José García-Alonso César Fonseca *Editors*

Gerontechnology III

Contributions to the Third International Workshop on Gerontechnology, IWoG 2020, October 5–6, 2020, Évora, Portugal



Lecture Notes in Bioengineering

Advisory Editors

Nigel H. Lovell, Graduate School of Biomedical Engineering, University of New South Wales, Kensington, NSW, Australia

Luca Oneto, DIBRIS, Università di Genova, Genova, Italy

Stefano Piotto, Department of Pharmacy, University of Salerno, Fisciano, Italy

Federico Rossi, Department of Earth, University of Salerno, Fisciano, Siena, Italy

Alexei V. Samsonovich, Krasnow Institute for Advanced Study, George Mason University, Fairfax, VA, USA

Fabio Babiloni, Department of Molecular Medicine, University of Rome Sapienza, Rome, Italy

Adam Liwo, Faculty of Chemistry, University of Gdansk, Gdansk, Poland

Ratko Magjarevic, Faculty of Electrical Engineering and Computing, University of Zagreb, Zagreb, Croatia

Lecture Notes in Bioengineering (LNBE) publishes the latest developments in bioengineering. It covers a wide range of topics, including (but not limited to):

- Bio-inspired Technology & Biomimetics
- Biosensors
- Bionanomaterials
- Biomedical Instrumentation
- Biological Signal Processing
- Medical Robotics and Assistive Technology
- Computational Medicine, Computational Pharmacology and Computational Biology
- Personalized Medicine
- Data Analysis in Bioengineering
- Neuroengineering
- Bioengineering Ethics

Original research reported in proceedings and edited books are at the core of LNBE. Monographs presenting cutting-edge findings, new perspectives on classical fields or reviewing the state-of-the art in a certain subfield of bioengineering may exceptionally be considered for publication. Alternatively, they may be redirected to more specific book series. The series' target audience includes advanced level students, researchers, and industry professionals working at the forefront of their fields.

Indexed by SCOPUS, EI Compendex, INSPEC, zbMATH, SCImago.

More information about this series at http://www.springer.com/series/11564

José García-Alonso · César Fonseca Editors

Gerontechnology III

Contributions to the Third International Workshop on Gerontechnology, IWoG 2020, October 5–6, 2020, Évora, Portugal



Editors
José García-Alonso
University of Extremadura
Cáceres, Spain

César Fonseca D University of Évora Évora, Portugal

ISSN 2195-271X ISSN 2195-2728 (electronic) Lecture Notes in Bioengineering ISBN 978-3-030-72566-2 ISBN 978-3-030-72567-9 (eBook) https://doi.org/10.1007/978-3-030-72567-9

© The Editor(s) (if applicable) and The Author(s), under exclusive license to Springer Nature Switzerland AG 2021

This work is subject to copyright. All rights are solely and exclusively licensed by the Publisher, whether the whole or part of the material is concerned, specifically the rights of translation, reprinting, reuse of illustrations, recitation, broadcasting, reproduction on microfilms or in any other physical way, and transmission or information storage and retrieval, electronic adaptation, computer software, or by similar or dissimilar methodology now known or hereafter developed.

The use of general descriptive names, registered names, trademarks, service marks, etc. in this publication does not imply, even in the absence of a specific statement, that such names are exempt from the relevant protective laws and regulations and therefore free for general use.

The publisher, the authors and the editors are safe to assume that the advice and information in this book are believed to be true and accurate at the date of publication. Neither the publisher nor the authors or the editors give a warranty, expressed or implied, with respect to the material contained herein or for any errors or omissions that may have been made. The publisher remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

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

Preface

The International Workshop on Gerontechnology (IWoG) aims to promote research and scientific exchange related to Gerontechnology, and to bring together researchers and practitioners from various disciplines of the academia, public administrations and industry in order to tackle emerging challenges in the Gerontechnology applications and associated technologies, as well as to assess the impact of these technologies on society, media and culture.

This volume collects the full research papers (field, statistics, technical and vision works) and short research papers presented at the Third International Workshop on Gerontechnology (3rd IWoG), held virtually, during November 16–20, 2020. On this occasion, there were three venues where the virtual sessions took place: University of Extremadura (Cáceres, Spain), University of Évora (Évora, Portugal) and University of Cauca (Popayán, Colombia).

The Third Edition of IWoG accepted contributions related to different dimensions of Gerontechnology: use of technology to improve functional ability and promote healthy aging; health interventions to support caregivers of elderly people; the effectiveness of public health initiatives and clinical interventions to prevent, reverse or mitigate decreases in physical and mental abilities; solutions for active aging, social integration and self-care; monitoring and management of chronic and non-chronic diseases in ambient-assisted living; learning, training and coaching systems to promote healthy life in ambient-assisted living environments; smart homes and sensor networks for ambient-assisted living; context-awareness in ambient-assisted living environments; use of context and location information in user interfaces; elderly nutrition; health, wellness and disease monitoring; knowledge management for health (context, cognition, behavior and user modeling); health ecosystems (frameworks, models and methodologies); smarts technologies and algorithms for health.

This workshop was organized by the Program Committee (PC), with a senior PC composed of well-known experts from the field in charge of monitoring the work and animating the discussions of the broader regular PC. This made it easier to run the virtual PC meeting of the full research papers track and the discussion about each paper.

vi Preface

The program for IWoG 2020 was versatile and multifaceted. In this workshop, there were only full papers, and we selected 40 out of 135 submissions, resulting in an acceptance rate of 29,62%. Last year, at IWoG 2019, we had 77 submissions, so this year, we have had a 75% increase.

This excellent and comprehensive program would not have been possible without the help of those who contributed to the success of the event. We would like to thank all the different chairs for their hard work. Our thanks also go to Daniel Miller, María Julieta Oddone, María Ángeles Durán and Ana María Porcel who imparted the main talks of the workshop.

