health emerged as some of the most significant findings is unsurprising. However, an unexpected finding was that optimism about the impact of CHNAs varied across hospitals despite recognized and oftentimes similar challenges. To the extent that the ACA promises to bring about change in some of the USA's high need areas, Appalachia represents one of the greatest challenges, as well as a site in which improvements may be most impactful. In other words, in Appalachia we may be able to more acutely observe whether or not the ACA's various mechanisms – of which CHNAs and new community benefit rules are merely one piece – can drive positive changes in health outcomes.

Although several major findings emerged related to the experience of conducting CHNAs in the Appalachian context, several distinctions are worth exploring. For example, concerns about financial resources underlie most hospital employees' perspectives on the CHNA process, and undercut many efforts at addressing health needs identified in the reports. Furthermore, hospitals within our sample were situated differently with regard to the number of employees dedicated to the CHNA process and financial resources available for both producing the official CHNA report and for supporting follow-up implementation activities. One particularly interesting finding was that employees from hospitals that are part of larger systems felt that there were adequate resources at their disposal, but faced challenges engaging the local community, whom they at times felt distanced and disconnected from.

Some hospital systems, for example, conducted CHNAs from one primary location, resulting in difficulties developing the relationships necessary to partner with local social service organizations, health departments, and residents to implement programs. As a result, financial resources should be seen as only one challenge underlying community health improvement in this region. Equally important is for hospitals who do not currently have ties to the communities they serve to focus their efforts on establishing pathways for communicating with local organizations who are already enmeshed in a community. Our interviews further suggest that an awareness of this challenge is a critical step toward ensuring that hospitals that are part of larger systems adequately represent community perspectives in their report. Because CHNAs produced by large systems must make sense of needs across large geographic areas, it is difficult to appreciate the diversity of local contexts and to facilitate the relationships necessary to develop site-specific interventions that will benefit all locales equally.

At the same time, however, many of the smaller hospitals that either were not part of a system, or whose CHNAs were not being done in coordination with their system, reported benefits stemming from their smaller status, especially as regards their knowledge of the community. In some cases, these hospitals felt that their closeness to community members and organizations yielded higher response rates in data collection and an advantage in developing the partnerships necessary to carry out CHNAs and subsequently develop collaborative implementation projects. In other words, although larger systems are better capitalized financially for large-scale CHNAs and general community benefit funding, smaller hospitals may subsidize their community benefit work through the social and cultural capital developed by virtue of their status within a rural community. This positioning may allow independent rural hospitals to expand existing relationships in the promotion of new community health initiatives. Likewise, larger health systems that possess the capital and lack the community relationships needed to implement their plan could use their capital to form relationships with stakeholders across their service area to foster social capital – instead of focusing on using the financial advantage they do have on a few site-specific interventions.

In addition to distinguishing between the different types of challenges that various hospitals face in this region, our findings also suggest important differences in the optimism that exists regarding the ability to improve health outcomes through hospital–community engagement. For many hospital employees, the opportunity to undertake CHNAs with the formal rigor required by ACA and IRS guidelines, serves as an opportunity to make good on their passion for public health. For these individuals, post-ACA CHNAs are seen as an opportunity to realize hospitals' ultimate goals of preventing illness and actively seeking out opportunities to tackle large, even seemingly intractable problems. Although most interviewees made clear that low resources and other challenges were significant impediments to progress, the process itself made sense to them and provided them with clear questions about what it would take to use the CHNA and post-CHNA programming to positively impact health outcomes and address social problems.

In contrast, some hospital employees and consultants were not confident that either CHNAs or the programs their results encourage would be enough to move the needle on local health outcomes. Our interviews suggest four main reasons for this pessimism. In each case, these attitudes reflected not only the CHNA process itself, but specific conditions owing to the challenges of doing CHNAs in underserved, rural areas such as Appalachian Ohio.

First, some participants believe that rural and Appalachian culture produces something of a culture of complacency that will result in hospital outreach falling on deaf ears. More specifically, many participants suggested that providing support for good health will not be effective if individuals do not take personal responsibility for their own health. In this way, some interviewees' perspectives reflected a common ideological thread in American health policy and politics, namely, an emphasis on individual behaviors and choices over systemic, socioeconomic, and structural conditions. These views draw upon ongoing debates about the cause of disparities, wherein those involved in devising solutions attempt to ascribe weight to quite different factors in an attempt to steer solutions toward one area over another (Resnik, 2007). For example, when attempting to address a disparity that is widely discussed as a function of individual behaviors – like physical activity or diet – the solutions to the problem will likely be focused on changing the behavior, not the conditions that caused the behavior. Thornton and colleagues explain that "if one's neighborhood is unsafe even during daylight hours and an individual lacks the resources to move to a safer neighborhood, interventions targeting outdoor physical activity are unlikely to be effective" (Thornton et al., 2016).

The reliance on personal factors as an explanation for inequality has been described as a "dominant ideology" among Americans (Kluegel & Smith, 1986). More specifically related to health, neoliberal ideology has been cited as an important framework for downplaying structural support for addressing health inequalities in favor of individual actions (Peacock, Bissell, & Owen, 2014). The language of personal responsibility has long been central to American identity (Franklin & Seavey, 2008; Lavin, 2008) and has persisted during ACA legislative debates and implementation (Gollust & Lynch, 2011). Instead of focusing only on this lens, however, some participants working on CHNAs emphasized individual-level factors such as motivation as major drivers of health outcomes *in addition to* structural barriers such as unemployment, access to care, or proximity of healthful, quality food outlets. Unsurprisingly, given these seemingly intractable barriers, many hospital employees believe that their efforts with CHNA and community benefit will only take hold if significant changes in individual behavior take place as well.

Second, some interviewees appeared to be weighing the potential population health benefits to the bureaucratic and resource intensiveness of the CHNA process. In these comments there is a palpable sense of being overwhelmed by the CHNA process itself, but also the conditions under which they, at their mostly under-resourced hospitals, were expected to carry out the process. Although not all of our participants described financial strain, there is evidence that taking on CHNAs might produce more challenges for small, rural hospitals which have fewer beds, staff, and more narrow profit margins than their urban counterparts (Kaufman et al., 2016; Younis, 2013). As a result, allocating personnel to carry out CHNAs or finding resources for developing new programs may be difficult for some hospitals. In addition, rural hospitals tend to be located within populations that have a disproportionate amount of aging residents, poverty, and morbidity (National Rural Health Association, 2016). The cumulative result of these factors may mean that if significant health issues arise in CHNA reports, hospitals may not have the resources to address problems if they are outside of existing expertise, require significant investment of resources, or rely on dedicated staff to engage geographically dispersed communities.

Third, while many interviewees expressed positivity regarding the CHNA process and what was required of hospitals, some were less than optimistic about the prospects of converting that process into tangible programs due to a lack of institutional buy-in. Here, it appears, our research illuminates a major crossroads for medicine, in general, and for nonprofit hospitals more specifically, as the latter adjust to quite different institutional contexts and even a revision of the traditional hospitals' mission. By expanding hospitals' responsibilities to the surrounding community in addition to specific patient populations, the CHNA process requires a willingness to reorganize existing community benefit practices and adjust both staffing and strategic planning. In addition, the potential inclusion of nonmedical social determinants of health as areas of focus for hospitals stands to radically change the role of hospitals – a change that cannot be done without buy-in. The extent to which hospitals are willing to change existing and ingrained practice models will likely mediate the effectiveness of new CHNA requirements in changing health outcomes and reducing health care costs (Rosenbaum, 2016).

Fourth, the most optimistic interviewees in our sample, we found, held this view for clear reasons. In particular, hospital employees whose professional backgrounds were based in community health, community benefit, or nursing departments, were consistently more optimistic than those located in business, marketing, or development. In this way, a sense of hope in our sample was seemingly related to whether a hospital connected community benefit activities with public health or with business practices tied to retaining nonprofit status. Institutional culture, in other words, may play a role in determining whether community benefit inspires a shift toward community health programming or retains a traditional focus on direct patient care with community benefit as a pesky side-requirement. In making progress toward community-level investments, we argue that optimism may play an important role. The motivational aspect of progress may be especially critical when those carrying out day-to-day efforts are residents of the communities they serve or facing barriers to improving significant health disparities.

Conclusion

The ACA's community benefit requirements stand to effectuate change in local communities by requiring nonprofit hospitals to assume new roles in the promotion of population health through community engagement. Yet, although the regulations themselves apply to nonprofit hospitals in general, our qualitative study finds that their impact varies – in some cases widely – depending on context. It is therefore difficult to make large claims about community benefit and CHNAs without engaging the contexts and particulars of hospitals as they are located in specific communities, with varying resources and histories. In the case of the present study, focused on Ohio's Appalachian region, we have underscored the specific challenges of undertaking CHNAs in rural and vulnerable communities, where expansive geographic space, low socioeconomic status, and access to health care present significant challenges. Despite these barriers, however, our study suggests that many hospital employees tasked with overseeing the CHNA process see promise, even if their optimism about the prospect of improving health conditions is muted in light of regional challenges. In each case, the degree of optimism can be read as thoughtfulness not only about the CHNA process, but the socioeconomic realities facing these hospitals. Given the contemporary embrace of population health interventions, and innovative strategies for investing in programs that promise to reduce health disparities, the possibility exists for well-capitalized funding sources – including and perhaps especially those emanating from the federal government – to see value in providing increased support for hospital-initiated programs that promise to promote wellness and reduce disparity in rural and vulnerable populations.

References

American Hospital Association. (2019). *Fast Facts on U.S. Hospitals, 2019*. https://www.aha.org/statistics/fast-facts-us-hospitals

Beatty, K. E., Wilson, K. D., Ciecior, A., & Stringer, L. (2015). Collaboration among Missouri nonprofit hospitals and local health departments: Content analysis of community health needs assessments. *American Journal of Public Health, 105*(S2), S337–S344.

Borak, J., Salipante-Zaidel, C., Slade, M. D., & Fields, C. A. (2012). Mortality disparities in Appalachia: Reassessment of major risk factors. *Journal of Occupational and Environmental Medicine, 54*(2), 146–156.

Burke, J. G., Truong, S., Albert, S., Steenrod, J., Gibert, C., Folb, B., et al. (2014). What can be learned from the types of community benefit programs that hospitals already have in place? *Journal of Healthcare for the Poor and Underserved, 25*(1 Suppl), 165–193.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative data analysis*. London, UK: Sage.

Evashwick, C. J. (2013). *Hospitals & community benefit: New demands, new approaches*. Chicago, IL: Health Administration Press.

Folkemer, D. C., Spicer, L. A., Mueller, C. H., Somerville, M. H., Brow, A. L. R., Milligan, C. J., & Boddie-Willis, C. L. (2011). *Hospital community benefits after the ACA: The emerging federal framework*. The Hilltop Institute Issue Brief, January.

Foucault, M. (1973). *The birth of the clinic* (A. M. Sheridan, Trans.). New York, NY: Vintage.

Franklin, B., & Seavey, O. (2008). *Autobiography and other writings*. Oxford: Oxford University Press.

Gollust, S., & Lynch, J. (2011). Who deserves health care? The effects of causal attributions and group cues on public attitudes about responsibility for health care costs. *Journal of Health Politics, Policy and Law, 36*(6), 1061–1095.

Goffman, E. (1961). *Asylums: Essays on the social situation of mental patients and other inmates*. New York, NY: Anchor Books.

Halverson, J. A., & Bischak, G. (2008). *Underlying socioeconomic factors influencing health disparities in the Appalachian region*. Washington, DC: Appalachian Regional Commission. Available at: http://www.arc.gov/assets/research_reports/socioeconomicfactorsinfluencing-healthdisparitiesinappalachianregion5.pdf

Hendryx, M. (2009). Mortality from heart, respiratory, and kidney disease in coal mining areas of Appalachia. *International Archives of Occupational and Environmental Health, 82*(2), 243–249.

Hendryx, M., & Ahern, M. M. (2009). Mortality in Appalachian coal mining regions: The value of statistical life lost. *Public Health Reports, 124*(4), 541–550.

Internal Revenue Service. (2018). *Private letter ruling: Certified mail -return receipt*. Dallas, TX: Tax Exempt and Government Entities Division. Available at: https://www.irs.gov/pub/irs-wd/201829017.pdf

Internal Revenue Service. (2013). *Community health needs assessments for charitable hospitals*. Federal Register, available at: https://www.federalregister.gov/articles/2013/04/05/2013-07959/community-health-needs-assessments-for-charitable-hospitals

Jacobs, L. R., & Skocpol, T. (2012). *Health care reform and American politics: What everyone needs to know*. Oxford, UK: Oxford University Press.

Kaufman, B. G., Thomas, S. R., Randolph, R. K., Perry, J. R., Thompson, K. W., Holmes, G. M., et al. (2016). The rising rate of rural hospital closures. *Journal of Rural Health, 32*(1), 35–43.

Kluegel, J., & Smith, E. R. (1986). *Beliefs about inequality*. New York, NY: Aldine de Gruyter.

Lavin, C. (2008). *The politics of responsibility*. Urbana, IL: University of Illinois Press.

Ludke, R. L., & Obermiller, P. J. (Eds.). (2012). *Appalachian health and well-being*. Lexington, KY: University of Kentucky Press.

Morrone, M., Kruse, N. A., & Chadwick, A. E. (2014). Environmental and health disparities in Appalachian Ohio: Perceptions and realities. *Journal of Health Disparities Research and Practice, 7*(5), 67–81.

National Rural Health Association. (2016). *What's different about rural health care?* http://www.ruralhealthweb.org/go/left/about-rural-health

Peacock, M., Bissell, P., & Owen, J. (2014). Dependency denied: Health inequalities in the neo-liberal era. *Social Science and Medicine, 118*, 173–180.

Pennel, C. L., McLeroy, K. R., Burdine, J. N., & Mataritta-Cascante, D. (2015). Nonprofit hospitals' approach to community health needs assessment. *American Journal of Public Health., 105*(3), e103–e113.

Resnik, D. B. (2007). Responsibility for health: Personal, social, and environmental. *Journal of Medical Ethics, 33*(8), 444–445.

Rosenbaum, S. (2015). Additional requirements for charitable hospitals: Final rules on community health needs assessments and financial assistance. *Health Affairs Blog, 23*.

Rosenbaum, S. (2016). Hospital community benefit spending: Leaning in on the social determinants of health, 94(2), 251–254.

Smith, L., & Hollorman, C. H. (2011). Health status and access to health care services: A comparison between Ohio's rural non-Appalachian and Appalachian families. *Family and Community Health, 34*(2), 102–110.

Starr, P. (1982). *The social transformation of American medicine: The rise of a sovereign profession and the making of a vast industry*. New York: Basic Books.

Starr, P. (2013). *Remedy and reaction: The peculiar American struggle over health care reform*. New Haven, CT: Yale University Press.

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage Publications.

Thornton, R. L. J., Glover, C. M., Cené, C. W., Glik, D. C., Henderson, J. A., & Williams, D. R. (2016). Evaluating strategies for reducing health disparities by addressing the social determinants of health. *Health Affairs*. (Project Hope)*,, 35*(8), 1416–1423.

Walker, D., & Myrick, F. (2006). Grounded theory: An exploration of process and procedure. *Qualitative Health Research, 16*(4), 547–559.

Wewers, M. E., Katz, M., Fickle, D., & Paskett, E. D. (2006). Risky behaviors among Ohio Appalachian adults. *Preventing Chronic Disease, 3*, 1–8.

Wilson, K. D., Mohr, L. B., Beatty, K. E., & Ciecior, A. (2014). Describing the continuum of collaboration among local health departments with hospitals around the community health assessments. *Journal of Public Health Management and Practice, 20*(6), 617–625.

Young, G. J., Chou, C., Alexander, J., Lee, S. D., & Raver, E. (2013). Provision of community benefits by tax-exempt U.S. hospitals. *The New England Journal of Medicine, 368*, 1519–1527.

Younis, M. Z. (2013). A comparison study of urban and small rural hospitals financial and economic performance. *Online Journal of Rural Nursing and Health Care, 3*(1), 38–48.

Chapter 9
Community-Based Political Interventions

Karie Jo Peralta and Krista McCarthy Noviski

Introduction

Community control is key for interventions to address local health concerns (World Health Organization, 1986). For this authority to be established, community participation is necessary. Underlying this element is an appreciation of a community's ability to contribute knowledge and skills to the planning and implementation of health initiatives (Israel, Checkoway, Schulz, & Zimmerman, 1994). Community-based projects thus take into consideration the capacities of individuals to communicate their intimate understandings of their well-being, grasp medical information, learn preventative measures, and implement primary care techniques (e.g., Rahman et al., 2019; Smallwood et al., 2015).

There are many examples of community-based training and capacity building efforts in community-based health initiatives. Typically, they aim to increase popular knowledge of medical issues, improve health-care delivery, and strengthen the research skills of individuals, organizations, and communities (Cueva, Cueva, Revels, & Dignan, 2018; Ruiz et al., 2012; Saad-Harfouche et al., 2011). What is often lacking in these endeavors is a focus on their institutional contexts and how they may prevent self-determination and local control.

This chapter addresses this gap by applying a community-based framework to examine structures that shape community health projects and their links with local participation. Special attention is given to the political dimension of traditional and community-based health organizations. The purpose is to illustrate how institutional facets may either undermine or support communities in taking charge of their health.

K. J. Peralta (✉) · K. McCarthy Noviski
Department of Sociology and Anthropology, The University of Toledo, Toledo, OH, USA
e-mail: Karie.Peralta@utoledo.edu; Krista.Mccarthy@rockets.utoledo.edu

© Springer Nature Switzerland AG 2019

S. L. Arxer, J. W. Murphy (eds.), *Community-Based Health Interventions in an Institutional Context*, International Perspectives on Social Policy, Administration, and Practice, https://doi.org/10.1007/978-3-030-24654-9_9

This analysis is important for identifying and demystifying oppressive structures in community health initiatives, as well as crucial for recognizing how institutions may be designed to reinforce a community's authority over its health.

At the outset of this chapter, the theoretical framework that guides the present analysis is described. Next, institutional barriers to community participation are explained, followed by a discussion of structures that support a community's control over its well-being. The last section concludes by stressing the importance of community-based theory for creating conditions that encourage communities to direct their own health progress.

Analytical Framework

A community-based lens reveals transformative possibilities for organizations and projects to become aligned with the aspirations of communities. In health contexts, using a community-based framework can bring into view aspects that obstruct a community's ability to make decisions about its well-being. Furthermore, applying this perspective can expose prospects for local participation, which is at the heart of community-based health initiatives (World Health Organization, 1986).

Central to community-based philosophy (Murphy, 2014) is its rejection of realism and dualism (Delanty, 1997). What is particularly problematic with realism is its assumption that there is a domain independent from individuals where principles and values reside, and these elements regulate human behavior and promote social order (Durkheim, 1974). Along these lines, the realities of a community are considered in structural terms (Parsons, 1951) and understood to be separate from its members (Delanty, 1997).

In this view, structures are believed to be objective and, given their universal and absolute basis for action, have a powerful influence over individuals (Durkheim, 1974). Realism may be at play in medical situations when, for example, nurses follow their rounding schedules and protocols for providing care, even when they see that they have a negative effect on the patient experience. These job-related conditions may appear to be solidified and not within the nurses' power to change (Berger & Luckmann, 1966), and so they continue their service as if they were unable to make adjustments in their schedules and tasks.

With regard to dualism, community-based philosophy takes issue with the assumption that value-free information exists in a realm outside persons (Murphy, 2014). The notion that the mind is separate from the body informs the belief that personal perspectives are invalid, due to their subjective nature (Bordo, 1987). Accordingly, objectivity is promoted as the gold standard. Dualism therefore grounds the positivist approach that suggests that only individuals with scientific training have the ability to grasp unbiased knowledge. The reason is that science entails following systematic procedures that remove prejudices and partialities (Delanty, 1997).

When health-care organizations operate according to dualism, efforts to humanize interventions are undermined from the start. Take empathy training in medical schools, for example. Teaching medical students to show empathy toward their patients is challenged by the dualistic biomedical model that physicians are expected to follow. This issue causes tension when diagnosing a medical condition and developing an understanding of a patient's life experience with illness (Pedersen, 2010).

Adherence to dualism results in two general issues that prevent institutions from truly supporting communities in the realization of their health goals. The first is the weakening of the belief in community agency through affirmations of the realist illusion that the social world is detached from individuals (Bourdieu, 1990). For example, organizational problems are seen as natural and, therefore, beyond human control. Communities may thus consider themselves to be incapable of creating change. The second issue is the marginalization of local knowledge through assertions that cling to ways of knowing that disregard individual and interpersonal understandings grounded in daily life experiences (Fals Borda, 1988).

Unlike dualism, a community-based view emphasizes social constructionism and participation (Murphy, 2014). The core idea is that communities co-create their social worlds and critical consciousness of their worlds through dialogue (Freire, 1970). Therefore, community members are not subjected simply to impinging social forces, such as norms, that shape their experiences. Nor are they ever severed from what is known. Rather, they construct their realities and knowledge and linguistically give meaning to them in an interpersonal and cooperative manner (Merleau-Ponty, 1968; Wittgenstein, 1958).

A participatory vision of health care positions the community at the center of interventions (World Health Organization, 1986). All guiding ideas, forms of organizing, and decisions emanate from the group and stem from the negotiated interpretations of its members (Minkler & Wallerstein, 2012). Despite the technical knowledge that medical experts may be able to offer, these persons do not dominate the scene. While their insights may be eventually deemed to be important by the community for an initiative, the indigenous knowledge (Fals Borda, 1988) co-generated by community members through intersubjective communication (Gadamer, 1975) is what establishes communal plans and actions.

Power in community-based projects is thus shared between all community members (Minkler & Wallerstein, 2012), including medical professionals committed to the group's health. Because all individuals are inextricably linked to knowledge, identifying and making sense of symptoms, as well as interpreting lived experiences of illnesses, are accomplished through face-to-face dialogue (Buber, 1970). In this way, community members are empowered and viewed as having the capacity to contribute significantly to processes intended to improve their health outcomes in forms other than merely checking boxes in a health history form or following a doctor's order. In a community-based sense, such actions are always up for discussion between all groups potentially affected by the decisions being made.

The next section applies this analytical framework to assess institutional facets of traditional organizations and projects. Determinations are made with respect to how they may inhibit community participation. Particular attention is given to elements that are typically taken-for-granted, but are, nevertheless, critical for recognizing necessary structural changes, if a project is to become community-based.

Institutional Barriers to Community Participation

Norms that Constrain Community Participation

Institutions are imbued with social norms that consist of expectations that guide the actions of group members. In the Western philosophical tradition that supports traditional health organizations, norms fall under the category of "social facts" (Durkheim, 1982/2013, p. 29). Durkheim (1982/2013) explains that social facts should be regarded as "things" (p. 29) that are disconnected from individuals. Accordingly, norms are believed to hold an objective status with an imposing influence that motivates people to behave in uniform ways and, thus, stabilizes an organization by producing social order.

When formally institutionalized in medical settings, norms become written rules and policies for practitioner conduct (Borkowski, 2015). Most health-care organizations, for example, have established procedures that range from proper practices for attending to patients to processes for executing successfully a community health needs assessment. When these official norms are broken, the result is often reprimand, if not punishment.

Informal norms, on the other hand, are the implicitly, shared understood standards for behaving and interacting (Durkheim, 1982/2013). For instance, Barnato, Tate, Rodriguez, Zickmund, and Arnold (2012) observed critical care physicians accept passively the instructions of specialists. They considered this submissiveness to be attributed to the general understanding of informal norms that allude to appropriate ways to respond to individuals with greater decision-making power.

From a community-based perspective, norms in and of themselves are not problematic. After all, they are significant cultural elements that can facilitate interactions and the co-generation of popular knowledge (Geertz, 1973). In endeavors intended to be community-based, however, norms that constrain community participation are the concern. Such norms likely originate from the dualistic view that assumes a division between communities and their knowledge bases and, therefore, do not give credence to the principles and ethics that are determined by community members. This issue typically plays out in a health context where there is a preoccupation with information that is value-neutral and when outlooks on treatments and healing are expected to be unbiased and free from emotion.

These objective data and views are believed typically to be acquired through the use of the scientific method that involves the implementation of standardized procedures and rules (Delanty, 1997). The emphasis is on applying the language of science to verify truths and confirm logical beliefs about empirical data (Sankey, 2000). In the ordinary medical environment, solely physicians and other health experts are thought to be capable of obtaining factual and, therefore, useful information because of their high-level technical education and scientific literacy. Consequently, the participation of regular community members would be judged to be a distraction to making and evaluating observations, based on the notion that these rules-based approaches for rationalization require specialized knowledge and sound methodological techniques of which average citizens are not aware.

In conventional health-care organizations, actions guided by norms that elevate professional perspectives over local insight restrict community contributions and participation on a regular basis in simple, yet important, ways. For example, patients are often made to feel more like a number than an individual. Their stories about their experiences of sickness are seldom given adequate time and attention by physicians, because of scheduling policies and the subjective nature of patient experiences (Rhodes, McFarland, Finch, & Johnson, 2001).

In sum, there is a need to recognize the issue with the traditional understanding of norms. When they are considered to be an external force, beyond the power of individuals, and seemingly natural (Durkheim, 1982/2013), there leaves little hope for realigning health organizations with a humanistic orientation. Planners informed by a community-based viewpoint do no buy into the function of norms as controlling a community. Rather, they presume that interpretation mediates understandings of norms (Barthes, 1987) and appreciate the ability of individuals to engage one another in the creation and maintenance of local arrangements (Berger & Luckmann, 1966) that encourage behaviors consistent with a community's ideals.