We are grateful to our local organizers 4IE team of University of Extremadura, University of Evora and University of Cauca for their logistical support, and to Springer for publishing this volume. In addition, we want to thank the PC members, the additional reviewers and the student volunteers for their effort to make IWoG 2020 a very special event, both in terms of academic ambition as well as practical arrangements.

Finally, we want to thank you, authors and the IWoG community, for taking the time and effort to participate in IWog 2020.

December 2020

José García-Alonso César Fonseca

Organization

Program Chairs

José García-AlonsoUniversity of Extremadura, SpainCésar FonsecaUniversity of Évora, PortugalCésar CollazosUniversity of Cauca, ColombiaManuel LopesUniversity of Évora, Portugal

Henrique Oliveira Polytechnic Institute of Beja, Portugal Maria Margarida Palma Goes Polytechnic Institute of Beja, Portugal

Proceeding Chair

Enrique Moguel University of Extremadura, Spain

Program Committee

Juan Manuel Murillo University of Extremadura, Spain Javier Berrocal University of Extremadura, Spain Lorenzo Mariano Juárez University of Extremadura, Spain Sergio Cordovilla University of Extremadura, Spain Carlos Canal University of Málaga, Spain David Mendes University of Évora, Portugal University of Helsinki, Finland Niko Mäkitalo University of Cauca, Colombia Julio Ariel Hurtado

Mohamed Mohamed Ubiquitous Platforms Almaden Research Center,

San Jose, California-USA

Luca Foschini University of Bologna, Italy

Elena Navarro University of Castilla-La Mancha, Spain

Javier Jaén University of Valencia, Spain Felismina Mendes University of Évora, Portugal

Pedro Parreira Nursing School of Coimbra, Portugal

viii Organization

Ana Paula Oliveira
Adriano Pedro
Rogério Ferreira
Ana Canhestro
Lucília Nunes
Lisete Mónico
Laura Ruotsalainen
Ángela Barriga

Alejandro Rodríguez

Fabio Casati
Sergio Ochoa
Patricia Paderewski
Francisco Luis Gutiérrez
John Edison Muñoz
Jeferson Arango
Francisco Chávez de la O.
Jaime Galán-Jiménez
Marino Linaie

Cristina Vicente-Chicote David Conde-Caballero

Sergio Rico Javier Rojo

Manuel Jesús-Azabal

Sergio Laso

Daniel Flores-Martin Juan Luis Herrera Rubén Rentero Sara Chimento Borja Rivero Luis López-Lago Enrique Moguel Polytechnic Institute of Portalegre, Portugal Polytechnic Institute of Portalegre, Portugal Polytechnic Institute of Beja, Portugal Polytechnic Institute of Beja, Portugal Polytechnic Institute of Setubal, Portugal University of Coimbra, Portugal

University of Coimbra, Portuga University of Helsinki, Finland

Western Norway University of Applied Sciences, Norway

Western Norway University of Applied Sciences, Norway

University of Trento, Italy University of Chile, Chile University of Granada, Spain University of Granada, Spain University of Waterloo, Canada

University of Caldas

University of Extremadura, Spain Organization ix

Sponsors



Fondo Europeo de Desarrollo Regional























Contents

| Smarts Technologies and Algorithms | |
|--|----|
| Detecting and Monitoring Depression Symptoms According to People's Behaviour Through Mobile Devices Daniel Flores-Martin, Sergio Laso, Javier Berrocal, and Juan M. Murillo | 3 |
| Time Series Forecasting to Predict the Evolution of the Functional Profile of the Elderly Persons Javier Rojo, Enrique Moguel, Cesar Fonseca, Manuel Lopes, Jose Garcia-Alonso, and Juan Hernandez | 11 |
| The Role of the Blockchain Technology in the Elderly Care Solutions: A Systematic Mapping Study | 23 |
| MoRES: A Mobile App to Help Elderly People Grasp and Comply with COVID-19 Restrictions José Ramón Lozano-Pinilla, Daniel García-Pérez, and Cristina Vicente-Chicote | 35 |
| Qualitative Research in Evaluation. An Usability Evaluation Protocol for the Assistant on Care and Health Offline (ACHO) | 43 |
| Technologies to Increase the Quality of Life of the Elderly Population | |
| A Self-sustainable DTN Solution for Isolation Monitoring in Remote Areas Manuel Jesús-Azabal, Javier Berrocal-Olmeda, José García-Alonso, and Jaime Galán-Jiménez | 57 |

xii Contents

| Training Proposal Technology for the Elderly with Changes in Self Care and for Their Caregiver: Rehabilitation Nursing Care | 60 |
|---|-----------|
| Contributions César Fonseca, Liliana Barbas, Patrícia Martins, Rogério Ferrinho, José Garcia-Alonso, Lara Guedes de Pinho, and Inês Cardoso | 69 |
| PSIQUE: A Computerised Neuropsychological Assessment App Daniel Diaz, Steban Cadena, Juan Gil, Deisy Chaves, and Maria Trujillo | 81 |
| Indicators Sensitive to Rehabilitation Nursing Care: A Functional and Technological Respiratory Rehabilitation Program for Elderly People Anabela Silva, Susana Silva, César Fonseca, Inês Cardoso, Rogério Ferrinho, Luís Sousa, Lara Guedes de Pinho, and Manuel Lopes | 87 |
| Experiences and Definitions of Loneliness. The Use of Technology for Anthropological Research. Borja Rivero Jiménez, David Conde-Caballero, Jara Bonilla-Bermejo, Jerónimo Luengo-Polo, and Lorenzo Mariano Juárez | 99 |
| Internet of Things (IoT) | |
| Human Data Model: An Approach for IoT Applications Development for Elderly Healthcare Niko Mäkitalo, Daniel Flores-Martin, Javier Berrocal, Juan M. Murillo, and Tommi Mikkonen | 111 |
| Enhanced Living Environments (ELE): A Paradigm Based on Integration of Industry 4.0 and Society 5.0 Contexts with Ambient Assisted Living (AAL) Edward Wilder Caro Anzola and Miguel Ángel Mendoza Moreno | 121 |
| Design of an App for the Awareness of Active Ageing Linked | |
| to Cultural Heritage Juan Francisco Ortega Morán, José Luis Moyano García-Cuevas, Francisco Manuel Esteban Gómez, Carolina Vila-Cha, Nuno Serra, Debora Zamillo, Aurelia Curaj, Francisco M. Sánchez Margallo, and J. Blas Pagador | 133 |
| TechCare - Training on the Adaptability of Assisted Living Technologies in Home and Community Care | 139 |
| Solutions for Active Aging, Social Integration and Self-care | |
| Promotion of Functional Independence in the Self-care Deficit of the Elderly Person with Orthopedic Disease and Technology Anabela Silva, Susana Silva, César Fonseca, José Garcia-Alonso, Manuel Lopes, Inês Cardoso, and Lara Guedes de Pinho | 149 |