Schemes that Sideline Community Members

Traditional health-care organizations typically strive to be effective by operating in accordance with Fayol's (1949) management principles. They include the establishment of order and a hierarchy of positions. Individuals are expected to employ their technical skills and carry out specialized tasks, while following administrative rules and codes of conduct. These bureaucratic elements support a top-down chain of command. Power is thus centralized at the top ranks (Weber, 1978).

This imagery is consistent with the realist framework that presumes reality is controlled by an elevated base where social norms and power exist (Durkheim, 1982/2013). Organizations constructed according to this assumption are likely led by persons with high qualifications, extensive training, and substantial proficiency, who are believed to be capable of offering unbiased and fair assessments geared toward increasing productivity. Accordingly, the expectation of low-status organizational members is that they obey directives and complete their duties without thinking critically about them.

At this point, the concept of roles is in need of consideration. Realists view roles as being interdependent parts of a social system. The functioning of the system is reliant on the execution of the responsibilities assigned to each role. When roles are not fulfilled, the connections between them weaken and, as a result, the system becomes unbalanced and may even fail. The purpose of social norms is then to guide role behaviors with the aim of ensuring order, and the system is set up in a way to discourage anyone from doing more or less than what their role requires (Parsons, 1951).

To illustrate, the organization of health departments is depicted commonly in the shape of a pyramid. The commissioner is often at the peak. This supervisory role is supported by a board committee that is full of medical professionals who advise on policy matters, provide guidance on programs and services, and handle the budget. Below this group is the administrative staff with managerial responsibilities, followed by the providers, who implement the services. What is evident in this case is not only the hierarchy but also the interdependence of roles. For example, the service providers count on the board to oversee responsibly the department's finances, otherwise there would be a reduction of services. At the same time, their position restricts them from implementing consequences if the higher-ups mismanage the organization. In the event that any role goes unfilled, there is bound to be instability, at least temporarily, because there is a low likelihood of anyone stepping seamlessly into another role.

These schemes are not consistent with a community-based orientation, because they impede community members from holding meaningful organizational positions and taking on leadership roles. Moreover, they exclude local persons from taking part in decision-making processes that concern their lives. A case in point is when a panel of researchers meet to discuss a virus that is spreading through a region and consider options to combat the epidemic without any community members present. In this example, the opinions of various professionals are taken into account and the pros and cons of different approaches to fight the outbreak are debated without the perspectives of the community.

The essence of community-based endeavors is community members and, without their direction, projects run the risk of being insensitive to a group's needs (Minkler & Wallerstein, 2012). Writing on his community-based efforts in Colombia, Fals Borda (1979) noted that "when the actual level of consciousness of the situation encountered (that of the members of the basic communities) was taken into account as a starting point for action…, political errors caused by excessive activism or ignorance were avoided" (p. 50). His work exemplifies how community-based projects are rooted in communal ideas and understandings, rather than in colonizing and imperialist assertions that dehumanize community members and relegate them to the periphery of their own realities.

Even seemingly minor symbols in traditional health-care intuitions should be reconsidered such as the sliding window in waiting rooms and online patient portals used for disseminating test results. These features may be interpreted as barriers between individuals and their care. Technology, in fact, is often assumed to be a tool to enhance neutrality, which is part of the positivist tradition (Delanty, 1997) and may impede local participation.

Routines that Restrain Community Action

Greenwood, Oliver, Sahlin, and Suddaby (2008) define a routine as a "more-or-less taken-for-granted repetitive social behavior that is underpinned by normative systems and cognitive understandings that give meaning to social exchange and thus enable self-reproducing social order" (pp. 4–5). In organizations, these context-specific behavioral patterns facilitate the coordination of individuals and transfer of information with minimal mental effort (Becker, 2004). Furthermore, institutionalized recurrent actions are believed to create organizational stability (Howard-Grenville, Rerup, Langley, & Tsoukas, 2016).

Essentially, this common view of routines relies on realism. Bourdieu (1990) explains that what allows behaviors to become repetitive over time and, eventually, institutions, is the dependence on seemingly autonomous structures for guidance. Individuals therefore perform routines as if they were merely mindless, passive actors. Because human agency is distinct from structure, the maintenance of the status quo is almost guaranteed.

Routines are commonplace in health-care settings (O'leary & Mhaolrúnaigh, 2012). To a large extent, patients can predict accurately how their appointments in a health clinic will come to pass. From check in to check out, routines are enacted continuously. Any deviation from expected patterns of behaviors is likely to be viewed as problematic, suspicious, or awkward. For example, a patient would probably feel uneasy if prescribed medicine before being examined thoroughly.

From a community-based standpoint, routines in health-care projects are not inherently troubling. Rather, they become concerning when they are reinforced by dualism and, thus, believed to be unalterable. Additionally, this understanding overlooks the abilities of individuals to innovate and create new practices (Howard-Grenville et al., 2016). In health-care institutions, dehumanizing routines are bound to undermine the self-determination of persons. This issue becomes evident when health professionals are so worried about upholding rules that they continue to follow them even while their actions undermine their ability to reach organizational goals (Merton, 1939).

In a public health survey, for instance, interviewers are expected to administer the questionnaire in the same way with each respondent. Because the principle of objectivity underpins this process, entertaining the perspectives of participants will only sidetrack researchers and taint the results. Therefore, what is not usually built into this standardized information gathering routine are opportunities for respondents to explain their health experiences in detail.

A community-based approach, however, would not view such a break from the routine as a distraction. In fact, this action would be common practice. Because knowledge is mediated by language (Lyotard, 1984), dialogue with survey participants is considered necessary for obtaining insight into local realities. Such engagement allows the interviewer access to the community's biography (Berger & Luckmann, 1966), which is composed of the interlinked meanings that individuals attach to their group's culture, history, and prospects for their collective future. Given the emphasis on anti-dualism in community-based philosophy (Murphy, 2014), accessing and correctly interpreting a community's biography should be standard in community-based projects.

Institutions that Support Community Authority

The rest of this chapter explores how community-based institutions foster local participation. Of primary focus are values, formations, and communication that center communities in health interventions. In contrast to a dualistic view that considers these institutional elements as autonomous and controlling (Durkheim, 1982/2013), a community-based perspective facilitates an understanding of these features as always interpretive and socially constructed (Berger & Luckmann, 1966). This theoretical shift is necessary to create institutional contexts that support social action and sustain community momentum.

Values that Promote a Community's Vision

Interventions that are community-based adhere to local values (Fals Borda, 1988). Therefore, community-based planners should learn the residents' ideals and ethics, as well as the meanings that they give to them. Only then may a planner begin to grasp a community's logic and contribute meaningfully to the design of project goals. Nonetheless, in a truly community-based initiative, a group's health aims are always determined by its members and are founded on their understandings of what objectives may be possible to meet. This process integrates the unique standpoints of community members by respecting their personal perspectives, interpretations of their collective experiences, and the lessons that they have learned from their everyday lives (Hancock & Minkler, 2012).

Traditional medical professionals and health practitioners, who rely on positivist procedures for project development, tend not to operate with this appreciation. These persons typically enter a community with the belief that their objective knowledge is what may serve the group best. For example, public health consultants may propose drafts of policies for medical clinics without engaging their communities of practitioners and patients together in dialogue about their health-care service experiences. In these cases, there is little reason to engage a community in the creation of health plans, because neutral information derived from the generalizable results of scientific research is what is considered important. Accordingly, conventional approaches involve the imposition of values that hold in high regard technology and strategies for obtaining unbiased data.

What a community-based lens brings into view is how social norms, including morals and customs, are established through "joint action" (Blumer, 1969, p. 17).

Moreover, behavioral patterns are believed to spring from arrangements of social action (Blumer, 1969). The implication for the development of community-based organizations is that institutional rules and expectations that are commonly thought to be outside the control of individuals, in actuality, may be created from local interpretations. Structures, therefore, may be grounded in the agreed upon meanings that group members give to their realities and, in turn, may be designed to be consistent with a community's vision.

From a community-based perspective, what is important to note is that traditional understandings of institutions are problematic, particularly with respect to who and what guides a project. When a medical organization is the result of local, interpersonal creations (Berger & Luckmann, 1966), the aspirations of a community to be free of environmental health hazards and disease may be articulated in ways that promote group "buy-in" (Woods, 2013) and, thus, allows for community participation to be the centerpiece of a project (Fals Borda, 1988).

In short, values that are generated by communities provide the appropriate guidance for their activities (Berger & Luckmann, 1966). Significantly, a community-based approach encourages communities to use their power to socially construct institutions that support local involvement. At the same time, this orientation takes into account the meanings that individuals give to these institutions, so that they may be (re)shaped in ways that promote local leadership.

Formations that Foster Community Leadership

Community members are the main leaders of community-based projects (Sandmann & Vandenberg, 1995). Without their guidance, interventions are not likely to be effective. Institutions with a community-based focus thus need a type of organization that espouses local control. Traditional organizations, with their top-down hierarchy, do not usually support this objective. Decision-making power is centralized and enacted by upper-level administrators and executives (Weber, 1978), who are often far removed from direct patient care, settings with barriers to health care, and the challenging realities of residents. This condition tends to marginalize communities in health initiatives and undermines their capabilities to lead.

A horizontal structure, however, intends to eradicate dominating relationships, encourage local participation, and allow for potentially any community member to step up, albeit temporarily, to contribute their skills to a project (Ramnarayan, 2011a). Local residents, for example, provide guidance on the activities of neighborhood health centers and ensure grassroots planning and supervision (Cooper et al., 2016). When power is decentralized (Ramnarayan, 2011a), communities have the opportunity to oversee their health development and take ownership of initiatives that are supposed to benefit them. Moreover, there is a collective commitment to the belief that shared decision-making is in the group's best interest (Locke, 2003) and an appreciation of the stock of local resources that can be drawn from for community improvement purposes (Ramnarayan, 2011b).

Because the ability to lead is not considered to be an inherent quality, persons are seen as capable of learning new skills and training others (Van Wart, 2003). Along these lines, all community members, not only individuals with a high-level proficiency and advanced education, are thought to have the capacity to take on responsibilities in planning and implementation processes (Raelin, 2003). In community-based organizations, even timid individuals who are not considered usually to make good leaders may feel encouraged to offer their voices and talents, rather than go ignored or wait to be asked by an authority figure for their opinion or to assist in an initiative.

Community health workers are a prime example of everyday people engaged in leadership positions (Cooper et al., 2016). These individuals may have low literacy skills and little experience in the health field, but what makes them ideal community leaders is that they have considerable familiarity with a locale, earned respect from their neighbors, and a strong desire to serve others. Their local knowledge may help to create an interpretive frame for identifying community issues and conceptualizing possible interventions (Fals Borda, 1988), while their solid social relationships and dedication to their community may be important unifying factors in a project. Indeed, community health workers have been found to be successful in implementing health services around the world and are valued by many health associations (Cooper et al., 2016; Kim, Farmer, & Porter, 2013; Rahman et al., 2019).

To be clear, health researchers, clinical practitioners, and other medical specialists may hold, at some point, important leadership positions during an initiative. However, they are not conferred high status in projects based on their academic background and medical expertise (Raelin, 2003). In fact, the egalitarian foundation of community-based projects provides an orientation that aims to empower everyone involved and facilitate democratic organization for constructing community knowledge and programs.

Communication that Creates Community Knowledge and Cohesion

Communication is a crucial aspect of participatory processes and community building initiatives (Walter & Hyde, 2012). Writings on practices for open and strategic communication abound in the body of literature on community health interventions. The emphasis is usually on developing technical skills, such as active listening, for effective communication (Li et al., 2018; Tran et al., 2004) and, therefore, considers communication in merely instrumental terms (Mumby, 1997). Clearly, these practical competencies are important, but community-based health promotion recognizes the need to consider health concerns using a discursive understanding of communication in conjunction with social constructionist views of community and culture (Ford & Yep, 2011).

Regarding communication as constitutive calls for engagement with how communities linguistically interpret health and illness and their experiences of these issues (Mokros & Deetz, 1996; Mumby, 1997). This anti-dualist orientation calls for dialogue that is rooted in reflexivity and focused on achieving shared understanding (Cunliffe & Easterby-Smith, 2004). Reflexivity involves the suspension of judgment (Buber, 1970) and the examination of personal assumptions and parameters of perspective. By becoming aware of one's stance and its limits with reference to a particular cultural frame, the foundation is formed for engaging the viewpoints of others (Gadamer, 1975). The challenge, then, becomes arriving at mutual comprehension, which requires grasping the realities of community members. This aim may be achieved through entering into open, reciprocal relationships and recognizing others as fully human (Buber, 1970).

When community members are committed to dialogue, they may discursively build prejudice-free, democratic spaces that allow all community members to express their ideas and challenge one another's views in what Habermas (1984) calls, "the ideal speech situation" (p. 25). In health contexts, a community-based approach involves linguistically contesting and undermining privileged perspectives on disease and medical concerns, so that ideas that are typically marginalized have a chance to be considered fully (Mokros & Deetz, 1996; Mumby, 1997). Accordingly, diversity of thought and the existence of different knowledge bases are not feared, because community members have the ability to understand divergent logics and can agree to disagree (Habermas, 1996). Any differences in statuses among the group are not given any meanings that could influence the marginalization of voices, advance authoritarian views, or result in manipulated consensus. What does rise are the ideas and arguments that stem from authentic communal agreement (Habermas, 1984), which provides the basis for a cohesive effort.

For illustrative purposes, a medical researcher who merely indicates that children need a healthier diet, based on where their measurements fall on a growth chart, may be viewed as futile information when their households lack food for days at a time. In such cases, the children's experiences of hunger would likely be more telling of the kinds of interventions needed than height and weight statistics. That is not to say that empirical and seemingly unbiased data should be disregarded completely. Rather, they should be generated and interpreted using a community's knowledge and logic.

No matter how critical and straightforward information may appear to be to a community's well-being, such as the contamination of a local water source or simple hand washing methods for preventing sickness, health professionals should understand that their knowledge needs to be conveyed in a way that is consistent with a community's worldview. In order to do so, they will need to engage in culturally sensitive ways and comprehend the community's modes of thinking (Airhihenbuwa, 1995).

Conclusion

This chapter explored the political side of health interventions by applying a community-based perspective. Using this lens revealed problems with placing confidence in the ability of traditional health organizations to address the well-being of communities. These institutions tend to be sustained through taken-for-granted assumptions about the organizational power of structures to encourage conformity and bring about order. Their abstractness conveys the image that they are beyond human influence, which leaves individuals and communities subject to domination (Berger & Luckmann, 1966). The "natural attitude" (Husserl, 1913/2014, p. 48) is to accept institutions as they exist. As a result, ineffective, and even irrelevant, organizations and interventions may persist (Berger & Luckmann, 1966).

A shift from dualism, however, reveals that organizations are a social product. Institutional transformation is thus predicated on justifications that are grounded in human action (Berger & Luckmann, 1966). This understanding should evoke a sense of optimism about community-based health initiatives. Community members can (re)construct norms to facilitate their participation in health projects and promote dialogue about their well-being. They can also make organizational arrangements that allow them to take on leadership responsibilities and make locally informed decisions about their group's future health. Of course, all of these activities are political. Yet, when a community-based approach is employed, the possibility is opened for the "people's power" (Fals Borda, 1988) to prevail.

References

Airhihenbuwa, C. O. (1995). *Health and culture: Beyond the western paradigm*. Thousand Oaks, CA: Sage.

Barnato, A. E., Tate, J. A., Rodriguez, K. L., Zickmund, S. L., & Arnold, R. M. (2012). Norms of decision making in the ICU: A case study of two academic medical centers at the extremes of end-of-life treatment intensity. *Intensive Care Medicine, 38*(11), 1886–1896.

Barthes, R. (1987). *Criticism and truth*. Minneapolis, MN: University of Minnesota Press.

Becker, M. (2004). Organizational routines: A review of the literature. *Industrial and Corporate Change, 13*(4), 643–677.

Berger, P. L., & Luckmann, T. (1966). *The social construction of reality*. New York: Doubleday.

Blumer, H. (1969). *Symbolic interaction: Perspective and method*. Englewood Cliffs, NJ: Prentice-Hall, Inc..

Bordo, S. (1987). *The flight to objectivity: Essays on Cartesianism and culture*. Albany, NY: State University of New York Press.

Borkowski, N. (2015). *Organizational behavior, theory, and design in health care*. Burlington, MA: Jones & Bartlett Publishers.

Bourdieu, P. (1990). *In other words: Essays towards a reflexive sociology*. Stanford, CA: Stanford University Press.

Buber, M. (1970). *I and thou* (2nd ed.). New York: Charles Scribner's Sons.

Cooper, L. A., Purnell, T. S., Ibe, C. A., Halbert, J. P., Bone, L. R., Carson, K. A., et al. (2016). Reaching for health equity and social justice in Baltimore: The evolution of an academic-community partnership and conceptual framework to address hypertension disparities. *Ethnicity & Disease, 26*(3), 369–378.

Cueva, K., Cueva, M., Revels, L., & Dignan, M. (2018). Culturally-relevant online education improves health workers' capacity and intent to address cancer. *Journal of Community Health, 43*(4), 1–7.

Cunliffe, A. L., & Easterby-Smith, M. (2004). From reflection to practical reflexivity: Experiential learning as lived experience. In M. Reynolds & R. Vince (Eds.), *Organizing reflection* (pp. 30–46). Burlington, VT: Ashgate Publishing Company.

Delanty, G. (1997). *Social science: Beyond constructivism and realism*. Minneapolis, MN: University of Minnesota Press.

Durkheim, E. (1974). *Sociology and philosophy* (D. F. Pocock, Trans.). New York: Free Press.

Durkheim, E. (1982/2013). *The rules of sociological method* (W. D. Halls, Trans.). New York: The Free Press.

Fals Borda, O. (1979). Investigating reality in order to transform it: The Colombian experience. *Dialectical Anthropology, 4*(1), 33–55.

Fals Borda, O. (1988). *Knowledge and people's power: Lessons with peasants in Nicaragua, Mexico and Colombia*. New York: New Horizons Press.

Fayol, H. (1949). *General and industrial management* (C. Storrs, Trans.). London: Pitman.

Ford, L. A., & Yep, G. A. (2011). Working along the margins: Developing community-based strategies for communicating about health with marginalized groups. In T. L. Thompson, A. Dorsey, K. I. Miller, & R. Parrott (Eds.), *The Routledge handbook of health communication* (pp. 241–261). Mahwah, NJ: Lawrence Erlbaum Associates.

Freire, P. (1970). *Pedagogy of the oppressed* (M. B. Ramos, Trans.). New York: The Continuum International Publishing Group Inc.

Gadamer, H. G. (1975). *Truth and method* (2nd ed., J. Weinsheimer & D. Marshall, Trans.). New York: The Continuum Publishing Company.

Geertz, C. (1973). *The interpretation of cultures: Selected essays*. New York: Basic Books.

Greenwood, R., Oliver, C., Sahlin, K., & Suddaby, R. (2008). Introduction. In R. Greenwood, C. Oliver, K. Sahlin, & R. Suddaby (Eds.), *The SAGE handbook of organizational institutionalism* (pp. 1–46). London: Sage.

Habermas, J. (1984). *Theory of commnicative action: Reason and the rationalization of society* (Vol. 1) (T. McCarthy, Trans.). Boston, MA: Beacon Press.

Habermas, J. (1996). *Between facts and norms: Contributions to a discourse theory of law and democracy* (W. Rehg, Trans.). Cambridge, MA: MIT Press.

Hancock, T., & Minkler, M. (2012). Community health assessment or healthy community assessment: Whose community? Whose health? Whose assessment? In M. Minkler (Ed.), *Community organizing and community building for health and welfare* (pp. 153–170). New Brunswick, NJ: Rutgers University Press.

Howard-Grenville, J., Rerup, C., Langley, A., & Tsoukas, H. (2016). Introduction: Advancing a process perspective on routines by zooming out and zooming. In J. Howard-Grenville, C. Rerup, A. Langley, & H. Tsoukas (Eds.), *Organizational routines: How they are created, maintained, and changed* (pp. 1–22). Oxford, UK: Oxford University Press.

Husserl, E. (1913/2014). *Ideas I* (D. O. Dahlstrom, Trans.). Indianapolis, IN: Hackett Publishing Company, Inc.

Israel, B. A., Checkoway, B., Schulz, A., & Zimmerman, M. (1994). Health education and community empowerment: Conceptualizing and measuring perceptions of individual, organizational, and community control. *Health Education Quarterly, 21*(2), 149–170.

Kim, J. Y., Farmer, P., & Porter, M. E. (2013). Redefining global health-care delivery. *The Lancet, 382*(9897), 1060–1069.

Li, L., Hien, N. T., Liang, L. J., Lin, C., Lan, C. W., Lee, S. J., et al. (2018). Efficacy of communication training of community health workers on service delivery to people who inject drugs in Vietnam: A clustered randomized trial. *American Journal of Public Health, 108*(6), 791–798.

Locke, E. A. (2003). Leadership: Starting at the top. In C. L. Pearce & J. A. Conger (Eds.), *Shared leadership: Reframing the hows and whys of leadership* (pp. 271–284). Thousand Oaks, CA: Sage.

Lyotard, J. F. (1984). *The postmodern condition*. Minneapolis, MN: University of Minnesota Press.

Merleau-Ponty, M. (1968). *The visible and the invisible*. Evanston, IL: Northwestern University Press.

Merton, R. K. (1939). Bureaucratic structure and personality. *Social Forces, 18*(4), 560–568.

Minkler, M., & Wallerstein, N. (2012). Improving health through community organization and community building: Perspectives from health education and social work. In M. Minkler (Ed.), *Community organizing and community building for health and welfare* (3rd ed., pp. 26–51). New Brunswick, NJ: Rutgers University Press.

Mokros, H. B., & Deetz, S. (1996). What counts as real?: A constitutive view of communication and the disenfranchised in the context of health. In E. B. Ray (Ed.), *Communication and disenfranchisement: Social health issues and implications* (pp. 29–44). Mahwah, NJ: Lawrence Erlbaum Associates.

Mumby, D. (1997). Modernism, postmodernism, and communication studies. *Communication Theory, 7*(1), 1–28.

Murphy, J. W. (2014). *Community-based interventions: Philosophy and action*. New York: Springer.

O'leary, D. F., & Mhaolrúnaigh, S. N. (2012). Information-seeking behaviour of nurses: Where is information sought and what processes are followed? *Journal of Advanced Nursing, 68*(2), 379–390.

Parsons, T. (1951). *The social system*. New York: Free Press.

Pedersen, R. (2010). Empathy development in medical education – a critical review. *Medical Teacher, 32*(7), 593–600.

Raelin, J. A. (2003). *Creating leaderful organizations: How to bring out leadership in everyone*. San Francisco: Berrett-Koehler Publishers, Inc..

Rahman, A. E., Perkins, J., Mazumder, T., Rifat Haider, M., Bakkar Siddiquel, A., Capello, C., et al. (2019). Capacities of women and men to improve maternal and newborn health: Effect of a community-based intervention package in rural Bangladesh. *Journal of Global Health, 9*(1), 1–16.

Ramnarayan, S. (2011a). Is your organization ready for change? In S. Ramnarayan & T. V. Rao (Eds.), *Organization development: Accelerating learning and transformation* (2nd ed., pp. 320–329). Thousand Oaks, CA: Sage.

Ramnarayan, S. (2011b). Participation: Considerations for designing process. In S. Ramnarayan & T. V. Rao (Eds.), *Organization development: Accelerating learning and transformation* (2nd ed., pp. 267–276). Thousand Oaks, CA: Sage.

Rhodes, D. R., McFarland, K. F., Finch, W. H., & Johnson, A. O. (2001). Speaking and interruptions during primary care office visits. *Family Medicine, 33*(7), 528–532.

Ruiz, Y., Matos, S., Kapadia, S., Islam, N., Cusack, A., Kwong, S., et al. (2012). Lessons learned from a community–academic initiative: The development of a core competency–based training for community–academic initiative community health workers. *American Journal of Public Health, 102*(12), 2372–2379.

Saad-Harfouche, F. G., Jandorf, L., Gage, E., Thélémaque, L. D., Colón, J., Castillo, A. G., et al. (2011). Esperanza y Vida: Training lay health advisors and cancer survivors to promote breast and cervical cancer screening in Latinas. *Journal of Community Health, 36*(2), 219–227.

Sandmann, L. R., & Vandenberg, L. (1995). A framework for 21st century leadership. *Journal of Extension, 33*(6), 1–9.

Sankey, H. (2000). The language of science: Meaning variance and theory comparison. *Language Sciences, 22*(2), 117–136.

Smallwood, S. W., Freedman, D. A., Pitner, R. O., Sharpe, P. A., Cole, J. A., Hastie, S., et al. (2015). Implementing a community empowerment center to build capacity for developing, implementing, and sustaining interventions to promote community health. *Journal of Community Health, 40*(6), 1122–1129.

Tran, A. N., Haidet, P., Street Jr., R. L., O'Malley, K. J., Martin, F., & Ashton, C. M. (2004). Empowering communication: A community-based intervention for patients. *Patient Education and Counseling, 52*(1), 113–121.

Van Wart, M. (2003). Public-sector leadership theory: An assessment. *Public Administration Review, 63*(2), 214–228.

Walter, C. L., & Hyde, C. A. (2012). Community building practice: An expanded conceptual framework. In M. Minkler (Ed.), *Community organizing and community building for health and welfare* (3rd ed., pp. 78–90). New Brunswick, NJ: Rutgers University Press.

Weber, M. (1978). *Economy and society: An outline of interpretive sociology*. New York: Bedminster Press.

Wittgenstein, L. (1958). *The blue and brown books*. New York: Harper and Row.

Woods, K. (2013). *Handbook on volunteer management.* Retrieved from http://www.ctcconnect.org/images/files/file/Volunteer%20Handbook%20For%20Lumity%20CTC%20Partners%20May-2013%20B.pdf

World Health Organization. (1986). Ottawa charter for health promotion. *Canadian Journal of Public Health, 77*(6), 425–430.

Chapter 10
Re-examining the Role of Patients in Community-Based Interventions

Khary K. Rigg, Amanda Sharp, Kyaien O. Conner, and Kathleen A. Moore

Introduction

The relationship between a healthcare provider and a patient has evolved over time. Until recently, this relationship consisted of a patient seeking treatment from a provider and the patient tacitly adhering to the provider's directives. In this traditional model of the patient-provider relationship (PPR), the provider uses his/her clinical expertise to select the intervention most likely to restore the patient's health. Patients play a passive role in this process and simply wait to be told by the provider what their pathology is and how to mitigate their issue.

This provider-dominated model of the PPR can probably be traced back as far as 1000 B.C. (Cushing, 2016). In fact, Edelstein (1937) proposed that the origins of this type of PPR model can be found in the priest-supplicant relationship, thus retaining the ideology of a parent-figure who manipulates events on behalf of the patient. Others point to medieval Europe as the beginning when physicians were thought to be healers imbued with "magical" powers (Kaba & Sooriakumaran, 2007). Again, providers are situated in a very high-ranking position that relegates patients to passive participants.

Another time period that laid the groundwork for the provider-dominated model of the PPR was the late eighteenth century when hospitals emerged as places to treat underprivileged patients (Jewson, 1976). Individuals of low socioeconomic status were widely regarded as inherently listless, which helped perpetuate a picture of the helpless patient (Kaba & Sooriakumaran, 2007). The emergence of the hospital coincided with the rapid growth of microbiological knowledge, which gave way to a new type of orientation to healthcare, one that focused on the accurate diagnosis

---

K. K. Rigg (✉) · A. Sharp · K. O. Conner · K. A. Moore
Department of Mental Health Law & Policy, University of South Florida, Tampa, FL, USA
e-mail: rigg@usf.edu

© Springer Nature Switzerland AG 2019

S. L. Arxer, J. W. Murphy (eds.), *Community-Based Health Interventions in an Institutional Context*, International Perspectives on Social Policy, Administration, and Practice, https://doi.org/10.1007/978-3-030-24654-9_10

of pathological abnormalities inside the body – the biomedical model of illness (Cushing, 2016). The biomedical model required an examination of the patient's body and the expert clinical knowledge possessed by the provider to produce a diagnosis. This arrangement made the patient highly dependent on the provider's expertise, while keeping the patient, once again, in a position of passivity.

Indeed, the provider-centric model of the PPR has remained the norm for some time, but starting in the 1950s, this relationship was increasingly criticized for being paternalistic. Hellin (2002) described this paternalism as analogous to the parent-infant relationship in which the patient is entirely dependent on the parent for decision-making. Thus, the provider's role involved acting in the patient's best interests, with providers regarding a "good patient" as one who submissively accepted the role of the infant (Hellin, 2002). As these criticisms became stronger throughout the 1950s, the deficiencies of such a paternalistic PPR became more apparent. This change also occurred when several psychoanalytic and psychosocial theories began to emerge that further conceptualized the patient as an active participant in the clinical relationship. With the popularization of writers like Parsons, Freud, Szasz, and Balint, coupled with the emergence of psychology and sociology, a shift was proposed to a more "therapeutic" model of the PPR that emphasized the importance of listening to the patient (Balint, 1969a, 1969b; Breuer & Freud, 1955; Parsons, 1951; Szasz & Hollender, 1956). This newfound interest in patients elevated the importance of engaging them in the therapeutic process and re-introduced them into the clinical conversation as active participants.

Towards Involving Patients in Their Own Care

In the mid-twentieth century, psychology and sociology joined the discourse about the PPR, mostly targeting the physician-patient relationship (Kaba & Sooriakumaran, 2007). With these new ideas inserted into the conversation, the proper nature of the PPR was now up for debate. Michael Balint, who was trained in both medicine and psychoanalysis, attempted to combine ideas from these new disciplines. Balint's work was hugely important in redefining the PPR because he was one of the first to argue that patients needed to be "understood as a unique human being" rather than entities that simply needed fixing. He argued that illness was as much a psychosocial phenomenon as a biological one (Balint, 1969a, 1969b). He encouraged doctors to look past the physical symptoms reported and focus on the patient's unique psychological and social context, thereby allowing them to understand the "real" reason for the consultation (Cushing, 2016). He also proposed that the unique emotional relationship that develops between provider and patient over many clinical encounters is a critical component of both the therapeutic and diagnostic process.

Important to note is that Balint was influenced by Thomas Szasz's model of mutual participation (Szasz, Knoff, & Hollender, 1958). In Szasz's model, the provider does not profess to know exactly what is best for the patient. Additionally, for mutual participation to exist, the interaction between patient and provider is based on both having equal power, mutual independence, and equal satisfaction. This ultimately creates a situation where the patients can take care of themselves. This model, therefore, provides the patient with a great degree of agency, is characterized by a high degree of empathy, and has elements often associated with friendship and partnership, in addition to imparting expert clinical advice.

George Engel and Carl Rogers expanded on the work of Balint and Szasz by viewing the PPR through the lens of "dynamic psychology" (Heidbreder, 1945). Engel advocated the need for a new medical model that linked science and humanism and used the term "bio-psychosocial-cultural" (Engel, 1977). This integrated information concerning *what was the matter with the patient* and *what mattered to the patient* (Cushing, 2016). Rogers, a humanistic psychologist, maintained that for patients to heal, they need an environment that provided genuineness, acceptance, and empathy (Rogers, Stevens, Gendlin, Shlien, & Van Dusen, 1967). Hence, any provider in a PPR needs to demonstrate unconditional positive regard, openness, warmth, and a willingness to listen and understand the patient (Rogers, 1961).

At their core, all of these writers advocate for a new way of looking at the PPR. One that calls for providers to communicate genuinely and involve their patients in their own care. The idea is that by incorporating patient perspectives into the diagnostic and treatment process, clinical outcomes will improve (Rigg & Murphy, 2013). This notion, first raised by Szasz and Balint, then further conceptualized by Engel, Rogers, and others, is now referred to in the literature as "patient-centered care." In fact, patient-centered care (PCC) appears with regularity in the medical, psychological, counseling, and social work literature (Kovacs, Bellin, & Fauri, 2006; McDaniel & Fogarty, 2009). The term is invoked to describe a type of healthcare where treatment is driven by the agenda of the patient. Other concepts such as "person-centered," "patient-led," and "personalized" care also exist for describing this type of PPR (Carey & Mullan, 2007; Fajt & Wenzel, 2015).

Although some of these concepts have slightly different emphases and definitions, they all generally refer to an idea that the "whole person" needs to be taken into account for proper treatment to occur. Most of the variations of PCC share the following components: (a) exploring both the illness and the patient's experience of that illness, (b) understanding the whole person within his/her social context, (c) finding common ground, (d) sharing power and responsibility, and (e) therapeutic alliance. PCC and its variants are clearly a departure from traditional models of PPR and call for greater involvement of patients in their own treatment. Fortunately, there is growing appreciation that such involvement will lead to improved health outcomes for patients, but questions still remain regarding the best ways to involve patients.

Obstacles to Genuine Patient Involvement

One barrier to involving clients meaningfully in their own care is the way that PPR quality is measured. Quality measures have been traditionally narrow, focusing mostly on accuracy in diagnosis and treatment outcomes (Chapman et al., 2011).

Indeed, quality measures are intended to standardize a high level of care across services, but some have argued that current measures do not accurately assess true PPR quality or address clinical meaningfulness (Blumenthal & McGinnis, 2015; Lindenauer et al., 2014). Research shows that provider and client characteristics may most accurately predict positive outcomes and satisfaction with care (Chaitoff et al., 2017; Johnson & Russell, 2015; Manary, Boulding, Staelin, & Glickman, 2013; Rigg & Wilson, 2013). As such, the question is whether current measures for quality of care actually enrich person-to-person interactions, or merely simplify them to an inflexible and externally dictated process. Therefore, the next incarnation of PPR quality metrics should probably represent a patient-centered skill set and be aligned with values like collaboration, empathy, and support for autonomy (Chaitoff et al., 2017; Manary et al., 2013; Zolnierek & Dimatteo, 2009).

Currently, the most popular indicator of PPR quality is patient satisfaction. For example, the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) is a widely used patient satisfaction assessment that contains 32 questions that measure nine key topics: communication with doctors; communication with nurses; responsiveness of hospital staff; pain management; communication about medicines; discharge information; cleanliness of the hospital environment; quietness of the hospital environment; and transition of care (Centers for Medicare & Medicaid Services, 2019). Research supports a link between HCAHPS scores and profitability (Herrin, Mockaitis, & Hines, 2018), but their connection to genuine quality of care remains dubious. In fact, studies have shown that several of the HCAHPS measures have no relationship to patient satisfaction, thereby raising serious questions about whether these measures are meaningful to patients.

Existing payment models are another barrier to authentic patient involvement. For example, the traditional fee-for-service model, which charges for each step in the process from diagnostics to treatment, means that not only is a sick patient worth more than a healthy patient, but care is often fragmented, uncoordinated, and redundant (Saver et al., 2015). The fee-for-service model incentivizes quantity over quality by motivating providers to see as many patients as possible to increase reimbursements and profits. Within this model, providers are not rewarded for ensuring strong PPRs and positive patient experiences.

A value-based payment model has emerged as an alternative and potential replacement for fee-for-service reimbursement. Within value-based payment models, providers receive financial incentives for higher quality care and are penalized when their quality of care is low. Ostensibly, quality is accounted for by both measures of patient outcomes and patient satisfaction, so the focus on the PPR becomes a top priority (Srinivasan & Desai, 2017; Timbie et al., 2017; Unützer et al., 2009). Value-based payment models are still not widespread, however, and the fee-for-service structure continues to dominate the delivery of care in the United States (Kaufman, Spivack, Stearns, Song, & O'Brien, 2019; Miller et al., 2017).

Patient-Centered Communication for Improved Experience

Increasing calls for a patient-centered approach continues to drive the shift from an outcome-driven focus to one that is experience-driven. The point is not to advocate that healthcare providers should focus only on patient experience to the detriment of clinical outcomes, but that the execution of the former becomes much more compelling when the issue becomes clear about the control clinicians have over quality improvement. Evidence has shown that effective communication and engagement yield improved patient satisfaction, and that patient outcomes and patient satisfaction are correlated (Hibbard, Greene, & Tusler, 2009; Linden, Butterworth, & Prochaska, 2010; Manary et al., 2013; Tsai, Orav, & Jha, 2015). Research has also demonstrated success in establishing meaningful patient-centered communication skillsets among providers in relatively short periods of time (Carpenter et al., 2012; Chéret et al., 2018; DiRosa, Gupta, & DeBonis, 2017; Noordman, van der Weijden, & van Dulmen, 2012). An improved patient-centered communication style that enhances patient satisfaction is one in which the patient not only becomes more informed, but also feels supported and engaged (Zolnierek & Dimatteo, 2009). Clinician characteristics such as empathy, compassion, support for autonomy, and collaboration are congruent with evidence-based approaches for patient-centered care and are shown to yield improved patient satisfaction (Butterworth, Linden, & McClay, 2007; Chaitoff et al., 2017).

Effective communication that has been shown to support PPRs includes technical characteristics such as information sharing and clear questioning, as well as psychosocial and interpersonal characteristics such as rapport building (Butterworth et al., 2007; Chaitoff et al., 2017; Noordman et al., 2012; Zolnierek & Dimatteo, 2009). These traits align with a patient-centered communication approach and a strong therapeutic alliance that can determine positive outcomes when associated with effective client engagement (Barber et al., 2001; Campbell, Guydish, Le, Wells, & McCarty, 2015; Epstein et al., 2005; Matalon, 2008; Moyers, 2014; Smith, Dwamena, Grover, Coffey, & Frankel, 2011). In multivariate models, the goal factor of a therapeutic alliance emerged as a significant and independent predictor of greater change in patient activation scores (Allen et al., 2017).

Empathy is one specific characteristic that has been repeatedly linked to improved patient outcomes (Del Canale et al., 2012; Elliott, Bohart, Watson, & Greenberg, 2011; Hojat et al., 2011). Empathic listening is not only a core component of cultural competence and therapeutic alliance, but a marker of overall clinical effectiveness. In one study (Del Canale et al., 2012), a physician's empathy scores were compared with the occurrence of disease complications. The researchers concluded that clinicians who were more empathetic generally had patients with better clinical results and less medical complications. Unfortunately, the current medical system does not place a premium on cultivating this clinical skill. In a systematic review of studies that looked at the empathy of medical students and residents, the authors concluded that empathy declines during medical school and residency and gradually threatens healthcare quality (Neumann et al., 2011). Also, clinicians do not seem to be able to accurately self-assess their own empathy during patient interactions (Miller, Yahne, Moyers, Martinez, & Pirritano, 2004); therefore, there is a need for additional interventions and training in this area.

Re-thinking Cultural Competence for Providers

Provider training today continues to focus heavily on the technical aspects of healthcare, thus resulting in many graduates who are deficient in skills important to clinical practice, including cultural competence. Cultural competence has become a staple of contemporary clinical education, but this concept is often deployed simplistically. Many training programs seemingly take the position that exposing trainees to static, prepackaged ideas of "culture" will assist them in estimating patient behaviors or preferences. But the idea that providers can diagnose patients by spending only a few minutes with them, and then quietly infer their cultural belief system, is unrealistic.

Therefore, rather than cultural competence that narrowly views patient preferences as a series of generalized stereotypes, training programs should embrace frameworks that do not attempt to "fit" patients into preconceived cultural rubrics (Chang, Simon, & Dong, 2012). Cultural humility is one such framework (Miller, 2009). This approach shifts the focus from providers to patients and community members. In other words, cultural humility recognizes the complexity of cultural identity and belief, inaugurates a lifelong commitment to self-evaluation and critique to redress the power imbalances in the patient-provider dynamic, and develops mutually beneficial and non-paternalistic partnerships (Tervalon & Murray-Garcia, 1998).

Similarly, structural competency addresses cultural competency's failure to look beyond the patient-provider dyad. Specifically, structural competency contends that many health-related factors previously attributed to culture also represent the downstream consequences of decisions about larger structural contexts, including healthcare and food delivery systems, zoning laws, local politics, urban and rural infrastructures, structural racism, or even the very definitions of illness and health (Metzl & Hansen, 2014). Both cultural humility and structural competency are important frameworks for preparing student clinicians to become competent providers. In view of the need for community-based interventions, these approaches should be adopted by more training programs as a component of a more overarching reorganization of clinician training.

Promising Strategies for Involving Patients in Treatment

Evidence has shown that a more engaged patient is a healthier patient, and because of this awareness the role of the patient continues to evolve. Whereas patients were once expected to be passive recipients of their care, with little to no personal agency, patients are now identified as active, equal partners in managing their health.

This new engaged patient feels more empowered to take charge, more activated to follow-through, and has a high sense of self-efficacy. While procedural components of health delivery systems like payment models, quality measurements, and provider education, may still be transitioning to embody these emerging patient roles, there are some current community-based interventions being implemented that do align with these objectives.

Partners in Health Model

Partners in Health (PIH) is an international health services organization that has successfully integrated the role of the patients, their cultural worldviews, and community-based needs into a healthcare delivery model (Katigbak, Van Devanter, Islam, & Trinh-Shevrin, 2015). Founded by Paul Farmer and a team of world-renowned global health researchers and providers, PIH has introduced modern medical interventions to parts of the world where people would otherwise go without these services (Furin et al., 2006). What is most person-centered about PIH is their commitment to the integration of culturally competent approaches for sustainable interventions (Drobac et al., 2013). PIH is grounded in the belief that charity alone cannot solve health disparities, but that partnerships and solidarity with the communities they serve can strengthen the capacity for local health systems to move beyond simply introducing temporary, clinician-led interventions.

This focus on long-term collaboration rather than the provision of immediate but short-term solutions is the organizational equivalent to the Chinese proverb, “give a man a fish and he will eat for a day; teach a man to fish and he will eat for a lifetime” (DePasse & Lee, 2013). They have intentionally shifted away from other imperialistic service models that adopt a hierarchical approach (wherein a foreign entity provides for a less equipped, impoverished community) and have instead focused their resources on establishing partnerships that promote self-sufficiency (Carlson et al., 2010). This model is not only a microcosm of the more empowered patient role witnessed in contemporary variants of patient-centered care, but also operationalizes key principles seen in the patient activation model. The patient activation model (PAM), developed by Judith Hibbard and colleagues, asserts that activation is developed with the presence of three key patient characteristics: (1) confidence, (2) knowledge/skills, and (3) empowerment (Hibbard, Stockard, Mahoney, & Tusler, 2004). Being equipped with these strengths, whether on an individual or community level, is likely to improve activation.

Community Health Workers/Promotores de Salud

In their pursuit for culturally competent collaboration, PIH, like many other national and international health entities, promotes the use of community health workers (CHWs). CHWs, also called lay health workers, or in Spanish, *promotores de salud*, typically serve as local advocates that link the voices and needs of their community members to relevant healthcare information and services (Andrews, Felton, Wewers, & Heath, 2004). At PIH, they hire and train CHWs who are themselves members of the communities they are serving. This practice is consistent with a systematic review of the definitions of CHWs that describes them as paraprofessionals (or lay individuals) with comprehensive knowledge and understanding of a community's culture and language (Tilahun et al., 2017). They receive standardized job training that is shorter than health professionals, and their principal purpose is to provide culturally appropriate health services to their community (Olaniran, Smith, Unkels, Bar-Zeev, & van den Broek, 2017).

Research has shown that not only do CHWs supplement an otherwise strained health services workforce, but they actually improve access to healthcare for underserved areas and marginalized populations (Lewin et al., 2005). In 2006, the World Health Organization (WHO) declared a global health crisis due to severe shortages in the health workforce and inappropriate skill-sets for the needs of mostly rural and low/middle-income communities around the world (World Health Organization, 2006). The WHO has since identified the use of CHWs as a method to help address the shortage of clinicians and to bridge the gap in health inequity on a global scale (Lehmann & Sanders, 2007). Additionally, in October 2018, The Patient-Centered Outcomes Research Institute (PCORI) invested nearly $300 million in support of 79 clinical effectiveness studies of CHW intervention projects (PCORI, 2018). One such project found that the use of CHWs improved patient satisfaction and reduced hospital stays (Kangovi, Mitra, Norton, et al., 2018). This project used CHWs to bridge communication between patients and their clinical providers, thus allowing more individualized attention and time for collaborative goal-setting. With CHWs acting as an intermediary between health professionals and their patients, there can be more opportunities to operationalize those person-centered communication strategies that leverage patient motivation and engagement. Ultimately, CHWs, while not new, are a promising evidence-based strategy for improving not only patient outcomes, but patient empowerment and community involvement in healthcare.

OurNotes

Taking shared goal-setting and self-care management a step further is a newly piloted program called OurNotes (OpenNotes, 2017). OurNotes is a documentation platform that changes traditional doctor visit notes by taking what has been traditionally a one-sided process and turning it into a partnership. The technology involved in OurNotes gives patients access to the notes their doctors write about them after a visit and allows them to modify their records, thus offering patients a more active role in their clinical care. The intention of this service is two-fold, to reduce the burden of documentation for providers and to increase patient engagement. The intention is that patient contributions will help the clinician to focus on what is most important to the patient by allowing them to provide a written interval history between visits and establish a shared agenda for upcoming visits (OpenNotes, 2017). A pilot study of the program used expert interviews to assess the feasibility and perception of usefulness for OurNotes among practitioners. The results, overall, were positive, with most participants valuing OurNotes as an option for improving patient engagement (Mafi et al., 2018).

Narrative Medicine

Narrative medicine also bears mention. Charon (2001a), often called the mother of narrative medicine, defines this activity as the ability to recognize, absorb, interpret, critically understand, and be moved by a patient's story of illness. More than simply an expanded medical history, the point is to discover the meaning or the existential character of illness (Murphy, 2015). This strategy places a premium on the patient's voice, and ensures not only that they are heard, but that their worldviews are valued in a way that informs the care they receive. Narrative medicine, now offered as a master's degree at schools like Columbia University, is medicine practiced with the competence to identify and operationalize the story of the patient's experience (Charon, 2001a).

With roots in public health and social justice, narrative medicine may exemplify the professional evolution needed to more fully embody a patient-driven healthcare system. Research has suggested that narrative considerations increase the capacity for practitioners to understand their patients and reflectively engage with them (Charon, 2001b). Charon describes narrative medicine not as a new specialty but as a new clinical framework that can give physicians the theory, methods, skills, and texts to permeate their practice with the individual needs of their patients (Charon, 2001b). Through training in narrative medicine, practitioners may improve the skills necessary to engage in authentic discourse with patients like empathy, support for autonomy, and cultural competency. These are skills that, as previously mentioned, are essential to involving patients authentically in their own treatment.

Conclusion

Patient-centered care and community-based interventions have become quite popular over the last several decades. The core idea is to embed interventions as much as possible in a community so that treatment is accessible and appropriately designed. Also important is to involve patients in the development and implementation of interventions, so that a new level of relevance is introduced into service provision. Their input is supposed to provide the insights necessary to increase treatment effectiveness and ensure interventions are not harmful. Although there is widespread appreciation that collaboration between patient and provider is key to interventions that claim to be patient-centered and community-based, the current healthcare system does not promote such collaboration, and obstacles to genuinely involving patients in their own care exist (e.g., fee-payment structures).

In an effort to help achieve these goals, several recommendations were made in this chapter. We call for more clinicians to be trained on communication styles known to foster collaboration and patient involvement (e.g., empathetic listening). Additionally, we argue that the healthcare system would benefit from a rethinking of cultural competence. Even though cultural competence has become a staple of contemporary clinical education, the concept is often deployed too simplistically. Instead, training programs should embrace frameworks, such as structural competency and cultural humility, as part of a broad reorganization of provider training. We also identified several promising strategies for involving patients in their own treatment (e.g., CHWs, OurNotes, narrative medicine). And while most of these approaches are not new, they have failed to become mainstream in healthcare and are still viewed as ancillary. These approaches have unique potential to bring the experiences of patients into conversations about clinical practice and help transform the PPR to become truly collaborative.

In sum, patient-centered services are the product of genuine partnership between patient and provider. From the earliest phases, an intervention should be defined and controlled by the patient. Therefore, their participation establishes the reality that informs the identification of needs, the development of interventions, and the criteria for determining a successful program of services. The role of the patient, in other words, is to have an active voice in every stage of an intervention, and not merely to be consulted periodically throughout their care. After all, their input provides the blueprint for diagnosing illness and successfully formulating appropriate treatments.

References

Allen, M. L., Lê Cook, B., Carson, N., Interian, A., La Roche, M., & Alegría, M. (2017). Patient-provider therapeutic alliance contributes to patient activation in community mental health clinics. *Administration and Policy in Mental Health and Mental Health Services Research, 44*(4), 431–440.

Andrews, J. O., Felton, G., Wewers, M. E., & Heath, J. (2004). Use of community health workers in research with ethnic minority women. *Journal of Nursing Scholarship, 36*(4), 358–365.

Balint, E. (1969a). The possibilities of patient-centred medicine. *The Journal of the Royal College of General Practitioners, 17*, 269e76.

Balint, E. (1969b). The possibilities of patient-centered medicine. *The Journal of the Royal College of General Practitioners, 17*(82), 269.

Barber, J. P., Luborsky, L., Gallop, R., Crits-Christoph, P., Frank, A., Weiss, R. D., et al. (2001). Therapeutic alliance as a predictor of outcome and retention in the National Institute on Drug Abuse Collaborative Cocaine Treatment Study. *Journal of Consulting and Clinical Psychology, 69*(1), 119.

Blumenthal, D., & McGinnis, J. M. (2015). Measuring vital signs: An IOM report on core metrics for health and health care progress. *JAMA, 313*(19), 1901–1902. https://doi.org/10.1001/jama.2015.4862

Breuer, J., & Freud, S. (1955). Studies in hysteria. In *The standard edition of the complete psychological works of Sigmund Freud* (Vol. II). London, UK: Hogarth Press, Ltd..

Butterworth, S. W., Linden, A., & McClay, W. (2007). Health coaching as an intervention in health management programs. *Disease Management & Health Outcomes, 15*(5), 299–307. https://doi.org/10.2165/00115677-200,715,050-00004

Campbell, B. K., Guydish, J., Le, T., Wells, E. A., & McCarty, D. (2015). The relationship of therapeutic alliance and treatment delivery fidelity with treatment retention in a multisite trial of twelve-step facilitation. *Psychology of Addictive Behaviors, 29*(1), 106.

Carey, T. A., & Mullan, R. J. (2007). Patients taking the lead. A naturalistic investigation of a patient led approach to treatment in primary care. *Counselling Psychology Quarterly, 20*(1), 27–40.

Carlson, J. W., Lyon, E., Walton, D., Foo, W. C., Sievers, A. C., Shulman, L. N., et al. (2010). Partners in pathology: A collaborative model to bring pathology to resource poor settings. *The American Journal of Surgical Pathology, 34*(1), 118–123.