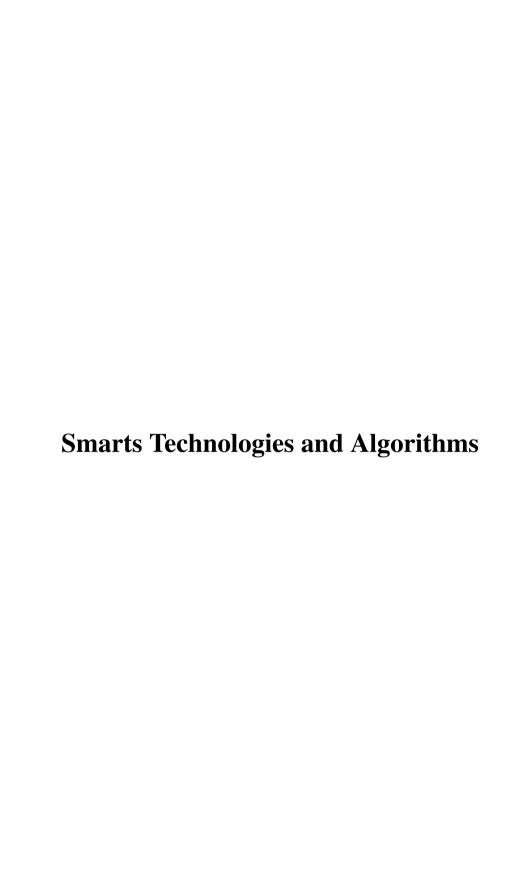
| Rehabilitation Nursing Technology Intervention Gains Based on the Model of Self-care, in the Elderly Person with a Proximal Femoral Fracture | 161 |
|---|-----|
| Ana Brandão, Elisabete Lopes, Liliana Barbas, César Fonseca, José Garcia-Alonso, Lara Guedes de Pinho, and Manuel Lopes | |
| Have People Over 64 Used Technological Devices During COVID-19? Sara Chimento-Díaz, Pablo Sánchez-García, Cristina Franco-Antonio, Esperanza Santano-Mogena, and Sergio Cordovilla-Guardia | 168 |
| Awareness of Intangible Cultural Heritage Through Videos Promoting Active Ageing Juan Francisco Ortega Morán, José Luis Moyano García-Cuevas, Francisco Manuel Esteban Gómez, Carolina Vila-Cha, Nuno Serra, Debora Zamillo, Aurelia Curaj, Francisco M. Sánchez Margallo, and J. Blas Pagador | 177 |
| Pictograms - A Useful (Digital and/or Physical) Tool to Assist Elderly Patients in Understanding Medication Instructions? - A Systematic Review Sara Faustino, Sofia Oliveira-Martins, and Ana Margarida Advinha | 184 |
| Impact of Socialization on Active Aging in the Geriatric Population: A Systematic Literature Review | 202 |
| Promotion of Self-care Management in the Person with COPD: Systematic Literature Review Nelson Esteves, Carla Basílio, Pedro Costa, Mauro Lopes, Célia Nicolau, Rogério Ferreira, Manuel Agostinho Fernandes, and César Fonseca | 217 |
| Monitoring and Management of Chronic and Non-chronic Diseases | |
| Factors Associated with Social Participation in People with Severe Mental Disorders Sara Chimento-Díaz, Pablo Sánchez-García, Cristina Franco-Antonio, Esperanza Santano-Mogena, and Sergio Cordovilla-Guardia | 235 |
| Digital Technology Scale to Coach People with Chronic Diseases: Evidence of Psychometric Validity in Four European Countries Pedro Parreira, Rafael A. Bernardes, Paulo Santos-Costa, João Graveto, Paulo Alexandre Ferreira, Anabela Salgueiro-Oliveira, Liliana B. Sousa, Beatriz Serambeque, Lisete Mónico, Marija Milavec Kapun, Tina Gogova, Pirjo Vesa, Hilde Vandenhoudt, Dorine Nevelsteen, and Raija Kokko | 245 |

xiv Contents

| Aging and Functionality of the Institutionalized Elderly People of Alto Alentejo: Contributions to the Diagnosis of the Situation | 253 |
|--|-----|
| Gains from Nursing Care in Mobilizing the Elderly Person After Hip Arthroplasty Iromisa Pereira, Rogério Ferreira, João Vieira, Maria M. Goes, Teresa Mestre, and Henrique Oliveira | 262 |
| Women with Stress Urinary Incontinence: The Impact of a Rehabilitation Nursing Program on Quality of Life | 277 |
| Promotion of Functional Independence in the Deficit of Self-care in the Elderly Person with Stroke in Home Context and Technology Anabela Silva, Susana Silva, César Fonseca, José Garcia-Alonso, Manuel Lopes, Inês Cardoso, and Lara Guedes de Pinho | 291 |
| Rehabilitation Nursing and Elderly People with Neurological Alterations - Home Context Technology Andreia Duarte, César Fonseca, Juliano Branco, José Garcia-Alonso, Lara Guedes de Pinho, and Inês Cardoso | 303 |
| Health Interventions to Support Caregivers of Elderly People | |
| Technological Solutions and Informal Care Culture for the Elderly: An Intervention Proposal for Training Actions L. López-Lago Ortiz, S. Arroyo Chacón, C. Cipriano Crespo, J. Bonilla Bermejo, and B. Muñoz González | 315 |
| Components of Care Models that Influence Functionality in People Over 65 in the Context of Long-Term Care: Integrative Literature Review. Bruno Morgado, César Fonseca, Manuel Lopes, and Lara Pinho | 324 |
| Transitional Care in Times of COVID 19: Opportunities for e-Health Interventions Cristina Lavareda Baixinho, Luís Sousa, and Óscar Ramos Ferreira | 336 |
| Partnership of Care in the Promotion of the Care-of-the-Self: An Implementation Guide with Elderly People | 345 |
| Lean Methodology in the Process of Prescribing and Administering Therapeutics in the Intensive Care Unit Maria do Céu Marques, Luís Sousa, Rui Cortes, Liliana Silva, Ermelinda Rebola, and José Aguiar | 357 |

Contents xv

| Public and Other Health Initiatives | |
|---|-----|
| Technology in the Face of the Challenges of the Long-Term Care System for the Elderly in Spain Luis López-Lago Ortiz, Sara Arroyo Chacón, Carmen Cipriano Crespo, Jerónimo Luengo Polo, and Beatriz Muñoz González | 371 |
| Inclusion and the Digital Divide from the Perspective of Digital Competence Trainers Lukasz Tomczyk, Anna Mróz, Katarzyna Potyrała, and Joanna Wnęk-Gozdek | 380 |
| Loneliness in the Quality of Non-institutionalized Elderly People Filomena Morais, Helena Silva, Inês Reis, Jorge Ramalho, Maria do Céu Marques, and Maria de Fátima Moreira | 391 |
| Perceived Loneliness by Elderly a Systematic Literature Review Sandra Gomes, Manuel Lopes, and César Fonseca | 402 |
| Development and Validation of a Short-Version of the European Portuguese WHOQOL-OLD Scale Isabel Gil, Paulo Santos-Costa, Elzbieta Bobrowicz-Campos, Liliana B. Sousa, Maria Manuela Vilar, and João Apóstolo | 414 |
| Management of the Pandemic in the Elderly. The Case of Pescueza Alfonso Vázquez Atochero, Jesús Seco González, and Santiago Cambero Rivero | 428 |
| Sociodemographic Profile of People Aged 65 or Over in Long-Term Care in Portugal: Analysis of a Big Data Ana Ramos, Manuel Lopes, César Fonseca, and Adriana Henriques | 438 |
| Author Index | 447 |





Detecting and Monitoring Depression Symptoms According to People's Behaviour Through Mobile Devices

Daniel Flores-Martin^(⊠), Sergio Laso, Javier Berrocal, and Juan M. Murillo

University of Extremadura, Cáceres, Spain {dfloresm,slasom,jberolm,juanmamu}@unex.es

Abstract. The symptoms of depression cause patients to face psychological barriers that dictate the search for treatment. Also, people's daily behavior allows us to identify different symptoms of depression in combination with intelligent devices that accompany us in almost any situation and contain a large number of sensors. In this sense, mobile devices can be used to monitor people's behavior and, thus, identify if people could have diseases such as depression. However, current technologies or applications require constant user intervention to provide an approximate diagnosis of possible symptoms, which is a major barrier for patients. This work presents a set of applications designed for mobile devices that passively detect the symptoms of depression, reducing possible obstacles in the identification of this disease. This detection is based on information obtained from mobile devices, such as device use, locations and text message content. In addition, this information can be monitored by experts in the field of health, with the aim of providing a more complete diagnosis. Therefore, thanks to the analysis of this information and the use of the developed applications, the detection of these symptoms is transparent to the person and can also be monitored by specialized health professionals.

Keywords: Depression \cdot IoT \cdot Healthcare \cdot Medical staff \cdot Context information

1 Introduction and Motivations

Depression can become a severe health problem, especially when it is long-lasting. In addition, it alters people's lives in terms of work, school and family activities. According to the World Health Organization (WHO) [1], depression is the leading cause of mental disorders and disability worldwide. More than 300 million people suffer from depression, or in other words, more than 4% of the world's population.

Depression cause people to not find professional help [2] and prevent them from identifying their disorders. Once detected, its measurement is conducted by professionals by means of tests, such as *Mood and Feelings Questionnaire* [3]

[©] The Author(s), under exclusive license to Springer Nature Switzerland AG 2021 J. García-Alonso and C. Fonseca (Eds.): IWoG 2020, LNBE, pp. 3–10, 2021. https://doi.org/10.1007/978-3-030-72567-9_1

or Beck's Depression Questionnaire [4]. Moreover, visiting the psychologist and completing these tests is another obstacle for patients with a low mood, which difficulties even more the search for treatment.

Modern smartphones allow us to monitor people's mental health conditions [5,6]. This is why mobile applications have been developed for this purpose such as *Moodpath* [7], that evaluates mental health through a series of questions and allows the results to be shared with specialized therapists; *MoodTools* [8], that helps people to combat depression and alleviate negative moods; or *Talk-Life* [9], that offers support with a community to do group therapy. These applications usually present some questionnaires that, once answered, are evaluated by a specialist or directly by an information system. However, they require that the patient actively performs the evaluation and does so periodically to maintain the control of their health.

Moreover, the capabilities of mobile devices to detect, store and compute contextual information has grown enormously. Therefore, psychological studies, such as [10] and [11] are based on their use to detect the people's behaviour and identify symptoms of depression. Nevertheless, these studies are mainly theoretical.

In this work we propose a series of extensible mobile applications that monitor their owners in order to detect symptoms of depression in a passive way. This detection is transparent for the mobile owner, reducing the barrier that presents the use of this type of applications. The applications allow us to monitor different dimensions (device usage, locations, text messages analysis, etc.), to store the information and to offer it to any other application that requires it. In addition, the system can be extended by adding new modules to monitor other dimensions.