Carpenter, K. M., Cheng, W. Y., Smith, J. L., Brooks, A. C., Amrhein, P. C., Wain, R. M., et al. (2012). "Old dogs" and new skills: How clinician characteristics relate to motivational interviewing skills before, during, and after training. *Journal of Consulting and Clinical Psychology, 80*(4), 560–573. https://doi.org/10.1037/a0028362

Centers for Medicare & Medicaid Services. (2019). *Hospital consumer assessment for healthcare providers and systems*. Retrieved from http://www.hcahpsonline.org

Chaitoff, A., Sun, B., Windover, A., Bokar, D., Featherall, J., Rothberg, M. B., et al. (2017). Associations between physician empathy, physician characteristics, and standardized measures of patient experience. *Academic Medicine, 92*(10), 1464–1471. https://doi.org/10.1097/ACM.0000000000001671

Chang, E. S., Simon, M., & Dong, X. (2012). Integrating cultural humility into health care professional education and training. *Advances in Health Sciences Education, 17*(2), 269–278.

Chapman, J. R., Norvell, D. C., Hermsmeyer, J. T., Bransford, R. J., DeVine, J., McGirt, M. J., et al. (2011). Evaluating common outcomes for measuring treatment success for chronic low back pain. *Spine, 36*, S54–S68.

Charon, R. (2001a). Narrative medicine: Form, function, and ethics. *Annals of Internal Medicine, 134*(1), 83–87.

Charon, R. (2001b). Narrative medicine; a model for empathy, reflection, profession, and trust. *Journal of the American Medical Association, 286*(15), 1897–1902.

Chéret, A., Durier, C., Noël, N., Bourdic, K., Legrand, C., D'Andréa, C., et al. (2018). Motivational interviewing training for medical students: A pilot pre-post feasibility study. *Patient Education and Counseling, 101*(11), 1934–1941. https://doi.org/10.1016/j.pec.2018.06.011

Cushing, A. (2016). History of the doctor–patient relationship. In *Clinical communication in medicine* (pp. 6–20). Chichester, UK: Wiley.

Del Canale, S., Louis, D. Z., Maio, V., Wang, X., Rossi, G., Hojat, M., et al. (2012). The relationship between physician empathy and disease complications: An empirical study of primary care physicians and their diabetic patients in Parma, Italy. *Academic Medicine, 87*(9), 1243–1249. https://doi.org/10.1097/ACM.0b013e3182628fbf

DePasse, J. W., & Lee, P. T. (2013). A model for 'reverse innovation' in health care. *Globalization and Health, 9*(1), 40–47.

DiRosa, L., Gupta, A. K., & DeBonis, S. (2017). Effectiveness of a clinically oriented motivational interviewing training program in increasing skills & changing perceptions. *Osteopathic Family Physician, 9*(3).

Drobac, P. C., Basinga, P., Condo, J., Farmer, P. E., Finnegan, K. E., Hamon, J. K., et al. (2013). Comprehensive and integrated district health systems strengthening: The Rwanda Population Health Implementation and Training (PHIT) Partnership. *BMC Health Services Research, 13*(2), S5.

Edelstein, L. (1937). Greek medicine in its relation to religion and magic. *Bulletin of the Institute of the History of Medicine, 5*(3), 201–246.

Elliott, R., Bohart, A. C., Watson, J. C., & Greenberg, L. S. (2011). Empathy. *Psychotherapy (Chicago, Ill.), 48*(1), 43–49. https://doi.org/10.1037/a0022187

Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science, 196*(4286), 129–136.

Epstein, R. M., Franks, P., Fiscella, K., Shields, C. G., Meldrum, S. C., Kravitz, R. L., et al. (2005). Measuring patient-centered communication in patient-physician consultations: Theoretical and practical issues. *Social Science and Medicine, 61*(7), 1516–1528. https://doi.org/10.1016/j.socscimed.2005.02.001

Fajt, M. L., & Wenzel, S. E. (2015). Asthma phenotypes and the use of biologic medications in asthma and allergic disease: The next steps toward personalized care. *Journal of Allergy and Clinical Immunology, 135*(2), 299–310.

Furin, J. J., Farmer, P., Wolf, M., Levy, B., Judd, A., Paternek, M., et al. (2006). A novel training model to address health problems in poor and underserved populations. *Journal of Health Care for the Poor and Underserved, 17*(1), 17–24.

Heidbreder, E. (1945). Toward a dynamic psychology of cognition. *Psychological Review, 52*(1), 1.

Hellin, T. (2002). The physician–patient relationship: Recent developments and changes. *Haemophilia, 8*(3), 450–454.

Herrin, J., Mockaitis, K. G., & Hines, S. (2018). HCAHPS scores and community factors. *American Journal of Medical Quality, 33*(5), 461–471. https://doi.org/10.1177/1062860618765977

Hibbard, J. H., Greene, J., & Tusler, M. (2009). Improving the outcomes of disease management by tailoring care to the patient's level of activation. *American Journal of Managed Care, 15*(6), 353–360.

Hibbard, J. H., Stockard, J., Mahoney, E. R., & Tusler, M. (2004). Development of the Patient Activation Measure (PAM): Conceptualizing and measuring activation in patients and consumers. *Health Services Research, 39*(4 Pt 1), 1005–1026.

Hojat, M., Louis, D. Z., Markham, F. W., Wender, R., Rabinowitz, C., & Gonnella, J. S. (2011). Physicians' empathy and clinical outcomes for diabetic patients. *Academic Medicine, 86*(3), 359–364. https://doi.org/10.1097/ACM.0b013e3182086fe1

Jewson, N. K. (1976). Disappearance of the sickman from medical cosmologies 1770–1870. *Sociology, 10*, 225e44.

Johnson, D. M., & Russell, R. S. (2015). SEM of service quality to predict overall patient satisfaction in medical clinics: A case study. *Quality Management Journal, 22*(4), 18–36. https://doi.org/10.1080/10686967.2015.11918448

Kaba, R., & Sooriakumaran, P. (2007). The evolution of the doctor-patient relationship. *International Journal of Surgery, 5*(1), 57–65.

Kangovi, S., Mitra, N., Norton, L., et al. (2018). Effect of community health worker support on clinical outcomes of low-income patients across primary care facilities: A randomized clinical trial. *JAMA Internal Medicine, 178*(12), 1635–1643. https://doi.org/10.1001/jamainternmed.2018.4630

Katigbak, C., Van Devanter, N., Islam, N., & Trinh-Shevrin, C. (2015). Partners in health: A conceptual framework for the role of community health workers in facilitating patients' adoption of healthy behaviors. *American Journal of Public Health, 105*(5), 872–880.

Kaufman, B. G., Spivack, B. S., Stearns, S. C., Song, P. H., & O'Brien, E. C. (2019). Impact of accountable care organizations on utilization, care, and outcomes: A systematic review. *Medical Care Research and Review, 76*(3), 255–290.

Kovacs, P. J., Bellin, M. H., & Fauri, D. P. (2006). Family-centered care: A resource for social work in end-of-life and palliative care. *Journal of Social Work in End-of-Life & Palliative Care, 2*(1), 13–27.

Lehmann, U., & Sanders, D. (2007). Community health workers: What do we know about them? The state of the evidence on programmes, activities, costs and impact on health outcomes of using community health workers. University of the Western Cape. *Evidence and Information for Policy, Department of Human Resources for Health Geneva*.

Lewin, S. A., Dick, J., Pond, P., Zwarenstein, M., Aja, G., van Wyk, B., et al. (2005). Lay health workers in primary and community health care. *The Cochrane Database of Systematic Reviews, 25*(1), CD004015. ISSN 1469-493X.. https://doi.org/10.1002/14651858.CD004015.pub2

Linden, A., Butterworth, S. W., & Prochaska, J. O. (2010). Motivational interviewing-based health coaching as a chronic care intervention. *Journal of Evaluation in Clinical Practice, 16*(1), 166–174. https://doi.org/10.1111/j.1365-2753.2009.01300.x

Lindenauer, P. K., Lagu, T., Ross, J. S., Pekow, P. S., Shatz, A., Hannon, N., et al. (2014). Attitudes of hospital leaders toward publicly reported measures of health care quality. *JAMA Internal Medicine, 174*(12), 1904–1911. https://doi.org/10.1001/jamainternmed.2014.5161

Mafi, J. N., Gerard, M., Chimowitz, H., Anselmo, M., Delbanco, T., & Walker, J. (2018). Patients contributing to their doctors' notes: Insights from expert interviews. *Annals of Internal Medicine, 168*, 302–305. https://doi.org/10.7326/M17-0583

Manary, M. P., Boulding, W., Staelin, R., & Glickman, S. W. (2013). The patient experience and health outcomes. *New England Journal of Medicine, 368*(3), 201–203. https://doi.org/10.1056/NEJMp1211775

Matalon, A. (2008). Person centered care or public health improvement. *BMJ, 337*, 1355.

McDaniel, S. H., & Fogarty, C. T. (2009). What primary care psychology has to offer the patient-centered medical home. *Professional Psychology: Research and Practice, 40*(5), 483.

Metzl, J. M., & Hansen, H. (2014). Structural competency: Theorizing a new medical engagement with stigma and inequality. *Social Science & Medicine, 103*, 126–133.

Miller, B. F., Ross, K. M., Davis, M. M., Melek, S. P., Kathol, R., & Gordon, P. (2017). Payment reform in the patient-centered medical home: Enabling and sustaining integrated behavioral health care. *American Psychologist, 72*(1), 55–68. https://doi.org/10.1037/a0040448

Miller, S. (2009). Cultural humility is the first step to becoming global care providers. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 38*(1), 92–93.

Miller, W. R., Yahne, C. E., Moyers, T. B., Martinez, J., & Pirritano, M. (2004). A randomized trial of methods to help clinicians learn motivational interviewing. *Journal of Consulting and Clinical Psychology, 72*(6), 1050.

Moyers, T. B. (2014). The relationship in motivational interviewing. *Psychotherapy (Chicago, Ill.), 51*(3), 358–363. https://doi.org/10.1037/a0036910

Murphy, J. W. (2015). Primary health care and narrative medicine. *The Permanente Journal, 19*(4), 90.

Neumann, M., Edelhäuser, F., Tauschel, D., Fischer, M. R., Wirtz, M., Woopen, C., et al. (2011). Empathy decline and its reasons: A systematic review of studies with medical students and residents. *Academic Medicine, 86*(8), 996–1009.

Noordman, J., van der Weijden, T., & van Dulmen, S. (2012). Communication-related behavior change techniques used in face-to-face lifestyle interventions in primary care: A systematic review of the literature. *Patient Education and Counseling, 89*(2), 227–244. https://doi.org/10.1016/j.pec.2012.07.006

Olaniran, A., Smith, H., Unkels, R., Bar-Zeev, S., & van den Broek, N. (2017). Who is a community health worker? - a systematic review of definitions. *Global Health Action, 10*(1), 1272223.

OpenNotes. (2017). *The next step for OpenNotes is OurNotes*. Retrieved from https://www.opennotes.org/news/the-next-step-for-opennotes-is-ournotes/

Parsons, T. (1951). *The social system*. New York, NY: Free Press.

Patient-Centered Outcomes Research Institute. (2018). Retrieved from https://www.pcori.org/research-results/2012/does-program-focuses-lifestyle-changes-reduce-heart-disease-risk-factors-rural#/

Rigg, K. K., & Murphy, J. W. (2013). Storylines as a neglected tool for mental health service providers and researchers. *International Journal of Mental Health and Addiction, 11*(4), 431–440.

Rigg, K. K., & Wilson, G. (2013). Can patient-physician race concordance improve health outcomes for African-American HIV patients? Evidence, insights, and implications. In M. S. Harris (Ed.), *African-American perspectives: Family dynamics, healthcare issues, and the role of ethnic identity* (pp. 155–168). New York, NY: Nova Science Publishers.

Rogers, C. R. (1961). *On becoming a person: A therapist's view of psychotherapy*. Boston, MA: Houghton Mifflin.

Rogers, C. R., Stevens, B., Gendlin, E. T., Shlien, J. M., & Van Dusen, W. (1967). *Person to person: The problem of being human: A new trend in psychology* (p. 56). Lafayette, CA: Real People Press.

Saver, B. G., Martin, S. A., Adler, R. N., Candib, L. M., Deligiannidis, K. E., Golding, J., et al. (2015). Care that matters: Quality measurement and health care. *PLoS Medicine, 12*(11), e1001902. https://doi.org/10.1371/journal.pmed.1001902

Smith, R. C., Dwamena, F. C., Grover, M., Coffey, J., & Frankel, R. M. (2011). Behaviorally defined patient-centered communication--a narrative review of the literature. *Journal of General Internal Medicine, 26*(2), 185–191. https://doi.org/10.1007/s11606-010-1496-5

Srinivasan, D., & Desai, N. R. (2017). The impact of the transition from volume to value on heart failure care: Implications of novel payment models and quality improvement initiatives. *Journal of Cardiac Failure, 23*(8), 615–620. https://doi.org/10.1016/j.cardfail.2017.06.005

Szasz, T., & Hollender, M. (1956). A contribution to the philosophy of medicine: The basic model of the doctor-patient relationship. *Archives of Internal Medicine, 97*, 585e92.

Szasz, T. S., Knoff, W. F., & Hollender, M. H. (1958). The doctor-patient relationship and its historical context. *American Journal of Psychiatry, 115*(6), 522–528.

Tervalon, M., & Murray-Garcia, J. (1998). Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education. *Journal of Health Care for the Poor and Underserved, 9*(2), 117–125.

Tilahun, D., Hanlon, C., Araya, M., Davey, B., Hoekstra, R. A., & Fekadu, A. (2017). Training needs and perspectives of community health workers in relation to integrating child mental health care into primary health care in a rural setting in sub-Saharan Africa: A mixed methods study. *International Journal of Mental Health Systems, 11*(1), 15.

Timbie, J. W., Bogart, A., Damberg, C. L., Elliott, M. N., Haas, A., Gaillot, S. J., et al. (2017). Medicare advantage and fee-for-service performance on clinical quality and patient experience measures: Comparisons from three large states. *Health Services Research, 52*(6), 2038–2060. https://doi.org/10.1111/1475-6773.12787

Tsai, T. C., Orav, E. J., & Jha, A. K. (2015). Patient satisfaction and quality of surgical care in US hospitals. *Annals of Surgery, 261*(1), 2–8. https://doi.org/10.1097/sla.0000000000000765

Unützer, J., Schoenbaum, M., Katon, W. J., Fan, M.-Y., Pincus, H. A., Hogan, D., et al. (2009). Healthcare costs associated with depression in medically ill fee-for-service medicare participants. *Journal of the American Geriatrics Society, 57*(3), 506–510. https://doi.org/10.1111/j.1532-5415.2008.02134.x

World Health Organization. (2006). *Working together for health: The World Health Report*. Retrieved at https://www.who.int/whr/2006/whr06_en.pdf?ua=1

Zolnierek, K. B., & Dimatteo, M. R. (2009). Physician communication and patient adherence. *Medical Care, 47*(8), 826–834.

Chapter 11
Work as Health: Tensions of Imposing Work Requirements to Medicaid Patients in the United States

Elaine Hsieh and Eric Kramer

Economic and political systems are reflections of dominant culture: its values, beliefs, expectations, motivations, and practices. Culture is expressed as an operant worldview. In the modern world, healthcare has shifted from being an expression of *religiō* to increasingly an economic-technological complex with political overtones. It may seem that issues of ethics and values have been reduced to the quantification of actuaries and accounting systems. But such calculations are means to other ends. Judgment is as pronounced as ever even as it has a veneer of objectivity. As individualism increases, the utilitarian ethics of hedonic calculus (I want to feel “good”) and of mass averaging (economies of scale) constitute a rhetoric to justify decision-making and judgments. We wish to look behind the justifications to expose the values and motives at work.

This paper seeks to expose the true motives behind healthcare policy rhetoric and policy. We want to call attention not to argumentation per se but how arguments are being used (Toulmin, 1958). A pragmatism is in effect that cynically exploits and directs logic and argumentation turning philosophical analytics itself into a mere tool of mytho-ideological purpose that itself remains largely implied. The making of philosophical analytics into a mere means in the service of pursuing ulterior goals also functions to whitewash motives and obscure genuine purposes and goals. Effective arguing can make motives and goals appear “innocent” and even inevitable, objective, and natural. By implication contrary arguments are made to appear unnatural, subjective, contingent (“political”), and uselessly deluded. This process of this paper is to turn the logic of values upside down and recognize the value of logic as use-value employed for irrational means (Kramer & Kim, 2009). Argumentation, specific to this paper, arguments against universal access to

---

E. Hsieh (✉) · E. Kramer
University of Oklahoma, Norman, OK, USA
e-mail: ehishe@ou.edu

© Springer Nature Switzerland AG 2019

S. L. Arxer, J. W. Murphy (eds.), *Community-Based Health Interventions in an Institutional Context*, International Perspectives on Social Policy, Administration, and Practice, https://doi.org/10.1007/978-3-030-24654-9_11

healthcare, involves exploitation of analytical techniques and moral traditions to promote interests that have nothing to do with reason, logic, natural law (instinct), or classical morality. If effective, this critique should offer a path for a rhetoric of exposure, a process that would uncover the motives behind the arguments and the tropes they deploy and also expose the hypocrisy of those tropes. If effective, this will also suggest a means of defeating arguments by turning their axiomatic antecedents against them. Hence, arguments against universal access to healthcare are self-contradicting. But to show this, the gambit must be launched using the same traditions and language exploited by those seeking to justify denial of coverage individually and categorically.

Healthcare Cost Trends

Medicaid represents a public health insurance program that involves collaborations between the federal and state governments to provide "health coverage to millions of Americans, including eligible low-income adults, children, pregnant women, elderly adults and people with disability" (Centers for Medicare & Medicaid Services, n.d.-a). As of November 2018, 66 million Americans were enrolled in Medicaid and nearly 6.6 million children are enrolled in Children's Health Insurance Program (CHIP; Centers for Medicare & Medicaid Services, n.d.-b). In total, more than 35.4 million children are enrolled in CHIP or Medicaid, representing 50.6% of total Medicaid and CHIP enrollment (Rudowitz & Garfield, 2018). Medicaid covers one in five Americans and plays a critical role for certain populations, covering "nearly half of all births in the typical state; 76% of poor children; 48% of children with special health care needs and 45% of nonelderly adults with disabilities (such as physical disabilities, developmental disabilities such as autism, traumatic brain injury, serious mental illness, and Alzheimer's disease); and more than six in ten nursing home residents" (Rudowitz & Garfield, 2018).

One of the primary objectives of Medicaid is to enable each State to furnish "medical assistance on behalf of families with dependent children and of aged, blind, or disabled individuals, whose income and costs are insufficient to meet the costs of medically necessary services" ("Social Security Act," 2019). Medicaid represents the ideals of American federalism through which state and federal governments collaborate to provide health services to states' poorest, elderly, and disabled citizens. Simply put, Medicaid is an essential social safety net for many marginalized and vulnerable populations to access services that are critical to maintaining their health (Hahn, 2018).

Medicaid represents a significant portion of federal and state budgets. In 2017, the total Medicaid spending reached $582 billion, accounting for 17% of the total national health expenditure (Centers for Medicare & Medicaid Services, 2018b). In 2010, the Affordable Care Act enabled states to opt-in Medicaid expansion, providing states significant incentives to expand Medicaid coverage to more people with low incomes. In particular, the federal government would pay 100% of the cost of Medical expansion during 2014–2016, and the state portion will gradually phase in, capping at 10% of the total Medicaid expansion budget by 2020. Despite the strong federal incentives, only 32 states in the United States have adopted Medicaid expansion as of February 2019 (Centers for Medicare & Medicaid Services, n.d.-b). This is because Medicaid already represents a significant portion of state budgets. While the percentage of Medicaid in state budget can vary significantly (from 26% in Missouri to 7% in Oregon), 21 states reported that Medicaid accounts for at least 15% of their total state budget (Kaiser Family Foundation, 2019a). In addition, Medicaid is projected to grow 5.8% per year in spending in 2017–2026 due to the increasing number of aged and disabled enrollees. As a result, many worried that any increase in Medicaid expenditure can pose substantial pressure to states' already strained financial status. "Ten percent of $5 billion is a lot of money," said one state representative (Leonard, 2015). Despite the immediate benefits of providing health access to individuals who otherwise would not have health access due to low income, states' reluctance highlights their concerns of limited resources and other priorities (e.g., education and infrastructures). The commitment to provide health access to "as many people as possible" may not be a sustainable goal to states who already face budgetary concerns.

Reducing Access Through Work Requirements

Because health spending is projected to grow 1 percentage point faster than gross domestic product and that state Medicaid budget increases due to Medicaid expansion, both the federal and state governments have proposed creative strategies to limit health expenditures. One of the strategies proposed is Medicaid work requirement. In January 2018, the Centers for Medicare and Medicaid Services (CMS) issued new guidance for state Medicaid waiver proposals that incorporates requirements in Medicaid as a condition of eligibility. When eligible individuals fail to meet the Medicaid work requirements set by the state, they are disenrolled from the Medicaid and barred from reenrolling for a certain period (e.g., usually a few months) even when they are otherwise eligible for Medicaid. As of February 2019, Arizona becomes the seventh state to receive approval from CMS to impose a work requirement: state citizens have to have a job and get employment training or community service to be eligible for Medicaid (The Commonwealth Fund, 2019). Another eight states have work requirement proposals currently under review by CMS (Kaiser Family Foundation, 2019b; The Commonwealth Fund, 2019).

Requiring welfare recipients to work as an eligibility requirement to participate in welfare programs is not new. Imposing a work requirement is consistent with the celebrated virtues of self-reliance and self-sufficiency (e.g., "God help those who help themselves") in western, capitalistic, individualistic societies (Greene, 2008). The famed "Protestant work ethic," a myth spread by social science as well as civic and religious leaders throughout the twentieth century, undergirds the ideology justifying work requirements. Harboring racist and ethnocentric biases, this myth expresses the notion of the White Man's burden to teach Others the value of work as a pseudo-religious virtue. Salvation comes from labor. This construct implies that Others (the poor) are lazy, stupid, and deceitful. This trope also expresses social Darwinian notions that poverty and the poor are a burden to the larger community. Labor is thus seen as little more than the largest cost to doing business, a necessary evil that can be minimized with consolidation, automation, and export of work. Otherwise, labor is nothing but a liability to the overall economic system. Of course most labor is accomplished by poor and working-class individuals who must sell their labor to those who can profit from it so that everything labor produces costs more than they are paid to produce it making the economic cycle of production/consumption a process by which labor loses value with each transaction.

As a result of the 1996 welfare reform law and debates in the 2000s, federal cash assistance (i.e., Temporary Assistance for Needy Families [TANF]), nutrition assistance (i.e., Supplemental Nutrition Assistance Program [SNAP], also known as food stamps), and some housing assistance agencies currently incorporate work-related requirements of some kind (such as that the recipient be engaged in a job search, job training, or employment and community engagement activities) as a condition of program eligibility (Falk, McCarty, & Aussenberg, 2016). The rationale for imposing work requirements involves four primary goals: "offsetting work disincentives inherent in social assistance programs; promoting a culture of work rather than one of dependency; rationing scarce taxpayer dollars to the truly needy; and combating poverty" (Falk et al., 2016, p. 2). Work requirements in these welfare programs have been carefully investigated with irrefutable findings (see also Hahn et al., 2017): (1) work requirements carry high administrative costs (Hahn, Kenny, Allen, Burton, & Waxman, 2018), and (2) the complex administration yields high error rates that deny otherwise eligible individuals benefits, including individuals living with disabilities and chronic illnesses (USDA Office of Inspector General, 2016). Previous studies also have demonstrated that some states would attempt to maximize the work participation rate by closing cases rather than helping welfare recipients find and maintain steady work (Kauff & Derr, 2008).

Work requirements for Medicaid recipients, however, are much more complicated than other welfare programs. For one, Medicaid is designed to ensure healthcare access for the most vulnerable and marginalized citizens of a state, whose health (and access to healthcare) is often faced with significant barriers (e.g., health status, old age, and poverty). In other words, modifications to existing Medicaid programs must not create barriers to achieve its legislative mandates and objectives. CMS argued that the work requirements, including community engagement such as job training and public service, can "strengthen" Medicaid programs by helping "non-disabled, working-age Medicaid beneficiaries" to "improve health and well-being and achieve economic self-sufficiency" (Centers for Medicare & Medicaid Services, 2018a). By reframing the meanings and functions of work, CMS further argued that "[t]his policy is anchored in historic CMS principles that emphasize work to promote health and well-being." Many of the state proposals have highlighted similar emphasis, noting how requiring individuals to engage with the society through work, job training, or public services can enhance their psychological well-being and social awareness.

Work requirements for Medicaid recipients are an intriguing proposal for another reason: the policy targets an extremely small number of participants. A large percentage of the nonelderly, non-dual, non-SSI Medicaid recipients are already working (i.e., 60%; 42% working full time and 18% working part time), at school (6%), or unable to work due to illness or disability (14%) (Musumeci, Garfield, & Rudowitz, 2018). Another 11% are not working due to caregiving responsibilities (e.g., single mothers with young children), which is often included as an exempted category in state proposals (Garfield, Rudowitz, & Musumeci, 2018). This leaves roughly 6% of the population to be subjected to the Medicaid work requirements. It is intriguing that stage governments are willing to design and implement complex reporting systems to implement Medicaid work requirements despite the anticipated high administration costs and the small percentage of targeted population. So much ado about 6% of the population indicates that this is a political, more than serious substantive, gambit.

Those within the effected population are being used by conservatives to demonstrate their bona fides as responsible budget hawks. A dichotomy is suggested between irrational, emotional sentimentality, the bleeding heart liberal who is increasingly presented as a weak individual, and the rational, mature, and responsible manager of scarce resources, presented as the strong “adult-in-the-room” who is capable of making “hard choices” for the greater good of all. Two issues are presumed by this trope: first that resources are scarce and second that, therefore, choices must be made that ration access to healthcare. The rationing process demands criteria of those who deserve healthcare and those who do not. And according to the work ethic, to deserve something means to have earned it through work.