The rest of this paper is structured as follows. After this introduction, Sect. 2 details the framework architecture. Then, Sect. 3 shows the obtained results. Next, in Sect. 4, the architecture is evaluated. Finally, in Sect. 5, the discussion and some final conclusions are drawn.

2 Framework Development

To improve the identification of depressive symptoms and their evolution over time, we used the People as a Service (PeaaS) [12] computational model. This model is used for monitoring people to identify what activities they perform, their frequency, duration, etc. As shown in Fig. 1, this system is divided into three applications. An application focused on capturing, storing and processing contextual information. Another application for the analysis of such information for the detection of symptoms of depression. And, additionally, an application for the control of patients with depression. Besides, to calculate the depression score, three mentioned dimensions are taken into account:

Device usage. [10] indicates that people with depression spend, on average, 68 min a day using the mobile phone (while non-depressives use 17). The application monitors the usage time of the device over a week. If the recommended limit is exceeded, the depression score is incremented proportionally. Similarly, points are subtracted proportionally if the limit is not reached.

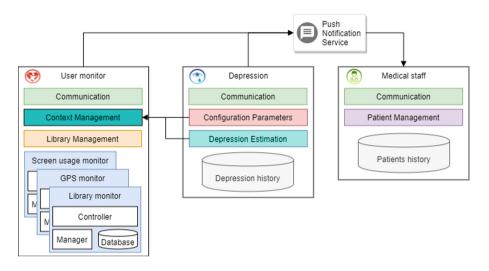


Fig. 1. Architecture of the depression monitoring environment.

- Position capturing. [13] indicates that non-depressed people spend an average of 49 min a day away from home doing leisure activities. The application monitors the location of the users to detect time spent doing leisure activities (restaurants, cafes, art galleries, shops, etc.). Again, the depression score is incremented or decremented based on the amount of time spent on these activities.
- Messaging applications. The users' conversations are analyzed by a developed model that categorizes the conversations moods as positive or negative [14].
 The depression score is again updated having into account the mood of the user's conversations.

3 Results

Using the architecture presented above, three applications have been developed [15] that help with the early detection of depression symptoms (Fig. 2). The three applications developed for this study are detailed below.

User Monitor Application: Health Tracker

This application monitors different dimensions of a person's context. It is composed of the following modules:

- Communication. It provides communication features, sending and receiving notifications based on the information captured from the person.
- Context manager. It exposes all the information captured by the different monitoring libraries, either to be accessible by other libraries, or to be

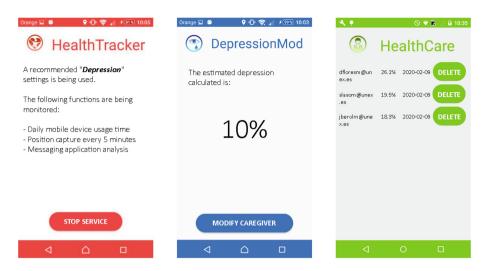


Fig. 2. Architecture of the depression monitoring environment.

consumed by third applications (e.g., the depression detection application). In this case, this information is related to the mobile device usage time, the places visited by the person and the mood of the user text messages.

 Libraries Management. Each library contains all the necessary logic to monitor one of the dimensions of the person's context. To identify symptoms of depression, the three dimensions mentioned above are monitored.

Thanks to this application, we can monitor the different contextual dimensions of people, add new dimensions in a simple way, provide the monitored data to other external applications and re-configure the monitoring depending on the specific requirements of external applications.

Depression Detection Application: DepressionMod

This application detects different symptoms from the contextual information captured by the previous application. It is composed by the following components:

- Configuration Parameters. It establishes the monitoring configuration necessary to identify symptoms of depression communicating with the monitoring application.
- Depression Estimation. It processes the information captured by the monitoring application to identify symptoms of depression and provide a depression score.
- **Depression History**. The different calculations of depression obtained weekly are stored in a database.
- Communication. Finally, the depression estimation can be sent to specialized medical staff or to a member of the person's family.

Thanks to the use of this applications, people can be transparently monitored to detect possible depression symptoms.

Medical Staff Application: HealthCare

This application allows the medical specialists to visualize the depression data received from each of the associated patients. It is composed by the following modules:

- Communication. It receives and manages the messages with the depression information from the different patients.
- Patient Manager. It allows the medical staff to associate the information received to a specific person and visualize its evolution.
- **Patients History**. It keeps the evolution of a patient and the different calculations of depression obtained in a temporary order.

By using the developed mobile applications, a person is monitored to detect possible symptoms of depression passively and professionals can be informed if necessary.

4 Evaluation

To evaluate these applications, 3 people have been followed for a week, which is how often the original application performs the analysis, using the libraries mentioned above. The Table 1 shows the values of the depression score calculated for each dimension, compared with the maximum depression score for that dimension, and the final depression score.

| Used libraries | Person 1 | Person 2 | Person 3 |
|-----------------------|----------|----------|----------|
| Position capture | 170/170 | 170/170 | 170/170 |
| Daily device usage | 230/230 | 230/230 | 230/230 |
| Messaging analyzing | 70/200 | 104/200 | 158/200 |
| Total points | 470/600 | 504/600 | 558/600 |
| Depression estimation | 78% | 84% | 93% |

Table 1. Depression estimation for 3 people monitored during a week

As can be seen in the table, all three volunteers have obtained the maximum score in location, which means that none of the users have stayed long enough in places considered to be anti-depression. As with the location, all volunteers scored the maximum number of depression points in screen usage time, which means that they all doubled, at least, the maximum usage time set. In the third aspect of the analysis, the results are more varied, we proceed to analyse each of the devices in-depth:

- Person 1: the first volunteer is the one with the least number of depression points (70 points). The volunteer presented a fairly small number of conversations. Moreover, many of these have been classified as negative.
- Person 2: the second volunteer scored a total of 104 points out of a maximum of 200, this being due to the large number of conversations he had during the test period, many of which had a negative connotation.
- Person 3: this volunteer has scored the most points (158 points). It is the one
 with the highest number of conversations, of which several are positive, but
 most have a negative connotation.