As a wedge issue, it purports to pit the hardworking good citizen against the lazy welfare cheat. Two wedges are at work: one that separates hardworking good people from lazy thieves and one that separates the vulnerable from the robust. The conservative rallying against such “theft” is thus presented as not merely a responsible steward of public funds but as a heroic leader of virtuous principle in accordance with the Protestant work ethic. In public pronouncements they, being good Christians, concede that vulnerable people, so long as they are citizens, must be helped. As during the 2016 presidential campaign, Trump stated that we cannot let people “die in the streets.” A moral imperative to help the weak while punishing the wicked is promoted. But this is a double façade.

The puzzle gets more complicated when one realizes that for some states, their proposed Medicaid work requirements not only seek to punish the sins of sloth, envy, and greed but to also sacrifice to save the deserving too weak to fend for themselves, to be “my brother’s keeper.” While punishing the sinful who would take what they do not deserve is presented as noble, a lie is also revealed. For in fact some states do not promote these vulnerable populations’ health or health access at all.

An analysis from Kaiser Family Foundation found that in Kansas and Mississippi, due to their Medicaid income-eligibility requirement, "meeting Medicaid work requirements through 20 hours of work per week at minimum wage could lead to loss of Medicaid eligibility. In addition, these jobs are unlikely to have health benefits" (Musumeci et al., 2018). In these states, individuals who are subject to work requirements are put in an impossible situation: "Damned if you do, damned if you don't" – If they do not meet the work requirements, they lose their Medicaid eligibility and access to health care; if they meet the minimum standard of work requirements, they will lose Medicaid eligibility, have no health insurance, and stuck with an income that barely supports basic cost of living, let alone health access. It would seem that such policy designs were not about "emphasiz[ing] work to promote health and well-being," as suggested by CMS, but about driving people out of Medicaid programs.

Insights into this puzzle are illuminated when one considers that as a health policy, Medicaid work requirements may simply be the pretext to minimize the financial burdens of Medicaid programs. Kentucky, the first state to receive CMS's approval to incorporate work requirement, projects that the policy will save the state and the federal government $2.2 billion over a 5-year period with an initial 3% decline in adult Medicaid enrollment in year 1 growing to 15% by year 5. By year 5, it's anticipated that nearly 100,000 will lose coverage (Meier, 2017; Solomon, 2018). In anticipation of the increasing costs of healthcare expenditure in Medicaid and the high administration costs for enforcing work requirements, large coverage losses allow the states' Medicaid programs limit state's expenses while maintaining budget neutrality (i.e., the cost to the federal government is not greater than the costs before incorporating work requirement; Hill, 2018), a necessary condition for CMS to approve states' Medicaid work requirement proposals. In other words, reducing the number of enrollees is essential to the cost-control elements *and the success* of the proposed Medicaid work requirement programs.

The experiences from Arkansas' Medicaid program, Arkansas Works, can provide some insight into the individuals who lose their Medicaid eligibility. Arkansas implemented its Medicaid work requirement in June 2018. By the end of October 2018, a total number of 15,081 individuals lose their Medicaid coverage, among whom only 3815 were due to noncompliance with work requirements (Arkansas Department of Human Services, 2018). However, work requirements are likely to be the reasons for many others to lose their Medicaid eligibility. For example, 28% of the participants lose their eligibility because they "failed to return requested information," another 25% were caused by "unable to locate client or moved out-of-state," 5% of enrollees requested to leave Medicaid, and 5% were listed as noncompliance. In contrast, only 13% listed their household increased income as the reason for becoming ineligible for Medicaid. While "churn" in Medicaid (i.e., individuals entering and leaving a welfare program) is normal, Arkansas experienced a larger percentage decrease of enrollees than any other state that expanded Medicaid (Hardy, 2018). To satisfy Medicaid work requirements, eligible Arkansans not only need to work at least 80 hours a month but also have to report their work activities monthly online, detailing hours spent in different eligible activities (e.g., working, education, volunteering, job training, or job search hours) (Arkansas Department of Human Services, n.d.). Given that Medicaid recipients who are subject to work requirements are individuals with low income, their lack of Internet access and technological literacy are likely to impose additional barriers to their ability and willingness to participate in *reporting* their work activities in order to remain in Medicaid. From this perspective, Medicaid work requirements is an over-inclusive policy, resulting in loss of eligible participants beyond the targeted population. This is not new, however. "[TANF] cash assistance program and from SNAP (food stamps) shows that considerable numbers of people who were working or should have qualified for exemptions from work requirements lost benefits because they didn't complete required paperwork or couldn't document their eligibility for exemptions" (Solomon, 2018).

By imposing work requirements, the state Medicaid programs can expect that more participants will leave the program than the actual number of people are targeted by the work requirements policy. For example, Kentucky anticipates "individuals with little to no claims activity choose to leave [Medicaid] rather than pay premiums" when they were not able to meet the work requirements. In a recent analysis, Kaiser Family Foundation explained, "Work requirements in Medicaid will *primarily affect people already working or exempt non-workers* by imposing new reporting requirements to document either their compliance or exemption with the rules regarding work [italics added]" (Garfield et al., 2018). Because the majority of Medicaid adults are already working or exempted, they will constitute the majority of people who are disenrolled under the Medicaid work requirements "even if they may lose coverage at a lower rate than those who are not already working but subject to work requirements" (Garfield et al., 2018). Depending on the different projected scenarios, Kaiser Family Foundation expected that between 1.4 and 4 million people may be disenrolled from Medicaid due to work requirements, among whom 77–91% are expected to be people who remain eligible but lose coverage due to new administrative burdens (e.g., not reporting work activities or exemption) (Garfield et al., 2018). By reducing the number of people covered by Medicaid and adopting a facially neutral yet over-inclusive-as applied policy, state governments can successfully control health expenditures while allowing the most vulnerable, marginalized citizens to "voluntarily disenroll" from Medicaid.

Unlike other welfare program that offers direct support (e.g., cash or food) to everyday life, Medicaid is ultimately a health insurance that provides access to healthcare – a recipient does not benefit from the welfare program until he or she utilizes healthcare services (i.e., Medicaid has no value to a person until one is ill or requires preventive care).

A New Rhetoric of Exposure

Our goal is to expose the motives behind the arguments. This paper presents a set of arguments based on common belief (culture), not moral principle or scientific fact, that must be acknowledged if policy change is to be successful. Deploying economic arguments against moral arguments, for instance, is mixing apples with oranges or, more accurately, competing in an apple-juice contest by using orange juice and expecting to win. We propose using apple-juice but in a different way. Headway in progressive healthcare reform must come from the grassroots.

We argue that one should make no mistake. Work requirements for medical aid are based on the Protestant work ethic and a common belief system that lies deeper than this contingent cultural-historical ideology. In this paper, we are not interested in arcane academic discussions of ethics and morality but rather the rhetorical sphere common to public communication and understanding. Thus, to understand the public sentiment about such policies, we must directly confront the cultural antecedents that motivate efforts to justify and demand rationing of healthcare. To do this we must directly access the mythological/cultural presumptions underlying such justifications. Hence, we recall the ideological complex variously canonized as the seven deadly sins and seven virtues presumed but rarely overtly stated that are the justifications for the policies discussed herein. But this ideological complex may emerge from and intertwine with an even deeper set of motives.

Ultimately, behind the value judgments and policy positions that limit access to healthcare is the belief that those who take what they do not deserve are selfish and being selfish encompasses all the capital vices (or cardinal sins). A concept of self is presumed and with it a construct of merit. Those with merit should be given aid. Merit involves the perceived worth of a person. The overall debate also presumes a zero-sum game. What I take is gone forever and is not available to you for sharing. It assumes a winner-takes-all hedonic calculus rooted in a particular cultural version of the self as a consumer.

Curiously, the United States and its people feel it necessary for the State to provide legal expertise to those who cannot afford it and who are charged with a crime, but this generosity does not extend to healthcare. Access to medical expertise for those who suffer an accident or disease is not similarly guaranteed. Why? Why do we choose to assure expert aid in one case but not the other?

Because, from the early US State's position, illness was beyond human interference. But a court could render great harm to a citizen through corruption. The Sixth Amendment thus provides for a jury of one's peers. This and other assumptions are obsolete and challenged herein.

It is true that the accused criminal is facing the power of the State for purported malicious actions against private or public goods, while the ill person faces the fates, often, in fact typically, without malign intent. Their illness may even be a just punishment by supernatural forces. Consequently, the State, *logically and justly*, has presumed that it has no role in health, illness, and healthcare. One would do better to throw oneself on the mercy of the fates or gods than the State. But this basic presumption no longer holds. In both cases the government has a hand in managing responses, and healthcare has become a very powerful economic and technological complex that demands regulation.

This divergence between care for the accused criminal and care for the patient is rooted in a fragmentation and divergence of the world splitting into what is morally good and what is legal, what is sacred and what is secular power, and what is right and what is economical. The shaman was both a healer and lawgiver. But these poles have diverged to the point of becoming competing spheres of interests. The modern secular State sees its dominion over human affairs and law, not nature or supernatural domains. This allows State actors to claim innocence with regard to moral and ethical issues. They deal only with legalities. Certainly, justice is inherent in law, but many legal experts will argue that unjust laws exist and that it is not the role of courts, judges, and juries to define law but to follow it. If you have a problem with a law, take it up with the legislative branch of government which has the power to make law. So, it is here, among the elected, that morality and ethics are exposed in the formulation of law. Too often underlying issues of what is right are brought up in courts where they are dismissed.

Therefore, the State (that saw itself as separate from the interests and purview of religion) seeks to limit its own power in the case of legal prosecution. The citizen must be protected from State power, and the State should have no influence over natural and supernatural domains. However, this dichotomy is increasingly erased as illness increasingly becomes an issue of science and economics: human pursuits where regulation is called for. Furthermore, what is natural is increasingly recognized as a matter of conceptualization; in other words "nature" has become recognized as a cultural artifact conceived as a resource base for technological manipulation, ownership, and management. Genetics is a prime example.

The argument is that the natural laws of market forces should determine access. State failure to recognize the need for regulation of healthcare access, or more to our point herein, State failure to be responsible stewards of public needs, belies a failure to recognize that illness is not an issue of religion or the fates but rather highly correlated with social and economic processes within the purview of secular power and administration. Being ill is less and less regarded as a function of god's will or luck. And yet this dichotomy persists. Consequently citizens facing State power in the courts are deemed to be deserving of attention and worthy of expert counsel, while citizens facing the random fates of accident or illness are not. Furthermore, when citizens are in the control of the State, such as incarceration, they are then afforded access to healthcare as a function of administrative responsibility.

Essentially, one ideology has dominated the regulatory process which insists that government is not responsible for the health and well-being of its citizens unless they are "wards of the State." We suggest a set of arguments based on the comparison between legal aid and healthcare aid. As noted, we argue that this incongruity is rooted in common beliefs and perhaps deeper motives. There are a few possible explanations. The distinction between the two, that one is the domain of State power while the other is the rightful domain of market forces and divine intervention, must be collapsed because this distinction is the structure that justifies denial of State power to “interfere” in healthcare. The call to “keep nanny government out of our lives” surrenders healthcare administration to the predatory practices of market forces and/or God’s preordained plan (fatalism). Government, essentially, is the instrument of free humans to exercise agency over their own lives rather than passively submit to the cliché “that’s just business,” as if no other possibilities exist.

Instinct as Justification for Limiting Access to Healthcare

We propose that one explanation for the divergent appeal for aid between the criminal and the patient is social Darwinian. The US policy states that a person, citizen, or noncitizen should not be compelled to engage in forensic defense without the aid of legal counsel. But the US policy does not extend medical aid to those who cannot afford it and who are in need of it. This is rooted in a cultural proclivity to see weakness in others as not worthy of support. It may even be an instinctual response and part of evolutionary psychology. Weakness is not seen as having any merit. The daring criminal is more esteemed than the sick worker. Going to prison generates “street cred.” But going to the hospital may, at most, generate empathy or pity. In the former case status is elevated. Some prisoners become celebrities. No one becomes a celebrity for being a patient. In the latter, the ill person is regarded as weak and passive. They may even be vilified if it is believed that they seek attention by faking illness. On the other hand, the criminal is perhaps misguided but bold and enterprising. I may secretly understand that what separates me from the thug is my own lack of courage and strength. I appeal to the police to fight my battles for me. Being a member of the sheep herd, I need the guard dog to fight the wolf for me. The wolf may be many things, but he is not weak or cowardly. The wolf’s story is entertaining. The sheep’s story is not interesting. The savior is willing to stand up to the bully. The greatest sin of all is of being weak, passive, and inert – uninteresting as Nietzsche (1987 Ger./1974 Eng.) put it. Criminal activity “makes the news.” Unless you are already a celebrity, illness does not.

Maligning and attacking such perceived weakness may even be part of evolutionary biology. We fear the illness that may be contagious and hence the contagious person. A sick army is a weak army. One must respect the power of the corrupt king but not of the sick king. I may respect the tenacity, daring, and intellect of my enemies but I fear, pity, or disregard the sick. History books are filled with the nefarious activities of powerful people, but their illnesses are barely mentioned unless they impact the overall story or take on a scale, such as a plague, as to pique the interest of the writer. Becoming ill is never a strategy for “success.” Illness and frailty are not paths to fame and fortune.

Hence, it may be that support for the sick is not nearly as sexy as tacit support if not adulation for the courageous and “genius” criminal. The deeds of the organized crime boss make “good copy.” The more heinous, the more popular. But his illnesses do not make the cut. Illness, to the contrary, is mundane. The criminal mastermind pits herself against the wits of the law. The antiauthoritarian in us secretly, or even openly, cheers for the criminal, especially if her rebellious actions are seen as just. We enjoy the drama of a "worthy opponent." The sick are not worthy. The sick resist no one. The sick compete with no one. Illness does not project agency or bravado. Who will "outlive" who is part of the larger evolutionary game of success? People take pride in the longevity of their "good genes." We want to live longer and longer but only if in robust health. Aging as the frailty of mind and limb is regarded as an illness too, and so there is a constant tension between committing resources to the young, to the future, or to the old, to past glories (Kramer & Hsieh, 2012).

The rhetoric of instinct is a naturalizing language that implies inherent permanence. It is debunked already by modern biology that recognizes the interaction between environment and genetic *predispositions* or tendencies (not predetermination). In lay rhetoric, instinct is used as a pseudoscientific synonym for fatalism. It is hopeless to suggest we can change our nature. Throwing money at certain defective persons is simply a waste of resources. In short, it is hopeless. This rhetoric can be intercepted by basic arguments from the very humanism that modern industrialists and capitalists claim as their procreant cradle. While religion may not offer strong cross-examination, humanism itself does. Here the rhetoric can be challenged by the trope of free will that capitalists espouse. Their rhetoric can be used against them. And it is not difficult to see a tropic landscape where such a battle can be waged. Furthermore, rewards and punishments are meted out in a belief that behavior can be modified. So the threat of withholding healthcare is expected to motivate people to work. Clearly, then, according to capitalists themselves, things are not preordained, genetically or spiritually.

Medical science is focused on extending human longevity. From the earliest magic to the most modern and complex technical treatments, healthcare has always been a process of confronting and attempting to defeat natural and supernatural forces. Healthcare is the application of human agency and ingenuity to defeat those forces that would threaten our desired quality and quantity of life. So to punt, to surrender to an argument from "instinct," is a direct contradiction of the rhetoric of free will and enterprise so central to capitalist mytho-ideology.

Mytho-ideology

As myth takes the form of written canon, it becomes disputative and ideological. Another aspect of the dichotomy between the worthy criminal and the unworthy patient has to do with Protestant (Calvanist) *ethics* as an evolution of older Catholic morality (themselves in part borrowed from Plato and Aristotle's *Nicomachean Ethics* via Thomism). Aristotle's modernistic take on ethics involved the introduction of an analytical mindset presenting "the good" as a strategic necessity for social stability. Rather than stating a virtue or vice without context as an absolute, Aristotle and later Kant, following in his mode, asked a more social question. What if everyone else acted in the same way? Thus, pragmatics via social stability enters into an ethical and moral judgment. Ethics becomes an issue of reliable consistency.

"The good" is not "in itself" sui generis, but a matter edging toward quantification: moral calculus. The hedonic characterization of this calculus would be added later with the utilitarianism of the Benthamites who shifted focus from collectivistic to individualistic reckoning. It violates its own attempts at generalized truth by elevating personal desires to the status of ultimate criteria. Thus, the calculus changes fundamentally and what is good, what is rational pivots on personal wants and needs rather than group wants and needs. What is rational becomes synonymous with what is the most efficient means to achieve personal wants and needs. This then is linked to the "greater good for the greater number" by means of production and identification of the self with the group via economic common ground, a sort of inescapable membership. Membership suggests personal choice like selecting one's church or religion, a process basically impossible in earlier times. As individualism and free will emerge with modernization, identities proliferate. Religious affiliations multiply. Sectarianism and fragmentation increase. But what all have in common is the growing market economics and labor.

As production became the dominant organizing structure of society (industrial society), the needs of the self become identified with the needs of one's firm or corporation – even nation. Fortunes rise and fall together. The unfortunate are those who have no affiliation and are typically careerless/homeless (literally and figuratively). They wander among us as people with no country (Kramer & Hsieh, 2019). While presented as an objective Darwinian process, the outcomes are utterly personal and strike at the core of character assessment and identity. Those "outside the system" are labeled "aimless." As burdens on the system, moral judgment follows with repercussions such as denial of access to systemic healthcare. Debtor's prisons have been replaced by even more inescapable economic profiles, credit ratings, job histories, criminal records, educational attainments, and so forth. The virtual person is more permanent and believable (consequential) than the actual one. And its identity is more economic, spiritual, social, or psychological.

Being unemployed is the most common crack through which individuals fall. Without a "safety net," they languish in a purgatory, present yet denied entrance into the shelter of civil society. This includes access, or the lack thereof, to basic healthcare. This is not seen as immoral but quite the contrary. Such denial of the unproductive is expressly justified by moral criteria. The only way to combat this situation is to recognize the rhetoric and implied morality and confront it at that level of judgment and in those terms. Only then can inconsistency, hypocrisy, and contradiction be clearly drawn. This is what we call the rhetoric of exposure. It is more than a rhetoric of values or motives (Burke, 1969). And it is more than mere storytelling as ontogenesis (Fisher, 1984; Kramer, 2013). It is the use of analytical skills to demonstrate the hypocrisy of an argument over time. Within the dialectic one finds the contradicting logic that decenters such claims to ultimate validity such as instinct, exposing a field for free will and innovation. It disrupts the orderly "coordination" of meaning. Healthcare for all is hardly a hopeless pipedream as some claim based on various warrants and claims.

The Presumed Criteria: The Linguistic Ground Staked Out and Where Disputation Must Engage

The seven deadly sins are *Luxuria* (Lust), *Gula* (Gluttony), *Avaritia* (Greed), *Acedia* (Sloth), *Ira* (Wrath), *Indvidia* (Envy), and *Superbia* (Pride). The seven corresponding virtues are *Castitas* (Chastity), *Moderatio* (Temperance), *Caritas Liberalitas* (Charity – Generosity), *Industria* (Diligence), *Patientia* (Patience), *Gratia* (Gratitude), and *Humilitas* (Humility). As this paper unfolds, you will see how these fundamental cultural presumptions are operant in justifying rationing access to healthcare. Because they are fundamental and only tangentially exposed in public pronouncements, they are very powerful antecedents to policy debates. They are powerful because they are uncritically presumed. Three such "sins" strongly influence policy justifications: greed, envy, and sloth. These are attacked in policies that ration access to healthcare. Concurrently and implicitly, those who attack such sins also present themselves as champions of the corresponding virtues of charity, diligence, and gratitude. Those who are not deserving of healthcare are portrayed as lazy greedy cheats. Those who warrant such help are presented as "vulnerable" and therefore deserving of charity given from the industrious, charity that should be received with humility and gratitude. This is the basic structure of the values-discussion underpinning policy debates and ultimately justifying selective access to healthcare.

In previous times health included cosmic balance involving ritualized respect for the sacred, what Cicero called *Cultum deorum*, "the proper performance of rites in veneration of the gods" (Cicero, 1933, p. 28.). Health had much to do with notions of balance and harmony between the temporal and the timeless, and in collectivistic societies, it was a community-wide condition. With secularization and increasing individualism, *religiō* became, as Max Weber put it, disenchanted and a new system for meaning- and value-creation emerged, namely, science. But as the larger rationalization and mathematical reduction of all things deconstructed all previous sources of meaning and value-creation, they themselves offered no unifying principles but rather an endless fragmentation of incompatible value spheres. All truths are destined to become obsolete as antithesis counters thesis in an endless process, an absurd process of progress with no final goal.

Science was not the answer. Rather, what came to be the answer to the traditional human questions of existence increasingly were answered by labor. The human as philosopher died along with the great existential questions, and the human as producer/consumer was born. Order no longer came from transcending criteria but from increased calls for self-discipline. The modern sees herself as an instrument of production. Use-value came to dominate industrial culture so that people could come to be seen as "useless" and "useful." A simple positivism emerged. You were either measurably profitable to the firm or you were not. The body came to be seen less as the receptacle of an eternal soul and more as an instrument of contingent production. "What have you accomplished for me lately" is the new measure of value. The grand durée has been supplanted by "time famine" and a chronic sense of urgency (Kramer, 1992, 2013; Levine, 1997). Even capitalism is suffering as day-trading has accelerated to algorithmic automatic nanosecond trading, making entrepreneurial planning increasingly difficult. The system is characterized by a "time famine" (Levine, 1997) and "temporal anxiety" (Gebser, 1985), distressing all involved.

The Body as Material Production

Maintenance of the body is now driven so that athletes can keep "producing stats" and workers can keep laboring through illness and injury. Measurable performance is the ultimate truth. Pain management is a relatively new idea. It emerges with the modern individual and industrial warfare and production. The idea that pain can and should be managed if not elevated entirely is one of the goals of modern healthcare. It is almost presumed without question. It is so different from the concept of righteous suffering previously dominant in religious tropes that religious institutions are grappling with the role of suffering within God's plan. Designed suffering from penance to self-flagellation is seen as quaint if not bizarre practice of a bygone world and abandoned moral practice. Modernity has promised convenience and a guilt-free and pain-free existence. But for the Buddhist, this means abandoning life itself. For the Christian it means abandoning identification with Christ and His suffering. The idea that happiness is a goal in life is relatively new, an essential goal of modern positivism. Only recent Christian doctrines have argued that leading a Christian life should not necessarily lead to more suffering. To the contrary, contemporary Evangelical doctrine suggests the opposite, which an appeal of Christian conversion is the material as well as spiritual rewards God will bestow. In either case, work must be done and performance efficiency must increase. True evil is that which threatens production.

Endless work without pain is the goal. Insofar as illness and pain slow the pace of production, they must be managed. Since inherent value has become a myth, value exists only in exchange. Thus, according to use-value, we become alienated from our own bodies as useless unless they can be pressed into productive labor. Being healthy is valuable not in itself but as a precursor to being productive. Performance evaluation marks the status of the individual within administrative logic. Illness and injury no longer threaten the quality of life directly but also indirectly through career attenuation and termination. In a highly individualistic cultural environment, poverty is the "just punishment" for being unproductive. "Missing work" is a constant threat to the modern worker's very livelihood. Reliable, cheap labor and fast exchanges constitute the "good" in the industrial world. The show is alienated from the players. The show must go on even as the players falter. The show is no longer the players in a systemic coordinated process. The process of production (in a play or factory) is separated from the hands that operationalize the logistics (Horkheimer & Adorno, 1987). The producers are interchangeable with each other, and it is the production process that must not pause or cease. This is why robotics is so valued and pursued because robots are better workers. They do not complain, they do not get sick, they do not unionize, and their output is highly predictable (consistent).

Just as actors are interchangeable but the play "is the thing," so too workers have become supplemental to work. Work and worker are separated. Producer and product are separated. Profit and salary diverge. The constant threat to the worker is that they are easily replaced. They are insignificant in and of themselves. Hence the other side of the coin of modern individualism is aggregation on a mass scale. The individual is meaningless, useless, unless they can be pressed into performing the tasks assigned by the logic of the production process. Illness and injury become existential and perpetual threats. Hence, debate over healthcare policy and practice rages. Why spend a great deal to repair a broken worker when they can be easily replaced? Even when workers spend a lifetime and go into debt to educate and train themselves for the workforce, still investing in a robot is more profitable in the long run. Robots are easily reprogrammable. And fixing them is relatively simple compared with a worker healing from an injury or illness. From the perspective of profit/logic, it makes no sense to waste resources on unproductive people. Consequently, where this ideology is more pronounced, the United States, "entitlements" are constantly debated even when they are paid for by workers' taxes. In this ideological milieu, the very word "entitlement" is pejorative even when it literally means something already earned. The word itself has fallen victim to the logic of undeserved or unearned privilege. And expenditures for warehousing the unproductive in child and senior daycares are systematically repressed (Kramer, 2004).

Evaluations reduce individuals to single numbers. Resumes and vitae constitute the modern portrait. Even in an environment of near-full employment, employers are so inundated by resumes that they increasingly are turning to standardized forms and algorithms to handle the sorting. The persona with a "preexisting condition" is flagged. Life as suffering, the ultimate preexisting condition, is itself deemed untenable according to the logic of production.