The results provided by the application are compared to the results of the Mental Health America (MHA) [16] test. None of the volunteers have been diagnosed with a depressive disorder, but they have been tested for symptoms of depression prior to testing. This test estimates a person's level of depression based on a questionnaire. The test estimates the number of points based on the answers entered by the user. The results obtained range from minimal depression (between 1 and 4 points out of a maximum of 27) to mild depression (between 5 and 9 points out of 27). Table 2 shows the comparison of the data obtained through both approaches.

| People | Applications results | MHA test results |
|----------|----------------------|------------------|
| Person 1 | 78% | 1 |
| Person 2 | 84% | 5 |
| Person 3 | 93% | 6 |

Table 2. Applications and MHA test results comparative

As we can see in the table, although the results obtained from the tests are quite high compared to those obtained from the survey, the increase in points obtained can be seen according to the device. The variations in the test results are very subtle, but this is because both in location and in screen usage time all the devices have obtained the maximum score.

Even so, there is a relationship between the values obtained through the applications and the MHA test, which indicates that the methods used in these three libraries offer a valuable result in the transparent detection of the symptoms of depression.

5 Discussion and Conclusions

As mentioned above, depression is a mental disorder. Among the most important symptoms are pathological sadness, loss of interest and ability to enjoy and a decrease in vitality that limits the level of activity and produces exaggerated tiredness. This work is based on the amount of time people spend using a mobile

phone, the time they spend at home, at work or doing different activities and the mood of their text message conversations. These factors have been selected because they can be monitored transparently through a smartphone.

The proposed applications allow us to detect possible symptoms of depression, but they are never a substitute for a health professional. However, they offer a complete tool to be able to act in time and establish a treatment when necessary.

Mental disorders are difficult to identify. In addition, this identification often requires the completion of a series of questionnaires that pose a strong barrier to the great majority of patients. Besides, people's daily behavior allows us to automatically identify some of the symptoms of these diseases.

As future work, there is a need to add additional parameters to the model such as age. Not everyone follows the same rules regarding the use and location of the device. An elderly person is not usually likely to move around as much or use a mobile device as much.

Mobile devices accompany us in practically any situation and contain a large number of sensors capable of identifying people behavior. This work presents an extensible system capable of monitoring different aspects to identify depressive symptoms passively. With this system, a person can detect possible symptoms of depression in a way that is completely transparent to them and, moreover, the healthcare staff is reported about his/her evolution to take such action as may be necessary.

Acknowledgments. This work was supported by (0499_4IE_PLUS_4_E) funded by the Interreg V-A España-Portugal (POCTEP) 2014–2020 program, by the project RTI2018-094591-B-I00 (MCIU/AEI/FEDER, UE) and FPU17/02251 grant, by project IB18030 funded by the Government of Extremadura.

References

- Depression: let's talk. https://www.who.int/mental_health/management/depression/en/. Accessed 21 Sept 2020
- Barney, L.J., Griffiths, K.M., Jorm, A.F., Christensen, H.: Stigma about depression and its impact on help-seeking intentions. Aust. N. Z. J. Psychiatry 40(1), 51–54 (2006)
- Costello, E.J., Angold, A.: Scales to assess child and adolescent depression: check-lists, screens, and nets. J. Am. Acad. Child Adolesc. Psychiatry 27(6), 726–737 (1988)
- 4. Beck, A.T., Steer, R.A., Brown, G.K.: Beck depression inventory-ii. San Antonio 78(2), 490–498 (1996)
- Torous, J., Friedman, R., Keshavan, M.: Smartphone ownership and interest in mobile applications to monitor symptoms of mental health conditions. JMIR Mhealth Uhealth 2(1), e2 (2014)
- Luxton, D.D., McCann, R.A., Bush, N.E., Mishkind, M.C., Reger, G.M.: mhealth for mental health: integrating smartphone technology in behavioral healthcare. Prof. Psychol. Res. Pract. 42(6), 505 (2011)

- Moodpath depression & anxiety test. https://play.google.com/store/apps/details?id=de.moodpath.android. Accessed 21 Sept 2020
- 8. Moodtools depression aid. https://play.google.com/store/apps/details?id=com. moodtools.moodtools. Accessed 21 Sept 2020
- 9. Talklife lonely, stressed or anxious? get help!. https://talklife.co/. Accessed 21 Sept 2020
- Saeb, S., Zhang, M., Karr, C.J., Schueller, S.M., Corden, M.E., Kording, K.P., Mohr, D.C.: Mobile phone sensor correlates of depressive symptom severity in daily-life behavior: an exploratory study. J. Med. Internet Res. 17(7), e175 (2015)
- 11. Osmani, V.: Smartphones in mental health: detecting depressive and manic episodes. IEEE Pervasive Comput. 14(3), 10–13 (2015)
- 12. Guillen, J., Miranda, J., Berrocal, J., Garcia-Alonso, J., Murillo, J.M., Canal, C.: People as a service: a mobile-centric model for providing collective sociological profiles. IEEE Softw. **31**(2), 48–53 (2013)
- 13. Muhlfeit, J., Melina, C.: The positive leader (2012)
- 14. Hassan, A., Mahmood, A.: Deep learning approach for sentiment analysis of short texts. In: 2017 3rd International Conference on Control, Automation and Robotics (ICCAR), pp. 705–710. IEEE (2017)
- 15. Developed applications repository. https://www.dropbox.com/s/45xewv1ttmg6b 93/C%C3%B3digoFuente.zip?dl=0. Accessed 21 Sept 2020
- 16. Mental health america. https://www.mentalhealthamerica.net/. Accessed 21 Sept 2020



Time Series Forecasting to Predict the Evolution of the Functional Profile of the Elderly Persons

Javier Rojo^{1(⋈)}, Enrique Moguel¹, Cesar Fonseca², Manuel Lopes², Jose Garcia-Alonso¹, and Juan Hernandez¹

University of Extremadura, Cáceres, Spain {javirojo,enrique,jgaralo,juanher}@unex.es
University of Evora, Évora, Portugal {cfonseca,mjl}@uevora.pt

Abstract. There are many pathologies and capacity losses that progress with a similar evolution profile in certain groups of people. Health professionals are becoming increasingly knowledgeable in anticipating the development of these pathologies through preventive medicine. However, the increasing amount of data, coming from the collection of information from a larger number of patients, makes it difficult to analyse it manually. In the case of gerontology, it is difficult to classify in groups the evolution of the elderly for common pathologies in that age group. To be able to do this would make it possible to know in advance how a pathology or capacity loss will progress in an ageing person and to apply the corresponding preventive procedures. There are already works that try to improve the results of preventive medicine, but these are focused on analysing the current state of the patient and not their foreseeable future. In this article, time series forecasting by means of recurrent neural networks is used to analyse the evolution of the functional profile of ageing people as a time series. Based on the patterns contained in the patient's time series and in the training of a model with data from previous patients, it is possible to determine the future evolution in patients with a similar history. To do this, functional profile data collected on an assessment platform developed by the authors of this article is used.

Keywords: Preventive medicine \cdot Medical informatics \cdot Recurrent neural networks \cdot LSTM \cdot Time series forecasting

1 Introduction

With the increase of age, many patients develop pathologies and capacity losses common in the ageing population. Many of these pathologies and losses are progressive and show a similar evolution in people with similar characteristics [1]. Examples of these are dementia [2] or the deterioration of the functional profile of elders with time [3]. In particular, the latter is something that affects most of the ageing population.

[©] The Author(s), under exclusive license to Springer Nature Switzerland AG 2021 J. García-Alonso and C. Fonseca (Eds.): IWoG 2020, LNBE, pp. 11–22, 2021. https://doi.org/10.1007/978-3-030-72567-9_2

These capacity losses present, in many cases, common patterns of evolution in patients with similar characteristics [1]. This makes it possible for health professionals to anticipate the progression of the capacity loss and combat it as soon as possible. However, to classify each patient case manually is sometimes difficult (or even impossible). Specially, in environments where many patients are treated and there is a need to distinguish between different types of evolution for a given condition. Therefore, in many cases it is complex to anticipate how a patient will evolve and to apply preventive procedures.

To solve this problem, there are proposals that provide software for health professionals to process patient data in order to help with their diagnostics. In the field of preventive medicine, there are proposals that allow, based on a patient's health measurements at a specific moment, to determine if the person suffers from any illness [4,5]. For this purpose, Machine Learning and Deep Learning techniques are applied. However, these proposals use the patient's current state. They do not allow to infer how the patient's condition will evolve in the future to determine if they will suffer from the disease or capacity loss in question or how it will progress. Other proposals analyse, on a theoretical level, the use of deep learning to be able to analyse patient data like a time series and predict future values [6].

This article implements a deep learning model that, based on training with data of the already known evolution of patients as time series, allows the prediction of the future evolution of other patients in the use case of the deterioration of the functional profile of the elderly. The information provided by the development of the *Multidimensional Integrated Assessment Platform for elderly (MIAPe)* [7] is also used as background. From this platform we use the data of the deterioration of the functional profile of the ageing people and their evolution.

Thanks to this proposal it will be possible to determine the future functional profile's evolution of patients with similar conditions. This will allow the creation of personalized treatments for each patient at an earlier stage.

To develop this proposal, the rest of the article is structured as follows. Section 2 shows the works that motivate this proposal. Section 3, details the proposal indicating the data processing performed, alongside the model developed to determine the evolution of a patient based on previous data. Section 4 describes the case study and the results of the validation. In Sect. 5 future work is introduced to increase the scope of this project. Finally, Sect. 6 gives some brief conclusions.

2 Motivations and Related Works

Preventive medicine has a very important place in the field of healthcare. Health researchers are increasingly stressing the importance of augmenting the number of educational resources in this field [8,9]. However, the great variety of diseases (new or not) and the wide range of symptoms that each patient may present for the same disease, makes it difficult for health professionals to detect them at an early stage.

To help health professionals, there are many proposals that try to offer soft-ware that facilitate their work and complement their medical assessments. An example of this type is the proposal of Yu et al. [4] that uses supervised and unsupervised Machine Learning tools to generate predictive models. Thanks to these models, online health assessments are offered to patients and physicians. In this way, personalized and preventive care can be offered through telemedicine. Another type of proposal is that of Sabra et al. in [5], where they are focused on the importance for preventive medicine of analysing and classifying the medical characteristics of patients before offering this data to systems that make predictions. Furthermore, it proposes the use of a hybrid architecture, which makes use of these classified characteristics on various Machine and Deep Learning classifiers, offering stronger predictions.

However, although these and other solutions help to generate diagnoses that allow the detection of diseases that would be complex to detect by a physician without the help of the system, they are limited to work with the patient's health data collected until that moment. Therefore, they do not allow to anticipate the development of a condition, checking out how a condition will progress from that point ahead. Many conditions show a similar evolution in certain groups of patients. Therefore, it could be determined how patients are going to progress according to the evolution of previous patients who presented a similar condition [1]. To make this type of analysis on the evolution of a patient, time series can be used [10]. In this way, the evolution of the disease in a patient can be treated as a time series.

Among the time series analysis techniques, Time Series forecasting is used to predict future values based on previously observed values, with which a prediction model is trained. Examples of the use of this type of technique are the prediction of Meteorological Weather [11] or the prediction of the evolution of cases in pandemics [12]. In the field of health, Hirschfeld pointed out many years ago in [13] that analysing the time series generated by regular observations of patient's health would help in the management of chronic and progressive diseases or capacity losses. To do this, he proposed the use of forecasting techniques on the automated systems of his time. It is not a coincidence that authors such as Bhavya et al. have continued to work on proposals of this type, analysing in [6] the use of different Deep Learning techniques for the generation of prediction models in healthcare. Thanks to this analysis, they have concluded that the use of Recurrent Neural Networks (RNNs) and, specifically, the Long Short-Term Memory (LSTM) RNN, is the best way to analyse time-series medical data.