Everything including health, justice, and ethics became increasingly conceived as a balance sheet in modern parlance. It may have begun with Pauline epistles to the Corinthian traders he sought to convert. Paul's language is one of business exchange. Christ pays for your sins. Balance and objectivity dominate discourse. Hence, life satisfaction must be earned, and thus the Puritan ethic of "innerworldly asceticism (*innerweltliche Askese*)" converts the soul to a record of accomplishments (Weber, 1992). Control finally wedded to the modern self, and systematic synchronicity as the binding principle of productivity gives birth to rigorous self-control and self-discipline without need for gods. Internalized governance, self-control, and conscience are the subroutines of culture. A subroutine is a set of presumed rules that govern cognition and behavior and are replicable. The "stable" "mature" person is consistent and reliable. The good person is the productive one. Work is no longer seen as a means to other ends, to leisure and the pursuit of the liberal arts (innovation), but instead as an end in itself (Hunnicutt, 2013), indeed as the only real end. Routinized patterns of thought and action are "programmed" through acculturation and enculturation (communication patterns) to assure "quality control." Feedback and control is the major type of communication between superordinate and subordinate. In fact, "personal" contact is increasingly outlawed.

According to this subroutine that justified cultural patterning itself, what one deserves is what one earns through sacrifice and self-discipline within the rationalization of administrative systemization, the organization of egoism that leads to the "iron cage" domicile of the assembly-line worker and salaryman. Modern rules of finance determine the credit rating of each person. The irony that one has what one earns, the self-made human, presumes the structures of production and administrative rationality. Agency in the making of the system is eliminated. Consequently, democratic modes of comportment and public sphere are increasingly seen as friction within the system. Education, critical assessment, and a free press are "enemies" of the system. They cause the system pain. Systems operate most efficiently without exogenous interference such as democratic institutions that may disrupt operation and reevaluate their founding purpose. Since value is no longer an inherent quality, to be of value is nothing other than a measurement of performance outcome. To be of value is to demonstrate utility within a system of production/consumption. No other value is recognized (Kramer, 2004). In fact, nothing, such as a rain forest, has value, until and unless it can be assimilated into the system, processed, and commodified. The value of the forest is calculated in board feet and current market demand (Kramer, 2004). Otherwise it is useless, valueless. Value and meaning are reduced to use: utility.

Domestication, the convergence of nature into an artifact of culture, is the first move of control (Kramer, Adkins, Kim, & Miller, 2014). The dominant ideas are the ideas of the dominant class, and it is the dominant class that establishes what counts as valid (not even valued) goals and purposes of life. Management posits a goal and since profit is actualized with each unity "moved," time becomes the dominant factor in production and the accumulation of wealth/power. Taylorism is but one expression of the modern utilitarian view with its presumption of objective rationality, but not a rationality based in a transcending principle but rooted in subjective desires and needs. Confronted with a profound expansion of empty, dead space, the modern becomes "encapsulated," isolated and must strive to be adequate. Modernity is thus characterized with endless confrontations. Encapsulated ego sees nothing but alterity and Otherness. Time is compartmentalized and schedules dominate life (Kramer, 1997a, 1997b). Time-rooms (boxes on calendars, subdivided down to minutes) dictate appropriateness. And timing "is everything." The good person is the reliable one, the one that is "just like clockwork." As time and space rigidify, the self responds, and identity becomes of paramount concern. Privacy of property and information intensifies. And increasingly production has nothing to do with democratic comportment except when regulation is suggested and then the relationship is adversarial. Thus access to healthcare is defined as a liability, especially when the worker's body is no longer necessary.

Robotics, artificial intelligence, algorithmic pattern recognition, and other innovations are meant to eliminate the worker's body and with it needs for its maintenance or nurturance. Work achieves increased efficiency by not just dissociating from the worker but by eliminating the worker's body entirely and along with it democratic institutions because without a body there is no perspective on issue including healthcare policy itself. Eliminating workers and their unions eliminates the need for regulation and social support. Thus domestication, the essence of production, reflexively applies to itself, doubling down. It thus rids itself of the last element that may resist control or offer an ulterior perspective. The worker that once conceived of the product and the mode of production is domesticated and reproduced. Mortal aspects are replaced by robotic action. The work ethic is fulfilled. Sin is eliminated with the elimination of the sinner.

References

Arkansas Department of Human Services. (2018). *Arkansas Works program*. Arkansas Department of Human Services. Retrieved from https://humanservices.arkansas.gov/images/uploads/newsroom/111518_AWreport.pdf

Arkansas Department of Human Services. (n.d.). *AR Works Information*. Retrieved from https://ardhs.sharepointsite.net/ARWorks/default.aspx

Burke, K. (1969). *A rhetoric of motives*. Berkeley, CA: University of California Press.

Centers for Medicare & Medicaid Services. (2018a, January 11). *1115 community engagement initiative*. Retrieved from https://www.medicaid.gov/medicaid/section-1115-demo/community-engagement/index.html

Centers for Medicare & Medicaid Services. (2018b). *NHE fact sheet*. Retrieved from https://www.cms.gov/research-statistics-data-and-systems/statistics-trends-and-reports/nationalhealthexpenddata/nhe-fact-sheet.html

Centers for Medicare & Medicaid Services. (n.d.-a). *Medicaid*. Retrieved from https://www.medicaid.gov/medicaid/index.html

Centers for Medicare & Medicaid Services. (n.d.-b). *November 2018 Medicaid & CHIP enrollment data highlights*. Retrieved from https://www.medicaid.gov/medicaid/program-information/medicaid-and-chip-enrollment-data/report-highlights/index.html

Cicero. (1933). *De natura deorum, Academica* (R. H. Rackham, Trans.). Cambridge, MA: Harvard University Press.

Falk, G., McCarty, M., & Aussenberg, R. A. (2016). *Work requirements, time limits, and work incentives in TANF, SNAP, and housing assistance*. (7-5700). Washington, DC: Congressional Research Service. Retrieved from https://greenbook-waysandmeans.house.gov/sites/greenbook.waysandmeans.house.gov/files/R43400%20-%20Work%20Requirements,%20Time%20Limits,%20and%20Work%20Incentives%20in%20TANF,%20SNAP,%20and%20Housing%20Assistance_0.pdf

Fisher, W. (1984). Narration as a human communication paradigm: The case of public moral argument. *Communication Monographs, 51*, 6.

Garfield, R., Rudowitz, R., & Musumeci, M. (2018). *Implications of a Medicaid work requirement: National estimates of potential coverage loss*. Kaiser Family Foundation. Retrieved from https://www.kff.org/medicaid/issue-brief/implications-of-a-medicaid-work-requirement-national-estimates-of-potential-coverage-losses/

Gebser, J. (1985). *The ever-present origin* (N. Barstad & A. Mickunas, Trans.). Athens, OH: Ohio University Press.

Greene, T. W. (2008). Three ideologies of individualism: Toward assimilating a theory of individualisms and their consequences. *Critical Sociology, 34*, 117–137.

Hahn, H. (2018). *Work requirements in safety net programs: Lessons for Medicaid from TANF and SNAP*. Retrieved from https://www.urban.org/sites/default/files/publication/98086/work_requirements_in_safety_net_programs_0.pdf

Hahn, H., Kenny, G. M., Allen, E., Burton, R., & Waxman, E. (2018, January 12). *Guidance on Medicaid work and community engagement requirements raises many important questions*. Retrieved from https://www.urban.org/sites/default/files/publication/95846/2018.1.12.questions_final_for_pdf_v1_0.pdf

Hahn, H., Pratt, E., Allen, E. H., Kenny, G. M., Levy, D. K., & Waxman, E. (2017, December 22). *Work requirements in social safety net programs: A status report of work requirements in TANF, SNAP, Housing Assistance, and Medicaid*. Retrieved from https://www.urban.org/research/publication/work-requirements-social-safety-net-programs-status-report-work-requirements-tanf-snap-housing-assistance-and-medicaid

Hardy, B. (2018, August 9). *Scrubbed from the system: Why Medicaid enrollment has dropped almost 60,000 in 18 months*. Retrieved from https://www.arktimes.com/arkansas/scrubbed-from-the-system/Content?oid=21285998

Hill, T. B. (2018). *Beduge neutrality policies for Section 1115(a) Medicaid demonstration projects*. Centers for Medicare & Medicaid Services. Retrieved from https://www.medicaid.gov/federal-policy-guidance/downloads/smd18009.pdf

Horkheimer, M., & Adorno, T. (1987). *Dialectic of enlightenment* (E. Jephcott, Trans.). Stanford, CA: Stanford University Press.

Hunnicutt, B. (2013). *Free time: The forgotten American dream*. Philidelphia, PA: Temple University Press.

Kaiser Family Foundation. (2019a). *Federal and state share of Medicaid spending*. Retrieved from https://www.kff.org/medicaid/state-indicator/federalstate-share-of-spending/

Kaiser Family Foundation. (2019b, January 23). *Medicaid waiver tracker: Approved and pending section 1115 waivers by state*. Retrieved from https://www.kff.org/medicaid/issue-brief/medicaid-waiver-tracker-approved-and-pending-section-1115-waivers-by-state/

Kauff, J., & Derr, M. K. (2008, December). *Achieving higher TANF work participation rates: Case studies from Maryland and Utah*. Retrieved from https://aspe.hhs.gov/system/files/pdf/75606/report.pdf

Kramer, E. M. (1992). Gebser and culture. In E. M. Kramer (Ed.), Consciousness and culture: An introduction to the thought of Jean Gebser (pp. 1-60). Westport, CT: Greenwood.

Kramer, E. M. (2004). Vanishing meaning, the ideology of value-addition, and the diffusion of broadband information technology. In J. M. Choi, J. W. Murphy, & M. J. Caro (Eds.). Globalization with a human face. Westport, CT: Praeger, 87-108.

Kramer, E. (2013). Dimensional accrual and dissociation: An introduction. In J. Grace & E. M. Kramer (Eds.), *Communication, comparative cultures, and civilizations* (Vol. 3, pp. 123–184). New York, NY: Hampton.

Kramer, E. (1997a). *Modern/Postmodern*. Westport, CT: Praeger.

Kramer, E. (1997b). In J. M. Choi, J. W. Murphy, & M. J. Caro (Eds.),. Globalization with a human face *Vanishing meaning, the ideology of value-addition, and the diffusion of broadband information technology* (pp. 87–108). Westport, CT: Praeger.

Kramer, E., Adkins, G., Kim, S., & Miller, G. (2014). *Environmental communication and the extinction vortex*. New York, NY: Hampton Press.

Kramer, E. M., & Hsieh, E. (2012). Anti-culture and aging. In S. L. Arxer & J. W. Murphy (Eds.), *The symbolism of globalization, development, and aging* (pp. 135–156). New York, NY: Springer.

Kramer, E. M., & Hsieh, E. (2019). Gaze as embodied ethics: Homelessness, the Other, and humanity). In M. J. Dutta & D. B. Zapata (Eds.), *Communicating for social change: Meaning, power, and resistance* (pp. 33–62). Singapore: Palgrave Macmillan.

Kramer, E. M., & Kim, T. (2009). The global network of players. In J. M. Choi & J. W. Murphy (Eds.), *Globalization and the prospects for critical reflection* (pp. 183–211). Delhi, India: Aakar.

Levine, R. (1997). A geography of time. New York: Basic Books.

Leonard, K. (2015). *Opposing Medicaid expansion*. U.S. News. Retrieved from https://www.usnews.com/news/the-report/articles/2015/12/04/opposing-medicaid-expansion

Meier, A. (2017). *Kentucky HEALTH §1115 demonstration modification request*. Retrieved from https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/ky/ky-health-pa2.pdf

Musumeci, M., Garfield, R., & Rudowitz, R. (2018). *Medicaid and work requirements: New Guidance, state waiver details, and key issues*. Kaiser Family Foundation. Retrieved from https://www.kff.org/medicaid/issue-brief/medicaid-and-work-requirements-new-guidance-state-waiver-details-and-key-issues/

Nietzsche, F. (1974). *The gay science* (W. Kaufmann, Trans.). New York: Vintage.

Rudowitz, R., & Garfield, R. (2018). *10 things to know about Medicaid: Setting the facts straight*. Kaiser Family Foundation. Retrieved from https://www.kff.org/medicaid/issue-brief/10-things-to-know-about-medicaid-setting-the-facts-straight/

Social Security Act, 42 U.S.C.A. § 1396-1 (2019).

Solomon, J. (2018). *Administration's re-approval of Kentucky's Medicaid waiver again ignores harm to beneficiaries. Center on Budget and Policy Priorities*. Retrieved from https://www.cbpp.org/blog/administrations-re-approval-of-kentuckys-medicaid-waiver-again-ignores-harm-to-beneficiaries

The Commonwealth Fund. (2019). *Status of Medicaid expansion and work requirement waivers*. Retrieved from https://www.commonwealthfund.org/publications/maps-and-interactives/2019/feb/status-medicaid-expansion-and-work-requirement-waivers

Toulmin, S. (1958). *The uses of argument*. Cambridge, UK: Cambridge University Press.

USDA Office of Inspector General. (2016, September). *FNS controls over SNAP benefits for able-bodied adults without dependents*. Retrieved from https://www.usda.gov/oig/webdocs/27601-0002-31.pdf

Weber, M. (1992). *The Protestant ethic and the spirit of capitalism* (T. Parsons, Trans.). London, UK: Routledge.

Chapter 12
Overcoming Institutional Barriers Faced by Community-Based Healthcare Institutions

Airín D. Martínez

> *However, a powerful lever has yet to be pulled: the implementation of upstream policies that change the underlying systems that promote health inequities*
>
> Alberti, Bonham, & Kirch, 2013, p. 1620.

Although the United States is the wealthiest nation, it is also a society with severe income inequality (Pickett & Wilkinson, 2015) that does not guarantee a basic standard of living, including access to medical care for all its members, not even US citizens. Through community organizing and coalition building, local communities in the United States have established grassroots community-based health centers to address the absence of clinics and healthcare providers, either in rural or low-resourced urban areas. Moreover, some of these needs have been the absence of providers that can address the unique health issues faced by members of marginalized groups such as women; lesbian, gay, bisexual, transgender, and queer (LGBTQ) persons; language minorities; and migrant communities.

The model of community-based health centers that we have in the United States has roots in South Africa. Dr. H. Jack Geiger (1926–), an internist, social activist, and health policy scholar, completed an internship in South Africa in the late 1950s. There, Dr. Geiger witnessed the first community health centers and community health workers program, which were created by Black communities in apartheid South Africa to address their exclusion from formal medical care. Specifically, in Pelola, South Africa, Dr. Geiger witnessed the transformative work of community health workers (CHWs) or lay health advisors that serve as a bridge between community members and the community health center.

A. D. Martínez (✉)
University of Massachusetts-Amherst, School of Public Health & Health Sciences,
Amherst, MA, USA
e-mail: admartinez@umass.edu

© Springer Nature Switzerland AG 2019

S. L. Arxer, J. W. Murphy (eds.), *Community-Based Health Interventions in an Institutional Context*, International Perspectives on Social Policy, Administration, and Practice, https://doi.org/10.1007/978-3-030-24654-9_12

Upon returning to the United States in the early 1960s, Dr. Geiger became part of the Civil Rights Movement's medical arm. During his civil rights involvement, Geiger realized he did not have to go to Africa or Latin America to promote public health, human rights, and social justice. There were plenty of inequalities and public health problems in the United States. He witnessed the immense poverty that many African American sharecroppers experienced in the South and the almost complete absence of medical facilities for the African American rural community. Moreover, Dr. Geiger realized that there was a high prevalence of infectious and communicable diseases that were preventable with improved sanitation, opportunities to well-paying jobs, low-cost public health interventions like vaccinations, and community gardens (National Association for Community Health Centers [NACHC], n.d.).

Taking advantage of President Lyndon B. Johnson's War on Poverty initiatives, Dr. Geiger sought to replicate the South African model of community health centers (CHCs) in rural and urban African American communities. In collaboration with an African American physician, Dr. John Hatch, Dr. Geiger helped established a CHC in Mound Bayou, Mississippi. Meanwhile, another CHC was established in a public housing complex in Columbia Point, Boston, Massachusetts. In addition to providing medical care, these CHCs created programs that addressed the social, economic, and environmental conditions that caused ill health, trained and empowered community health workers, and most importantly, shared governance and operating ownership with community resident boards. Every African American household in poverty in northern Bolivar County, where Mound Bayou stood, had at least one adult member actively participating in decision-making, program planning, and program operation through a local health association (Geiger, 2016, p. 1739). So, one of the initial goals of the CHCs was to empower patients and community health workers to reverse the inequalities in their communities through structural intervention and political advocacy.

These two clinics were the birth of the community health centers in the United States. The initial institutionalization of the community health centers commenced with government funding from the Office of Economic Opportunity, directed by Sargent Shriver (1915–2011). Since these two CHCs were successful in improving population health outcomes, eight more opened around the country in a demonstration project to evaluate the provision of comprehensive health services to the nation's poorest populations. Today, there are more than 1600 community health centers in the United States serving more than 27 million patients (NACHC, 2018). The primary funding source for community health centers is Medicaid, the public health insurance program for very poor individuals and disabled persons in the United States (NACHC, 2018).

Present Chapter

Although CHCs in the United States have a foundational history in grassroots advocacy and community autonomy, today they face multiple barriers in promoting the community's values and addressing the community's material, political, and health needs. The goals of this chapter are to identify the institutional barriers that CHCs in the United States face to promote health in their communities and to propose solutions to overcome these institutional barriers in order to return to CHC's purpose of empowering local community members to eliminate health inequalities. This topic is significant because since the inception of the Mound Bayou and Columbia Point clinics, the policy and regulatory landscape of the publicly financed medical delivery system in the United States has become more neoliberal after the implementation of the Patient Protection and Affordable Care Act (ACA) of 2010, all while participatory discourses have become institutionalized in health policy discourse. Representation of marginalized groups has become the equivalent of transformative participation.

I argue that one of the fundamental ways that US community-based health institutions can overcome these barriers and foment the grassroots advocacy that shaped the community health center movement of the 1960s and 1970s is if the United States implemented a single-payer universal healthcare system. Given the current administration, a single-payer system may not be feasible in the near future, but there are less strident policies that can be implemented at the federal, state, and local levels to increase the political and financial autonomy of CHCs and their patients. The neoliberal marketization of publicly financed care in the United States has stymied the autonomy that CHCs have to eliminate health inequalities by having CHCs focus on financial deliverables instead of improving the social determinants of health that produce their "sicker" populations.

I will begin by providing some clarifying definitions about the types of community-based health institutions that I address in this chapter and the conceptual frameworks that I will use to guide this analysis. Then, I will identify the institutional barriers that CBHIs face to circumvent constant fiscal threat, deliver patient-centered care, and empower marginalized populations. In response to each barrier, I will propose solutions which include legislative and regulatory recommendations, organizational changes, grassroots involvement, and finally, implementing a single-payer system.

Clarifying Definitions

Institutions consist of a system of behavioral and relational patterns that are densely interwoven and enduring to function across an entire society. Institutions order and structure individuals and organizations' behavior through norms (Scott, Ruef, Mendel, & Caronna, 2000). In this chapter, community-based health institutions (CBHIs) refer to healthcare delivery organizations that deliver clinical care and health goods and services to marginalized populations. The provision of care and delivery of goods and services are not limited to consultation with healthcare providers (e.g., dentists, nurse practitioners, and physicians) or allied health professionals (e.g., chiropractors, dental hygienists, physician's assistants) but also include the receipt of prescription drugs, personalized medical technologies, health information, health promotion activities, and material necessities. CBHIs are a field that consist of privately funded CHCs, publicly funded CHCs, community-based organizations, home health agencies, tribal organizations, and hospitals. The two main archetypes of CBHIs that I will discuss in this chapter are federally qualified health centers (the current iteration of Dr. Geiger's CHCs) and specialty CHCs like Planned Parenthood Clinics because they serve the most patients and are some of the most regulated CBHIs by federal and state government agencies. Although hospitals are part of the CBHI field, the majority of community-based hospitals have been consolidated to larger hospital systems through mergers since the early 2000s (Anderson, Hussey, & Petrosyan, 2019).

Most CHCs in the United States have the designation of being federally qualified health centers (FQHCs), which receive funding from Section 330 of the Health Care Consolidation Act of 1996 (Peters & Wooley, 1996). FQHCs maintain their designation by providing comprehensive medical care (including oral health, mental health, and substance use services) to medically underserved areas and/or medically underserved populations, without refusing care to patients who do not have medical insurance and/or the ability to pay for services up front. FQHCs must also have 51% or more representation from the patient population to serve on their governing advisory boards (NACHC, 2018).

However, there are other CHCs that do not have the FQHC designation to provide specialized healthcare that is often politicized, such as family planning. For example, Planned Parenthood Federation of America (Planned Parenthood) has several programs, but one of the most important is the Planned Parenthood Clinics, which provide preventive sexual and reproductive healthcare to youth, family planning, and gynecological care to one in five patients with Medicaid in the United States. Similar to FQHCs, Planned Parenthood Clinics often serve medically underserved areas or populations and do not refuse care to patients without health insurance or the ability to pay (Guttmacher Institute, 2017).

In the last 10 years, Planned Parenthood has been threatened by conservative Republicans in state and federal legislatures to be defunded of Title X Family Planning Funds and Medicaid reimbursement on the grounds that the organization uses federal dollars to subsidize abortion. Although Planned Parenthood is the largest provider of abortions in the United States, only 2% of Planned Parenthood's care consists of abortions, and under Section 1008 of the Title X statute, Title X grantees are prohibited from recommending abortion as a method of family planning. Moreover, the Hyde Amendment of 1977 prohibits the use of Medicaid funding for abortion care, unless it is a case of life endangerment, rape, or incest (Planned Parenthood Federation of America, 2019). More recently, the Trump Administration will deny Title X funding to any clinic that provides or even provides patients information about abortion. This will go into effect on April 1, 2019, and will certainly disqualify Planned Parenthood Clinics from receiving Title X funds (Salganicoff & Rice, 2019). If Planned Parenthood Clinics were to close as a result of this exclusionary regulation, millions of low-income women who do not qualify or live in a state with expanded Medicaid would lose their only source of medical care, and FQHCs do not have the capacity to absorb these millions of patients (Guttmacher Institute, 2017). Ultimately, this institutional barrier reduces healthcare providers' ability to provide necessary medical care and denies women of their corporal liberties.

In addition to these two examples of CBHIs, FQHCs and Planned Parenthood clinics, there are more archetypes of CBHIs that do not have professional healthcare providers treating patients with biomedical approaches but rather provide health interventions that are directly developed and administered by community members. For example, Reyna Montoya's organization, *Aliento*, is an undocumented and youth-led organization committed to organize people who are directly affected by immigration enforcement policies by providing art therapy to Dreamers (undocumented youth brought to the United States as children) and children in mixed-status families, whose parents face or have experienced immigration detention and deportation. There is no clinical curriculum that is being administered, but *Aliento* provides an intervention that was developed by undocumented youth and solely supported from philanthropic grants and personal donations.

LGBTQ persons face discrimination in medical encounters and often avoid seeking care as a result. When they do receive care, studies indicate that LGBTQ persons are not treated with respect, nor do they receive quality care. Moreover, transgender and gender diverse persons face the most discrimination in the LGBTQ community, not only in healthcare but also in securing their basic needs such as completing their secondary education, obtaining state-issued identification, securing employment, and trusting local law enforcement to protect their safety (Human Rights Campaign, 2019; Stroumsa, 2014). Part of the problem lies in the fact that there is no comprehensive, federal nondiscrimination law that includes gender identity (Human Rights Campaign, 2019). Thus, CBHIs like the TransActive Gender Center in Portland, Oregon, are created to address the needs of transgender persons. The TransActive Gender Center is a nonprofit organization founded by transgender individuals in 2007 to provide healthcare and support to transgender and gender diverse children and their families (TransActive Gender Center, 2019).

A Note on Positionality

I come to this space to write about the institutional barriers that CBHIs face and their solutions as a Latina medical sociologist and public health scholar with some disillusionment in community-engaged research and advocacy approaches. I was in the final cohort of the W.K. Kellogg Health Scholars Community-Track program (2010–2012) which, among its many goals, sought to train the future generation of health disparities researchers who conduct community-based participatory research (CBPR). Briefly, CBPR is a research approach that is based on producing an equitable research collaboration that includes representatives from community organizations, with their broad experiences working in and on behalf of communities, and community members affected by the particular health issue in all aspects of the research process—from research question development, study design, and implementation to interpretation and dissemination of results.

Although I continue to appreciate the experience I gained from this program, I felt that the institutionalization of the CBPR's approach to nine principles (see Israel et al., 2005, citing W.K. Kellogg Foundation), the lack of autonomy that community members have to independently obtain or administer federal research funding, and the bureaucratic administration of academic research, often prolonged the development of interventions or policy recommendations that could reverse health inequalities. I am devoted to acknowledging the diversity within marginalized communities in order to address structural sources of health inequity, but I am cautious when dominant institutions in the civil society, such as government agencies or research universities, claim that they "engaged the community" to create a specific recommendation, product, or solution.

For Antonio Gramsci (1929/2015), one of the ways that hegemonic processes can thrive in modern capitalist societies is if the society provides the possibility of resistance through civic participation. Through ideologies and ideological practices that allow the masses to cooperate and "civilly" challenge institutional arrangements, we are led to believe that we can influence politics and make a systemic difference. Yes, small gains are made every day in the United States to reduce health disparities through CBPR, despite our vast limitations from corporate influence on health policy and healthcare delivery. Yet, it is not large enough to prevent the social and health inequities from recurring, nor does it grant authority and legitimacy to community members' grievances, recommendations, and innovative ideas for local health improvements. This is not only based on my anecdotal experience of conducting participatory research and volunteering at CBHIs, but also by how the community's health and material needs have been ignored. This is witnessed in areas with decades-long concentrated poverty, whether they be places like Appalachia, Southwestern *colonias*, or the West Baltimore.

That being said, I take the sociological conflict perspective to examine the institutional barriers that US CBHIs face because CBHIs are not meant to benefit every member of the US society. Hegemonic processes stabilize current power arrangements where only certain populations obtain the care that they need with few material or cultural barriers. The system and policies that maintain and fund CBHIs in the United States are not designed to transform the unequal social and economic arrangements, which could promote social justice and human rights for all of the country's members. Paradoxically, the proliferation of CBHIs in the last 50 years represents an overarching system that does not value all humans as deserving because it is absent of universal access to care.

Institutional Barriers that Community-Based Health Centers Face

Community health centers' ability to address the community's needs and empower local members to advocate for improving the health and living conditions of their local geographies are impeded because most community health centers are bound to regulations and deliverables that are imposed upon them by their main funding source and regulator, the Centers for Medicare and Medicaid Services (CMS). In addition, diverse state and local policies and politics exclude large segments of the population, such as unauthorized immigrants and their children, from receiving culturally-specific care (see Rodríguez et al., 2015 and Suro et al., 2015).

We cannot discuss institutional barriers that CHCs face without discussing the Patient Protection and Affordable Care Act (ACA) of 2010. The ACA was President Barack Obama's signature healthcare legislation, which, among its many policies, increased access to medical insurance for millions of uninsured and underinsured Americans. Moreover, it lifted several barriers imposed by insurance companies such as denying insurance coverage to persons with pre-existing conditions, having a lifetime cap, allowing young adults up to the age of 26 to remain on their parents' health insurance, and discriminating prices for preventive, gender-specific healthcare goods and services (Kominski, 2013). Insurance companies were also required to provide a suite of essential benefits such as comprehensive preventive care, well-woman visits, chronic disease management, emergency care, and prescription coverage (Kominski, 2013). In order to subsidize the money needed to cover sicker patients, who utilize more health services, individuals are mandated to have either public or private health insurance or pay a penalty when they file taxes with the Internal Revenue Service. To reduce total federal spending, much of the costs were passed onto individuals by increasing their premiums, deductibles, or co-pays (White, 2018). Besides these individual changes, the ACA includes several policies that are meant to increase patient engagement, increase research activity on the social determinants of health and health disparities, and create cost-savings in Medicaid and Medicare expenditures.

The challenges that FQHCs face as a result of the ACA are the budget cuts to their discretionary funding for programming, the increased patient demands given increased access to care with the expansion of Medicaid and health insurance enrollment in one of the exchanges, and more importantly, the new payment structure from a fee-for-service reimbursement to payment for value (Wright & Martin, 2014). Value-based care is the new payment structure being employed by the CMS to reduce costs and improve quality of care by bundling payments for "episodes of care" offered in medical homes and accountable care organizations (ACOs; Alberti et al., 2013), instead of paying for each service provided by a healthcare provider. ACOs consist of consolidation of independent clinics, FQHCs, hospital clinics, and specialty care facilities that are part of the same geographic area, serve the same patient population, and share savings via value-based reimbursements from the Medicare Shared Savings Program (MSSP) (Barnes, Unruh, Chukmaitov, & van Ginneken, 2014). The ACA authorized and established a "Medicare Shared Savings Program for ACOs, to take effect no later than January 2012… the law makes contracts with ACOs a permanent option under Medicare" (Merlis, Berenson, & Fisher, 2010, p. 2). The ACA also establishes a new Center for Medicare and Medicaid Innovation within CMS to test a variety of new payment and delivery models for both Medicare and Medicaid (Merlis et al., 2010).

The Integration of FQHCs into Accountable Care Organizations (ACO)

The concept of the ACO emerged from a group of health policy scholars led by John Wennberg and colleagues (The Engelberg Center for Health Care Reform & the Dartmouth Institute, 2013) at the Dartmouth Institute for Health Policy and Clinical Practice. They wrote a report indicating that healthcare costs in the United States were high because 30% of the services received by patients were due to "unnecessary care" (White, 2018). The Dartmouth team also wrote that these costs could be reduced with patient behavioral changes, reducing medical error and improving communication between providers using electronic health records. They pushed for paying for performance, not volume of care given. Overall, the cost-savings assumption behind ACOs is that if there is coordinated care and there are fewer duplicative services given to patients reducing "unnecessary costs" and, supposedly, fewer medical errors. The CMS gives a financial incentive to ACOs that save money, which is then shared among the organizations in the ACO. However, there was little procedural information on how to allocate this incentive among the organizations, and these are being developed as more CBHIs join ACOs. White (2018) observes that there were few ACOs in existence during the time when the ACA was drafted; thus, there was little evidence that ACOs could reduce costs and improve the quality of patient care. ACOs are primarily a theoretical idea, from a group of elite academics who are geographically and socioeconomically sheltered from the realities of CBHIs (White, 2018). The very workers in FQHCs are not the main catalysts for organizational or financial innovations in the delivery of care.

One of the other challenges for FQHCs has to do with the metrics used to evaluate quality care in ACOs. These metrics are an interpretation of Section 1899 of Title XVIII of the Social Security Act, which have generally included clinical processes and outcomes, patient and caregiver experiences, and utilization. Quality metrics vary by the number of Medicaid and Medicare enrollees in a state and the most pressing disparities of an ACO's patient population. Yet, most of the measures have focused on clinical processes and outcomes and utilization such as nosocomial infections, 30-day hospital readmissions, hospitalizations for chronic diseases manageable with medication adherence and behavior modification (e.g., congestive heart failure, COPD/Asthma, diabetes), preventive screenings like mammograms, and preventative services for diabetes (hemoglobin A1c, lipids panel, and retinal exams) (McWilliams, Hatfield, Chernew, Landon, & Schwartz, 2016). These quality metrics are problematic for several reasons. First, because older patients and low-income patients tend to have multiple chronic conditions, they are more difficult to medically control, and they may require hospital readmission. On the other hand, ACOs that serve affluent patient populations will skew quality results. Second, these metrics are almost exclusively clinical and based on providers' report of their own performance (Woolhandler & Himmelstein, 2017b). If they do request patients or caregivers' level of satisfaction, these measures still do not reflect the patients' interpretation of quality, including respectful encounters with staff and healthcare providers.

Third, these quality metrics may not be achievable when patients' socioeconomic conditions and their physical environments have not changed. There are social, economic, or environmental conditions that are keeping patients from managing their chronic conditions such as the lack of safe and walkable streets, healthy food access, and money for adequate housing, transportation, and out-of-pocket health expenses. The Centers for Disease Control and Prevention attribute over 75% of health disparities to the social and environmental conditions that people have encountered throughout their life course, not solely their biological or genetic precursors (National Center for HIV/AIDS, Viral Hepatitis, STD, & TB Prevention, 2014, citing Tarlov, 1999). Patients using FQHCs are usually in poor and under-resourced areas with a lack of services, dilapidated housing, with communities that have been historically deprived of economic opportunities and political participation. FQHCs could be penalized for not meeting quality benchmarks, but they serve the most vulnerable populations (Alberti et al., 2013). In turn, their ACO may not achieve savings, and at a later day, may have to assume risk, and pay back losses from not delivering "quality" of care. The new electronic health records shared between CBHIs in ACOs are supposed to capture social determinants of health such as housing, neighborhood safety, and food security, with hopes that community health workers (CHWs) including *promotores de salud* and patient navigators will put patients into contact with programs that fill their material and social needs. FQHCs (before and after the ACA) heavily rely on community health workers to connect their patients to these resources.

The ACA also sought to increase patient engagement in research, the service delivery agenda of CBHIs, and in the governance of FQHCs. For instance, the ACA requires hospitals receiving Medicaid and Medicare funding to conduct community health needs assessments of their residents in their service areas every 3 years. These community health needs assessments are not only supposed to identify needs in the community but also inform interventions based on patient participants' recommendations (Alberti, 2014). In the specific community where I live, Springfield, Massachusetts, residents of this city have claimed that they are "community-assessed to death" but are disappointed that the environmental and economic conditions of their city have yet to change for the African American and Latinx communities, whom are the racial/ethnic majority.

The implementation of ACOs is one strategy that the ACA attempts to reduce healthcare expenditures, but these controls are relegated to publicly financed community-based health institutions and the Centers of Medicare and Medicaid Services. The ACA did not contain any cost-saving measures used in other countries toward the private sector, such as provider rate-setting or the government negotiating lower prices on pharmaceuticals or the provision of high-cost technological diagnostics, such as magnetic resonance imaging, which are the primary drivers of healthcare spending in the United States (Anderson et al., 2019). Also, as Woolhandler and Himmelstein (2017a) write, the incentives created to control costs are "weak" because doctors and hospitals can still expand profit opportunities. The proliferation of ACOs has been one of the largest financial and organizational changes affecting FQHCs and other community health centers receiving Medicare and Medicaid funding.

In 2009 there were only a few ACOs being developed in the private sector (JSI & NACHC, 2013), and by the end of 2016, there were 458 ACO initiatives (Kaiser Family Foundation, 2017). Preliminary evidence suggests that incorporating quality measures were burdensome for staff, and compliance with the top-down metrics redistributed resources away from more meaningful structural changes (Blustein et al., 2011). In their early implementation, traditional ACOs (MSSP Track 1) have cost Medicare $72 million more than traditional pay-for-service payments, but the ACO systems overall have reduced Medicare spending by only $47 million (Kaiser Family Foundation, 2017).

FQHC Community Advisory Boards

The earliest iteration of FQHCs, community health centers, addressed local health issues and needs through active community participation in community advisory boards. To this day, FQHCs, under Section 330, are mandated to have governing boards that consist of 51% or more of their patients who are representing the patient population. Patient members of the governing boards should receive their primary care from the FQHC and represent the patient population in terms of race, ethnicity, and gender (Wright, 2013, citing HRSA 1998). However, studies by Wright (Wright, 2013; Wright & Martin, 2014) indicate that over 60% of patients on FQHCs community advisory boards are patients from high-status occupations, whose socioeconomic status does not reflect that of the majority of FQHC patients. He also demonstrates that representative patient trustees are less likely than higher SES members to hold a position on the executive member or serve as board chair, which limits the authority that community members have in shaping the delivery of care and programming at FQHCs (Wright, 2015). Similarly, Sharma and colleagues (2018) found in their study that most members in these community advisory boards do not engage in financial or hiring decision-making but do influence the quality improvement of materials and day-to-day operations at the clinic. Decision-making regarding the organization's operations and strategic development is often delegated to the FQHC's senior management like the CEO and CFOs. This current level of participation from the community advisory boards is far from the structural interventions that were led, developed, and executed by the patients of the Mound Bayou and Columbia Point Clinics in the 1960s. Moreover, they are not addressing social determinants of health, the way those programs did with the creation of community gardens and economic development programs.

Another issue with community advisory boards in FQHCs rests on the government-issued categories of marginalized populations. Steven Epstein (2008) wrote about the paradoxical consequences of the US federal government's attempts to institutionalize the inclusion of women, children, communities of color, and other vulnerable populations in biomedical research and randomized clinical trials. Instead of ameliorating the health inequalities produced on diverse, overlooked, or silenced populations in the United States, this *niche standardization* has circumscribed the meaning of representation and has perpetuated biological difference in biomedical and public health discourses to represent women and racial/ethnic minorities in particular. For example, by circumscribing diverse "representation" to the Office of Management and Budget Statistical Directive No. 15's one ethnic group (Hispanic/Latino) and four racial groups (Asian/Pacific Islander, Black non-Hispanic, Native American/Alaskan Native, and White, non-Hispanic), FQHCs do not receive input from people who are outside of these racial and ethnic designations and fail to create programs along other lines of difference that may be more important for delivering equitable care that represents a specific communities' needs.

The configuration of community advisory boards rests on gender, racial, and ethnic categories that are not historicized and depoliticized. When a specific marginalized group does not have a niche that is standardized by Statistical Directive No. 15, our major health agencies—the Centers for Medicare and Medicaid Services, the Centers for Disease Control and Prevention, the Health Resources and Services Administration, and the National Institutes of Health—there will be little to no federal dollars earmarked for other marginalized groups who share an identity, such as minority religious groups like Muslims. More importantly, having a member on the CAB that is one of the "designated" minorities does not guarantee representation of the patient population receiving care at the FQHC. Complying with narrow federal rules and regulations hinders the ability for community advisory boards and community liaisons in CBHIs to identify and represent the needs of heterogeneous, medically underserved populations. For example, in the Latinx community, there are intragroup heterogeneities, stratification, and discrimination along multiple dimensions (racial/ethnic, nationality, immigration, gender, and sexuality) that are silenced like that of non-Spanish-speaking indigenous Latin Americans or members of mixed-immigration status families.

The community advisory boards that emanated from Dr. Geiger's community health center demonstration project have evolved from a serious driver of programming and community asset-building to a symbolic collective that fulfills an administrative checklist. Moreover, I wondered how much influence community advisory boards had in deciding whether or not their FQHC would join an ACO. The goals behind the ACO to reduce duplicative care and increase care coordination and resource sharing are important for efficiency (Alberti et al., 2013). However, health policy analysts are still figuring out if many savings are being produced and if the quality of care is being improved (see Levinson, 2017; Schulman & Richman, 2016; Song & Fisher, 2016) and how to equitably distribute Medicare and Medicaid savings across organizations. Moreover, the measures used to assess quality lack the patient's humanity. We still need to better understand what encourages patients to return to a healthcare facility or adhere to a care plan. Also, these quality metrics may jeopardize FQHCs in an ACO agreement if they do not take into consideration the economic, environmental, and social conditions which patients are living in that exacerbate their conditions. The requirements for representation and promoting "patient-centered" input from hospital community health needs assessments or FQHC community advisory boards need to go beyond categories of difference related to race/ethnicity or gender in order to capture the material and political needs of diverse FQHC patient populations.

Recommendations to Overcome These Institutional Barriers

The solutions that will be presented in this section try to promote patient and community participation in the governance and operations of CBHIs and health equity. Health equity refers to a condition in which the nation-state provides every single person in the society the material resources and opportunities to achieve health (Braveman et al., 2011). Health inequality is a health disparity that is avoidable, unnecessary, and unjust (Whitehead, 1991). Promoting health equity requires actions from the bottom (community health workers, community residents, small business owners, local workers collectives, and youth-led groups), the middle (CBHIs and other organizations), and the top (federal and state agency policies and regulations).

The implementation of the ACO is an intervention at the clinical and organizational levels and will not address the problems emanating from the larger society and environment driving health inequalities. That is why having as much of the community involved in the process of shaping the healthcare services and programming that are delivered at FQHCs is so important. FQHCs need to be utilized as conveners for diverse community members to design, plan, and implement structural interventions that improve local social and environmental conditions. Community health centers are spaces to collaborate and incorporate multiple diverse perspectives from the side of service providers, researchers, and patients or community members. More effort is needed to improve the social and environmental conditions patients face.

Janet K. Shim (2005) demonstrates why people who are affected by a specific social or health inequality need to be a part of the decision-making processes. Shim's research investigates the lay-scientific divide in the social determinants of cardiovascular disease, in which biomedical and epidemiological researchers include race, gender, and age in their studies to capture diverse health disparities. The researchers she studies could not articulate the mechanisms by which these three structural positions can shape one's risk for cardiovascular disease and mortality. In contrast, people of color suffering from various cardiovascular diseases identify their low-paying jobs, occupational status, skin color, accents, neighborhoods, and historical trauma as drivers of their disease. Moreover, they interpret them as consequences of institutionalized racism.

The "lay" audience had a more complex understanding of the mechanisms, whereas the health researchers conflated race with culture or biological determinants. Similar to Marx, the oppressed have a more comprehensive perspective of society and social relations of production than do the privileged healthcare administrators who are limited by regulations from the Agency for Healthcare Research and Quality and their primary funder, CMS. It is also safe to say that most clinical administrators and healthcare providers are not from nor do they live in the same geographic areas as their patients. For this reason, it remains paramount for community members to have active collaborations and governance in the workings of FQHCs.

Social and health needs differ by locality because each place is shaped by a history of economic, demographic, and environmental changes. To ameliorate social determinants of health that are the cause or are strongly associated with health inequalities requires that we restructure and democratize community advisory boards (CABs), refine community health needs assessments, and provide additional financial resources for FQHCs and other CBHIs to implement structural interventions or engage in multilevel political advocacy. The restructuring of the CABs starts by changing the language at HRSA regarding the categories of patients that need to be represented in CBHI's advisory boards. Representation of women and racial and ethnic minorities needs to be interpreted by health center executives as a bare minimum. HRSA should not only include more diverse categories of marginalized and minority populations (disabled, immigrants, rural residents, sexual and gender minorities, etc.) but also provide flexible language that allows the composition of community advisory boards to represent other patient subpopulations identified from the triannual community health needs assessment and by the CAB members. Beyond representation, community advisory boards need to be democratized by being given more authority to vote and influence organizational re-structuring, hiring decisions, the use of financial resources, and the overall vision and mission of the community health center. This also means that the CAB shares ownership of data, resources, and products from programming and grant writing opportunities.

To ameliorate social determinants of health that are strongly associated with local health inequalities requires FQHCs to refine community health needs assessments (CHNAs). The ACA created three federal agencies to increase the research activity on the social determinants of health and health disparities: the Patient-Centered Outcomes Research Institute (PCORI), the Centers for Medicare and Medicaid Innovation (CMMI), and the Prevention Trust. However, these centers are meant to create evidence and recommendations that work within our existing healthcare delivery system, which favors the profits gained by managed care organizations, health insurance companies, hospitals, and pharmaceutical and biotechnology companies. They are not meant to transform the entire system to the benefit of the people.

In addition to identifying the needs and barriers that community members and patients face to access medical care, these needs assessments need to identify the community's strengths, assets, and *recommendations* for improving health promotion and their local communities. Although I am cautious about identifying a community's sources of resilience because it can minimize the community's suffering or the state's responsibility to intervene in social and political conditions, I also believe that viewing marginalized populations as solely deficient is not empowering or transformative. Knowing a community's strengths and assets facilitates the construction of interventions that leverage and promote the preservation of these assets.

Moreover, the CHNA can be used to identify and plan structural interventions that can be undertaken by community task forces in partnership with CHCs and other agencies or local businesses.

To implement structural interventions that engage in multilevel political advocacy requires that FQHCs have access to additional financial resources outside of the healthcare services and goods that they sell to patients. These financial resources can be leveraged by reviving discretionary funds given to FQHCs and CHCs prior to the implementation of the ACA or fund multisector collaborations to address a specific issue that is associated with a health inequality. For instance, the Medicaid Innovation Accelerator Program has a Medicaid Housing Agency Partnerships demonstration project in some states to ensure that patients who are unstably housed or living in poor housing conditions are placed in affordable housing (Medicaid Innovation Accelerator Program, 2017). In another example, "Live Well Springfield" is a coalition working to modify the built environment, which requires changes in zoning, land use, and resource management policies (see https://www.publichealthwm.org/what-we-do/coalition-building/live-well-springfield).

Sadly, improving the quality of care given to patients utilizing publicly funded CBHIs gained importance in the ACA as a strategy to reduce government spending and not toward actually improving quality of life for patients. Community-based health institutions, and FQHCs specifically, should continue to capture the quality of care in their patient populations to identify areas for improvement in the delivery of healthcare services in marginalized populations. Quality metrics need to go beyond clinical outcomes and reflect patients' perspectives. Their interpretation of "quality" is so important if we are to create trust between healthcare providers and patients, especially from groups that have a history of biomedical research abuse, like African Americans and the USPHS-sponsored Tuskegee Syphilis Study (Washington, 2006) and the randomized control trial of the oral contraceptive pill in Puerto Rican women on the island (Briggs, 2002).

Moreover, quality metrics collected from CBHIs need to ascertain that patients are not facing discrimination from the facility's staff or healthcare providers on the grounds of age, criminal status, gender, income, occupational status, race, and sexuality. Besides grievances reported by patients, there is little way of knowing on what grounds a provider or staff person provides unfair treatment to a patient. With feedback from diverse CABs, health services researchers examining FQHC data FQHCs need to create novel and community-specific quality indicators or construct categories of vulnerable populations not captured by government guidelines. For example, a healthcare provider denying gynecological care to a preoperative trans female-to-male because they are uncomfortable providing care to someone who presents physically as male. Another data source for CHNAs are the patient records. With feedback from diverse CABs, health services researchers examining FQHC data need to create novel and community-specific quality indicators or construct categories of vulnerable populations not captured by government guidelines.

If policy makers and economists are truly concerned about reducing federal spending and promoting health equity, there are only a few solutions in our current healthcare delivery system that could place some accountability on providers, especially medical doctors, and the private sector. First, the CMS could set prices with pharmaceutical companies, doctor's fees, and expensive medical diagnostics. Second, if the United States insists on maintaining the Medicare Shared Savings Program and Medicaid ACOs, they need to modify their quality metrics and take into consideration the social, economic, and environmental conditions of the patients utilizing FQHCs to avoid penalizing these safety-net organizations. CMS should also incentivize how ACOs develop participatory solutions with multiple sectors and diverse representation. Diverse representation on these interventions could be assessed by the number of community members serving as researchers and research assistants and on the level of shared decision-making, interpretation, and governance of those interventions. Another solution for CMS to reduce spending is for private or for-profit CBHIs to cover the risk of entering an ACO, by paying back for any losses they acquired in the process. However, these are merely marginal solutions that will not address larger ideological and structural issues in the United States and its dwindling welfare state. Surely, these propositions will be met with immense resistance from hospital systems, large pharmaceutical corporations, medical insurance lobbyists, and individual taxpayers.

In order to prevent large corporations from influencing the politics of health and eliminate the many institutional barriers that CBHIs face, the United States needs to implement a single-payer healthcare delivery system. The United States is one of the few OECD countries that does not have a single-payer system and the only country in the Americas that does not ensure health as a human right. In order to implement a single-payer system, we need to institutionalize health as a human right in our constitution and, again, in the vision of the Department of Health and Human Services (DHHS). This double commitment is so that in the event that health as a human right is overturned at the legislative or executive branches, at least health as a human right will permeate throughout all DHHS agencies. This will facilitate multisectoral collaborations between DHHS agencies to create programs that address the social determinants of health that are being promoted by the Centers for Medicare and Medicaid Innovation.

The public will face many hurdles to change a medical delivery system that is the fifth largest segment of the US gross domestic product. The fact that the single-payer option was never on the table during Barack Obama's healthcare reform negotiations (Navarro, 2010) makes it difficult to believe that there is now a possibility to reform healthcare. As I write this chapter, there is yet another attempt by President Trump to eliminate the ACA. This is not only a public health crisis with insurmountable repercussions, but it is not a reflection of what the majority in this country wants. A Reuters-Ipsos survey in 2018 indicated that 70% Americans support Medicare-for-All (Keller, 2019).

Given that people's healthcare has been constantly under threat by legislative, judicial, and executive actions since the inception of the ACA, having a single-payer Medicare-for-All entitlement program would curtail private or political action to eradicate any health protections. If voters were central to shaping the healthcare delivery system in the United States, there would be a smaller likelihood that these executive actions would be entertained. These political actions violate several government agencies' commitment to health equity. Below, I describe the ways in which a single-payer system, like Medicare-for-All, would lower many institutional barriers that CBHIs face such as financial detriment and threats to patient participatory engagement.

There are two Medicare-for-All bills that I will discuss in this final analysis: Senator Bernard Sanders (I-VT) Medicare-for-All Senate Bill (S. 1804) proposed in 2017 and, more recently, Representative Pramila Jayapal's (D-WA) Medicare-for-All House Bill (H.R. 1384). I will discuss both of them because researchers at the University of Massachusetts-Amherst Political Economy Research Institute (Pollin, Heintz, Arno, Wicks-Lim, & Ash, 2018) have conducted a very thorough economic analysis of Senator Sanders' bill, while Representative Jayapal's builds on Senator Sanders' bill by adding more patient protections.

One of the institutional barriers that was discussed in this chapter was that providers are often limited in providing certain medical goods and services that are considered controversial to conservative politicians and agency heads, with the consequence of losing their federal funding, such as Planned Parenthood Clinics losing Title X funds. There have been many court challenges to Section 1557 of the ACA, which prohibits individuals from being excluded from, denied benefits, or subject to discrimination by health providers, programs, and activities. H.R. 1384 tries to circumvent legal challenges to whom is protected under this law by "… explicitly defining sex discrimination to include sex stereotyping and discrimination based on gender identity, sexual orientation, and pregnancy and related medical conditions, including termination of pregnancy" (Keith, 2019). H.R. 1384 also ensures that providers are allowed to override national practice standards if the service is a medical necessity, appropriate, and consistent with the individual's wishes.

A more pressing institutional barrier that CBHIs face is that they have historically struggled to remain financially viable. Medicare-for-All would eliminate the complexity of value-based payment structures. Cost-savings will not be confined to the most vulnerable of healthcare organizations, like FQHCs, but will be universal across healthcare organizations. By having one payer (Medicare), the government will have the power to negotiate prices with service providers, pharmaceutical companies, and healthcare service organizations and promote universal cost-sharing (Pollin et al., 2018). The fear of unnecessary care and fraud that shaped the ACO would be greatly reduced as electronic health records will be part of a universal system across states.

The healthcare system will produce savings by eliminating much of the administrative costs associated with insurance claims (by 9%), prescription pricing (by 5.9%), and uniform Medicare rates of hospitals, clinics, and healthcare providers (by 2.8%) (Pollin et al., 2018, p. 1). Lastly, there are also broader economic implications such as the increase in job productivity (regaining lost days from illness), a reduction in income inequality due to families spending 2.6–14% less of their income on healthcare expenditures, and job creation by lowering the costs small- and medium-size businesses spend on employee health insurance (Pollin et al., 2018, p. 3).

Another institutional barrier that CBHIs face is how to democratize patient engagement in center governance and programming. Both S. 1804 and H.R. 1384 would maintain community advisory boards for community health centers, but H.R. 1384 would also create regional governance boards. However, as discussed above, we have to ensure that those board members reflect the diversity of the patient population in a specific geographic area. Medicare-for-All facilitates the creation of democratic processes in shaping the clinical practices that shape the ways that healthcare should be delivered.

Conclusion

A single-payer system like Medicare-for-All will not resolve all of the health inequalities experienced by marginalized populations in the United States, because this program alone will not automatically change social, economic, environmental, and political conditions that are responsible for health inequalities. However, Medicare-for-All would free up resources to focus on primary prevention and structural interventions. Additionally, it would eliminate politicians and healthcare lobbyists' main argument against improving quality and access to healthcare in community-based health institutions—the rising costs of healthcare. Surely, costs are rising partly because of the aging population, but more importantly, the US healthcare expenditures are far higher than any other country because we do not have policies that adequately contain costs or set the price of goods and services provided by healthcare providers and healthcare organizations (Anderson et al., 2019; Pollin et al., 2018). Piecemeal healthcare reforms are strangling patients and community engagement, giving private enterprise too much power. The very regulations (not to price-set) and political practices (legislators receiving campaign finances from health lobbies) violate the possibility for the United States to achieve health equity.

Health equity and profit cannot be in the same equation with equitable healthcare reform as the outcome. The jury is still out on ACOs ability to save CMS money and provide quality care to vulnerable populations. However, healthcare financing policies like the implementation of ACOs for the receipt of Medicare and Medicaid funds are based on neoliberal ideologies that give health insurance companies, biotechnology companies, and pharmaceuticals too much power and influence in shaping health policy, but little in institutional regulations that could shape their behavior in the healthcare delivery system. Meanwhile, we need to end symbolic participation of community members in patient advisory boards in order to increase the representation of other marginalized patient populations and gain authority over deciding the services that community-based health institutions provide. Nevertheless, we are in a critical moment in the United States with support from the public and the new politicians trying to strengthen the welfare state in an effort to reverse decades of exclusionary practices and institutional barriers that disenfranchise the public from influencing the politics and services provided in community-based health institutions.

References

Alberti, P. M. (2014). Community health needs assessments: Filling data gaps for population health research and management. *eGEMs, 2*(4), 1174.

Alberti, P. M., Bonham, A. C., & Kirch, D. G. (2013). Making equity a value in value-based health care. *Academic Medicine, 88*(11), 1619–1623.

Anderson, G. F., Hussey, P., & Petrosyan, V. (2019). It's still the prices, stupid: Why the US spends so much on health care, and a tribute to Uwe Reinhardt. *Health Affairs, 38*(1), 87–95.

Barnes, A. J., Unruh, L., Chukmaitov, A., & van Ginneken, E. (2014). Accountable care organizations in the USA: Types, developments and challenges. *Health Policy, 118*(1), 1–7.

Blustein, J., Weissman, J. S., Ryan, A. M., Doran, T., & Hasnain-Wynia, R. (2011). Analysis raises questions on whether pay-for-performance in Medicaid can efficiently reduce racial and ethnic disparities. *Health Affairs, 30*(6), 1165–1175.

Braveman, P. A., Kumanyika, S., Fielding, J., LaVeist, T., Borrell, L. N., Manderscheid, R., et al. (2011). Health disparities and health equity: The issue is justice. *American Journal of Public Health, 101*(S1), S149–S155.

Briggs, L. (2002). *Reproducing empire: Race, sex, science, and US imperialism in Puerto Rico* (Vol. 11). Berkeley, CA: University of California Press.

Epstein, S. (2008). *Inclusion: The politics of difference in medical research*. Chicago: University of Chicago Press.

Geiger, H. J. (2016). The first community health Center in Mississippi: Communities empowering themselves. *American Journal of Public Health, 106*(10), 1738–1740.

Human Rights Campaign. Understanding the transgender community. Retrieved on 15 March 2019 at https://www.hrc.org/resources/understanding-the-transgender-community

Israel, B., Eng, E., Schulz, A., & Parker, E. (Eds.). (2005). *Methods in community-based participatory research for health*. San Francisco, CA: Jossey-Bass.

Kaiser Famiy Foundation. (2017). Medicare delivery system reform: The evidence link. Retrieved from https://www.kff.org/medicare-delivery-system-reform-the-evidence-link/

Keith, K. Unpacking the House Medicare-for-All Bill. 3 March 2019. Health Affairs Blog: Following the ACA. Retrieved on 31 March 2019 at: https://www.healthaffairs.org/do/10.1377/hblog20190302.150578/full/

Keller, M. Seventy percent of Americans support 'Medicare for all' in new poll. 23 August 2019. *The Hill*. Retrieved on 30 March 2019 at: https://thehill.com/policy/healthcare/403248-poll-seventy-percent-of-americans-support-medicare-for-all

Kominski, G. F. (2013). *Changing the US health care system: Key issues in health services policy and management*. San Francisco: Wiley.

Levinson, D. (2017, August). Medicare Shared Savings Program Accountable Care Organizations have shown potential for reducing spending and improving quality. Department of Health and Human Services Office of the Inspector General. Retrieved 27 January 2019 at: https://oig.hhs.gov/oei/reports/oei-02-15-00450.asp

McWilliams, J. M., Hatfield, L. A., Chernew, M. E., Landon, B. E., & Schwartz, A. L. (2016). Early performance of accountable care organizations in Medicare. *New England Journal of Medicine, 374*(24), 2357–2366.

Medicaid Innovation Accelerator Programs. (2017, 18 May). Promoting Community integration through long-term services & supports in state medicaid-housing agency partnerships:

Program overview. Retrieved on 25 January 2019 at: https://www.medicaid.gov/state-resource-center/innovation-accelerator-program/iap-downloads/program-areas/partnerships-program-overview.pdf

Merlis, M., Berenson, R. A., & Fisher, E. S. (2010). Health policy brief: Accountable care organizations. *Health Affairs, 7*, 27.

National Association for Community Health Centers. (n.d.) Dr. H Jack Geiger and Dr. John Hatch on the earliest CHCs. Retrieved at: https://www.chcchronicles.org

National Association for Community Health Centers & John Snow, Inc. (2013). Health centers and payment reform: A primer. Emerging issues #7, October 2013. Retrieved at: http://www.nachc.org/wp-content/uploads/2015/11/Health-Centers-and-Payment-Reform.pdf

National Association for Community Health Centers. (2018). About our health centers. Retrieved from: www.nachc.org/about/about-our-health-centers/

Navarro, V. (2010). Consequences of the privatized funding of medical care and of the privatized electoral process. *American Journal of Public Health, 100*(3), 399–402.

Peters, G., & Woolley, J. T. (1996). "William J. Clinton. "Statement on Signing the Health Centers Consolidation Act of 1996," October 11, 1996". The American Presidency Project. University of California-Santa Barbara.

Pickett, K. E., & Wilkinson, R. G. (2015). Income inequality and health: A causal review. *Social Science & Medicine, 128*, 316–326.

Planned Parenthood Federation of America. "Hyde Amendment." Retrieved on 3 March 2019 at: https://www.plannedparenthoodaction.org/issues/abortion/hyde-amendment.

Pollin, R., Heintz, J., Arno, P., Wicks-Lim, J., & Ash, M. (2018). Economic analysis of Medicare for all. November. Political Economic Research Institute. University of Massachusetts-Amherst. Retrieved on 30 November 2018 at: https://www.peri.umass.edu/publication/item/1127-economic-analysis-of-medicare-for-all

Rodríguez, M. A., Young, M., & Wallace, S. P. (2015). *Creating conditions to support healthy people: State policies that affect the health of undocumented immigrants and their families*. Los Angeles, CA: University of California Global Health Institute.

Salganicoff, A. & Rice, C. (2019). Alina Salganicoff answers 3 questions on final title X regulations for family planning clinics. Kaiser Family Foundation, 27 Feb 2019. Retrieved at: https://www.kff.org/womens-health-policy/issue-brief/ask-kff-alina-salganicoff-answers-3-questions-on-final-title-x-regulations-for-family-planning-clinics/

Schulman, K. A., & Richman, B. D. (2016). Reassessing ACOs and health care reform. *JAMA, 316*(7), 707–708.

Scott, W. R., Ruef, M., Mendel, P. J., & Caronna, C. A. (2000). *Institutional change and healthcare organizations: From professional dominance to managed care*. University of Chicago Press. Chicago, IL.

Sharma, A. E., Huang, B., Knox, M., Willard-Grace, R., & Potter, M. B. (2018). PatientEngagement in community health center leadership: How does it happen? *Journal of Community Health, 43*(6), 1069–1074.

Shim, J. (2005). Constructing 'race' across the science-lay divide: Racial formation in the epidemiology and experience of cardiovascular disease. *Social Studies of Science, 35*(3), 405–436.

Song, Z., & Fisher, E. S. (2016). The ACO experiment in infancy—looking back and looking forward. *JAMA, 316*(7), 705–706.

Stroumsa, D. (2014). The state of transgender health care: Policy, law, and medical frameworks. *American Journal of Public Health, 104*(3), e31–e38.

Suro, R., Suárez-Orozco, M. M., & Canizales, S. (2015). Removing insecurity: How American children will benefit from President Obama's Executive Action on Immigration. USC Sol Price School of Public Policy, Tomas Rivera Policy Institute, April 2015, USC/UCLA. Retrieved on April 27, 2015 from: http://trpi.org/pdfs/research_report.pdf.

Tarlov, A. R. (1999). Public policy frameworks for improving population health. *Annals of the New York Academy of Sciences*, *896* (Special Issue: Socioeconomic Status and Health in Industrial Nations: Social, Psychological and Biological Pathways), 281–293.

The Engelberg Center for Health Care Reform & the Dartmouth Institute. (2013, June). Opening Plenary Session of the Fourth National Accountable Care Organization Summit, Washington, D.C.

The Guttmacher Institute. "Federally Qualified Health Centers Could Not Readily Replace Planned Parenthood." 17 May 2017. https://www.guttmacher.org/news-release/2017/federally-qualified-health-centers-could-not-readily-replace-planned-parenthood

The TransActive Gender Center. (n.d.). "About Us." Retrieved on 22 March 2019 at: https://www.transactivegendercenter.org/about-us

Washington, H. A. (2006). *Medical apartheid: The dark history of medical experimentation on black Americans from colonial times to the present*. New York: Doubleday.

White, J. (2018). Hypotheses and hope: Policy analysis and cost controls (or not) in the Affordable Care Act. *Journal of Health Politics, Policy and Law, 43*(3), 455–482.

Whitehead, M. (1991). The concepts and principles of equity and health. *Health Promotion International, 6*(3), 217–228.

Woolhandler, S., & Himmelstein, D. U. (2017a). The Affordable Care Act: How Nixon's health reform proposal became Democrats' Albatross. *International Journal of Health Services, 47*(4), 612–620.

Woolhandler, S., & Himmelstein, D. U. (2017b). Single-payer reform the only way to fulfill the President's pledge of more coverage, better benefits, and lower costs. *Annals of Internal Medicine, 166*(8), 587–588.

Wright, B. (2013). Who governs federally qualified health centers? *Journal of Health Politics, Policy and Law, 38*(1), 27–55.

Wright, B. (2015). Do patients have a voice? The social stratification of health center governing boards. *Health Expectations, 18*(3), 430–437.

Wright, B., & Martin, G. P. (2014). Mission, margin, and the role of consumer governance in decision-making at community health centers. *Journal of Health Care for the Poor and Underserved, 25*(2), 930.

Chapter 13
Conclusion: A Re-evaluation of Institutionalized Health Care

Steven L. Arxer

Introduction

Community-based health care is a growing interest to academics and policymakers. As questions are raised about the status of the Affordable Care Act and rising health-care costs, scholars and practitioners are exploring the benefits that community-based models can offer healthcare delivery, service, and management. The nature of health care is thus changing, and alternative, "local," solutions are being integrated into the mainstream.

In *The New Public Health*, Baum (2016) emphasizes the growing scope of a new public health vision. Health and environment planners are faced with challenges to improving community health outcomes. In this vein, scholars have examined the link between theory and practice in community-based health care, with some providing general guidelines (Bartholomew, Parcel, Kok, Gottlieb, & Fernandez, 2016; Minkler & Wallerstein, 2008). Others have highlighted community-based theory in various professions, such as nursing (Billings & Halstead, 2016) and social work (Gould & Baldwin, 2016). Still others note the importance of community-based theory across disciplinary boundaries (Nelson & Stagger, 2018).

A trend found in the literature is the "institutionalization" of alternative health models in the professional sphere. However, investigations are lacking that have explored the theoretical and practical considerations of institutionalizing a community-based model. In other words, community-based theory is designed to overcome the limitations associated with traditional organizations of health care. In

---

S. L. Arxer (✉)
Department of Sociology and Psychology, University of North Texas at Dallas,
Dallas, TX, USA
e-mail: steven.arxer@untdallas.edu

© Springer Nature Switzerland AG 2019

S. L. Arxer, J. W. Murphy (eds.), *Community-Based Health Interventions in an Institutional Context*, International Perspectives on Social Policy, Administration, and Practice, https://doi.org/10.1007/978-3-030-24654-9_13

this respect, a theory of organizations and institutions is implied by community-based theory that is often overlooked.

The aim of this volume, accordingly, is to focus on the theoretical and practical implications of institutionalizing a community-based approach to health care. Discussions of community-based work often are focused on human agency and community well-being. And these traits should not be overlooked. A problem, however, is that community-based practitioners' work in institutions is assumed to have a unique status, more significant than either individuals or communities. Nonetheless, discussions of institutional challenges to community-based work are rare. The goal of this collection has been to remedy this shortcoming and address some important institutional issues in community-based projects.

The chapters in this volume emphasize the benefits of institutionalizing community-based health projects, but in a manner different from the past. To the extent that community-based efforts are described as substantially different from conventional practices, service institutions must be conceptualized and operationalized to preserve the intention of communities. Furthermore, an entirely new ethic of health care is presumed by institutionalizing a community-based philosophy. In short, a careful examination of how community-based projects can be institutionalized has the prospect for advancing effective strategies for community health planning.

A recurring theme in this book is that planning should not be reduced to simply assisting communities or managing health services within certain locales. At the center of community-based theory is also a new image of social planning that goes beyond traditional models of leadership and management. Rather than developed and controlled by expert professionals, planning efforts emerge from below or, as Ulrich Beck (1997, p. 157) suggests, from a "sub-politics" that represents the direct action and goals of community members.

Reimagining Institutions Through Community-Based Philosophy

Clearly, community-based approaches seek a deeper involvement of community members because their biographies and contextual perspectives on community life shed important light on discussions about community well-being. However, the radical centering of community members in social planning suggests a reimagining of how these efforts are institutionalized. In short, being community-directed supplies important insight into how organizational life is transformed and a style of health organization emerges that is different from traditional health interventions. An important part of this movement toward self-directed projects is a need to reconceptualize the institutional contexts in which health projects take place.

Perhaps important to appreciate is the traditional descriptions of institutions, particularly their social imagery for the operation of organizations and the implications for the delivery of health services. Most often, institutions are understood to give stability and regularity to society. Institutions are meant to restrict idiosyncratic behavior and foster predictable interactions. As Anthony Giddens (1987, p. 11) notes, an institution represents "patterns of social activity reproduced across time and space." In short, institutions offer the continuity necessary to organize social life.

This description of institutions emerges alongside the positivist thinking of the latter half of the nineteenth and early part of the twentieth century. The continued development of industrial capitalism and the growing prestige of science led to a preference for scientific management as a means to regulate institutional behavior. In particular, specialization and technical knowledge became favored tools to guide how persons run businesses, economies, political organizations, and schools (Bentley, 1908). Using the techniques and guidelines of science to bring rationality, efficiency, and objectivity to any endeavor is thought to be a welcomed contribution to any organization.

Important for this discussion is that formalizing the practices of human organization has been presumed a positive development. By the 1930s, the Human Relations School began to argue that successful organizations train a cadre of professional managers (Whitley, 1984). For example, through principles of standardization and formalization characteristic of bureaucracies, managers can better regulate key individuals (workers) by developing discrete roles and clear lines of communication. The message becomes that human organizations simply work better when managed by an elite group of individuals who possess technical skills. These talents, moreover, allow them to think beyond their individual experience, so as to conceptualize the broader needs of the organization.

This image of human organization, nonetheless, is anathema to a community-based approach to health care. The problem is that a penchant for technical and formalized skills leads to the marginalization of the non-initiated. In the context of social research in academic and health institutions, professional researchers or health practitioners are in charge of most projects (Leitz & Zayas, 2010). Particularly insidious about this conceptualization of institutions is how the hierarchical system of authority, which situates professional experts on top of the organizational structure, means that inequality and marginalization of laypersons gain a sense of legitimacy. Because institutions and their leaders are presumed to be impersonally guided by formalized rules, they are not implicated in the process of prejudice or exclusion.

Considering the emphasis on self-direction in community-based theory, institutions and the hierarchy between professional and community members cannot be justified easily. Following the linguistic turn to knowledge, no perceptive is unbiased, even those of scientific professionals (Ugalde, 1985). The organization of institutionalized research pursued by academics and health professionals is no exception. As opposed to being objective, institutions and roles that make them up represent just one rendition of how social interaction should take place. The cultural hegemony of research is difficult to sustain, since their standardized methods are not neutral nor do they offer persons a more privileged position to judge reality.

Making Institutional Health Planning Transparent

From a community-based perspective, the institutional context where community health planning takes place needs to be made transparent. Here transparency is used in a way similar to Jean Gebser (1985, pp. 6–7), who defines this term as "everything latent behind and before the world" is revealed. Put differently, what Gebser means is that human action is recognized to pervade all that is known and thus nothing is preserved as an unbiased foundation. Thinking in terms of community-based institutions, this claim means that all persons can be legitimate participants in fomenting a vision of how social behavior should unfold.

This view of institutions is grounded in what Marx called *praxis* or human action. In this light, Tervalon and Murray-Garcia (1998, pp. 117–125) argue that from a community-based perspective, professional practitioners, researchers, and other social service agents should base their work in "cultural humility." They suggest that rather than centering the views of experts, these individuals should work toward a "lifelong commitment to self-evaluation and self-critique" so as to not obscure the views of community members through a power imbalance (Tervalon & Murray-Garcia 1998, pp. 117–125). This attitude is meant to curb the impact of professional cultures that can unnecessarily shadow the ideas and efforts of the community.

When institutions are reclaimed through collective praxis and partnership with communities, the rationale for community-based work becomes visible and a pathway is available for its actualization. Simply put, with collective praxis at the heart of institutions, the behavioral repertoire that goes along with community health research is expanded and power differentials minimized between communities and health professionals. When the deliberative process is opened in this manner, a democratic view of institutions is promoted, which is consistent with the aim of community-based social planning to have community members direct all local projects.

Instead of representing universal standards, the institutional context of community-based health care represents a human endeavor that may include competing views of need, risk, and illness. The point is that institutions are not sacrosanct; they are rooted in human actions and local language games. Institutions are thus made out of human praxis and do not represent a set of idealized traits. Treating institutions as monuments can promote the idea that certain skilled individuals best characterize the properties of institutions (formalism, standardization, technical), and thus, professionals should be granted special status.

And yet this type of hegemony is antithetical to community-based theory. What community-based strategies emphasize is that institutional arrangements are positional in nature and, thus, emerge from the outcomes of debate. As Stanley Fish (1992, p. 261) describes, institutions should be imagined to be "always emerging and re-emerging in response to historical needs and conditions." Rather than structural and mechanical, institutions are based on contingent understandings. In this way, institutions are never finalized, but always available for modification arising from local initiatives.

Issues of Power and "Community-Driven" Health Institutions

A central focus of community-based health planning is self-governance; self-regulation is the hallmark of a community-based style of institutionalization. To the extent that institutions represent human praxis, persons have nothing else to rely on but themselves for order. Institutions are thus discursive and represent the record of human activity. An important element of participatory health care is the idea that the community should drive health planning at all levels. Given the nonrealistic stance that community-based practitioners adopt, institutions and the power concealed by these entities can be examined. Subsequent to the demise of dualism, a neutral or universal standpoint is not possible to attain. Institutions are not an exception; they do not carry inherent autonomy due to their formal character. Institutional arrangements, instead, represent a set of specific assumptions made about human organization. Given the perspectival origin of institutions, these organizations should be receptive to local challenges and become polyvalent.

When community health projects unfold, however, a range of challenges often emerge. Most notably, community health initiatives "paradoxically … would not occur without the initiative of someone outside the community" (Minkler, 2005, p. ii8). And as is often noted, these individuals have the time, skills, commitment, and privilege to engage in these endeavors (Minkler, 2005, p. ii8). This reality, in turn, leads to "insider-outsider tensions," which has been discussed by community-based practitioners for some time (Ugalde, 1985). In this situation, community members remain on the periphery of the decision-making process, such as in the selection and understanding of health issues, the research process, and intervention strategies. At worst, these persons are used and exploited for information and labor, with the local communities seeing few benefits. As Wallerstein (1999) argues, community-based researchers and practitioners do not recognize the degree of power that is embedded in the privileges of professionals and other outsiders.

A key philosophical ingredient behind the insider-outsider dynamic, however, is often overlooked. The metaphysical claims that have been used to describe and justify institutions and the hierarchal relationships within them need to be exposed. To paraphrase Marx (1952), individuals create institutions but not always in terms of their own interests. More esteemed discursive formations gain power over institutions, such as those of technical experts, and may begin to inferiorize others. Here certain behaviors are institutionalized and are allowed to discriminate against community members who do not carry organizational positions or possess specific competencies. Moreover, this type of inequality carries the allure of neutrality given that they are associated with formal, institutional relationships.

But when institutions are reclaimed through human praxis and reflection, the rationale for institutional hierarchies is made visible for critique. Community-driven planning thus should include a new raison d'être for institutions, as well as for the health work accomplished within these settings. With institutions imagined to be mediated fully by human interpretation and action, these organizations should represent collective deliberations and the choices made to pursue one course of action or another. However, now these choices cannot be understood to be value-free but rather as political. In this context, political refers to the idea that human involvement and intentionality are inextricably tied institutions (Lyotard, 1993, p. 5). Community-based planning, accordingly, involves a re-evaluation of how persons and their communities have been positioned with respect to health-care institutions and the policies that emerge from these organizations.

References

Bartholomew, L. K., Parcel, G. S., Kok, G., Gottlieb, N. H., & Fernandez, M. E. (2016). *Planning health promotion programs: An intervention mapping approach*. California, USA: Jossey-Bass.

Baum, F. (2016). *The new public health*. South Melbourne, Australia: Oxford University Press.

Beck, U. (1997). *The reinvention of politics: Rethinking modernity in the global social order*. Cambridge, MA: Polity.

Bentley, A. (1908). *The process of government: A Study in social pressures*. Chicago, IL: The University of Chicago Press.

Billings, D., & Halstead, J. (2016). *Teaching in nursing: A guide for faculty*. St. Louis, MO: Elsevier.

Fish, S. (1992). The common touch, or one size fits all. In D. J. Gless & B. H. Smith (Eds.), *The politics of liberal education* (pp. 31–50). Durham, NC: Duke University Press.

Gebser, J. (1985). *The ever-present origin*. Athens, OH: Ohio University Press.

Giddens, A. (1987). *Sociology*. New York, NY: Harcourt Brace Jovanovich.

Gould, N., & Baldwin, M. (Eds.). (2016). *Social work: Critical reflection and the learning organization*. New York, NY: Routledge.

Leitz, C. A., & Zayas, L. E. (2010). Evaluating qualitative research for social work practitioners. *Advances in Social Work, 11*(2), 188–202.

Lyotard, J. F. (1993). *Libidinal economy*. Bloomington, IL: Indiana University Press.

Marx, K. (1952). The eighteenth Brumaire of Louis Napoleon. In R. C. Tucker (Ed.), *The Marx-Engels reader: A second edition*. New York, NY: Norton.

Minkler, M. (2005). Community-based research partnerships: Challenges and opportunities. *Journal of Urban Health, 82*(2), ii3–ii12.

Minkler, M., & Wallerstein, N. (Eds.). (2008). *Community-based participatory research for health: From process to outcomes*. California, USA: Jossey-Bass.

Nelson, R., & Stagger, N. (2018). *Health informatics: An interpersonal approach*. St. Louis, MO: Elsevier.

Tervalon, M., & Murray-Garcia, J. (1998). Cultural humility vs cultural competence: a critical distinction in defining physician training outcomes in medical education. *Journal of Health Care for the Poor and Underserved*, 9, 117–125.

Ugalde, A. (1985). Ideological dimensions of community participation in Latin America health programs. *Social Science & Medicine, 21*, 41–53.

Wallerstein, N. (1999). Power between evaluator and community: Research relationships within New Mexico's healthier communities. *Social Science & Medicine, 49*, 39–53.

Whitley, R. (1984). The development of management studies as a fragmented adhocracy. *Social Science Information, 23*(4–5), 775–818.

Index

© Springer Nature Switzerland AG 2019

S. L. Arxer, J. W. Murphy (eds.), *Community-Based Health Interventions in an Institutional Context*, International Perspectives on Social Policy, Administration, and Practice, https://doi.org/10.1007/978-3-030-24654-9