The solution proposed in this paper uses Time Series forecasting to predict the future values of the functional profile of the elderly based on the previously observed values. For this purpose, time series are generated with the parameters that measure the functional profile of the elderly and are analysed with RNNs, offering an automated analysis tool. The data collected by caregivers and nurses in MIAPe for the functional profile of different ageing people are employed as the starting point.

MIAPe is a platform for monitoring and grouping information about the health of the ageing population. For this purpose, the platform employs the concept of virtual profiles and the integration of health data from IoT devices [7]. Solutions to automate the interaction with these devices [14] are also being worked on. Thanks to the integration of the health data of an ageing person in this platform, it is possible to generate their *Personal Health Trajectory* [15].

3 Predicting Evolution Using Deep Learning

The solution presented in this paper is divided into two different parts. First, the acquisition and preparation of the data needed to train the deep learning model. Next, the definition of the deep learning model, using a LSTM RNN, for the time series forecasting.

3.1 Data Acquisition and Processing

The first step, before starting to define the model with which the time series forecasting will be performed, is to prepare the data to be used. To do this, the data that compose the functional profile of an ageing person has been collected, according to the functional profile evaluation method used in the MIAPe platform.

According to MIAPe, the functional profile of an elderly person is composed of five measures: (1) overall score of functionality, (2) self-care, (3) learning and memory functions, (4) communication and (5) relationship with friends and caregivers. The values of these measures are calculated with the value obtained for the three aspects evaluated in the Elderly Nursing Core Set (ENCS) [16] form: body functions, body structure and ambiental factors. So, knowing the numerical value obtained in each of these three aspects, the functional profile of the ageing person at any given time can be calculated.

Having the data of these three parameters for the evaluations that have been done until that moment, a time series is generated with the evolution of each parameter for each elder. This way, the evolution of the functional profile of an elderly is represented by three time series: one for each parameter. So, the aim is to predict the value that will be obtained in the next evaluation for each parameter, taking into account that the time between evaluations is equidistant.

In order to generate the time series of each parameter, it is necessary to collect the ordered values that have been obtained in the successive evaluations of an elderly person and store them in a structure that maintains this order. For the given implementation, the values have been stored in an array, so that each elder has a vector for each of their parameters (see Fig. 1). The values of these vectors are those given to the prediction model for training. At the time of forecasting with the trained model, the values of the three time series (one per parameter) of the new elder must be provided as input to the model in the same format.

| | functions | structures | ambiental factors |
|----------------|------------------------------|------------------------------|------------------------------|
| Elderly Number | | | |
| 0 | [12, 12, 12, 12, 12, 33, 28] | [67, 70, 63, 52, 50, 55, 83] | [33, 33, 33, 27, 27, 53, 20] |
| 1 | [40, 22, 40, 17, 22, 17, 20] | [95,82,95,65,82,68,58] | [87, 67, 87, 80, 80, 60, 60] |
| 2 | [22, 23, 17, 17] | [68, 68, 52, 42] | [67, 60, 60, 60] |
| 3 | [13] | [52] | [53] |
| 4 | [27] | [100] | [60] |

Fig. 1. Dataframe that store the time series of the functional profiles.

3.2 LSTM's Model for Time Series Forecasting

The model used to make the type of predictions proposed in this paper (time series forecasting) is a Recurrent Neural Networks (RNNs) model. A neural network of this type is employed because of its ability to maintain data memory. This means that its neurons have feedback, taking the outputs obtained with previous inputs as new inputs. Thanks to this, long data sequences can be analysed step by step. In particular, between the different types of RNNs, the use of the Long Short-Term Memory (LSTM) is chosen. This type of RNN has a better long-term memory than classic RNNs.

After selecting the type of model to be used, each of the sub-sections that had to be considered for the definition of the model are discussed below.

Type of Forecasting. When a model for this type of analysis is defined, it is also important to define what type of time series forecasting is being done. Specifically, it is carried out a type of forecasting known as Multivariate Forecasting, due to the fact that, for a specific time mark in the evolution of the data, there are more than one observation (one for each of the three parameters/time series used). Specifically, within Multivariate Forecasting, this is a Multiple Parallel Series problem because, at the moment of predicting it is necessary to calculate a new value for each of the parameters/time series that are used as input. So, there are as many outputs as inputs.

Inputs and Outputs. It is also essential to define which are the inputs and outputs of the model. In the case of outputs, the model must predict three numerical values (one per parameter of the functional profile). This is a regression problem (not a classification one, as it is often the case with neural networks), so the output values will be continuous values (not discrete).

As input, the three time series representing the evolution of the patient's functional will be taken. However, there is no type of RNN that supports a time series (coded as a vector, for example) of variable size as input. The input that is given to the model must be of a fixed size. As not all the elders have the same amount of evaluations and this number is changing (increasing) over time, the solution is to send to the model a fixed amount of the last samples of the time series. This amount must be defined and this data is the one used to calculate the output of the model. In this case, because there are few elderly people with many evaluations in the dataset, only the last two samples of each time series

that make up the evolution of the elderly person are taken as inputs. This number of samples is small but enough for the proposal presented in this paper. For the application of this proposal in a real environment, a greater number of samples would be required.

In this way, to be able to analyse the full evolution of an elderly person, each of their time series will be fragmented into overlapping fragments of three values, for training (two input and one output), and of two values, for predictions (two input). For example, a person with 6 evaluations will generate 4 such fragments for training and one fragment with the two last values to predict the next value with the model.

Predictions. To predict new values, for each time series delivered as input to the model, an array with two (ordered) values from this time series must be given to it. With these values and the learning obtained, the model gives as output a new value for each of the time series to which the values belong. In this way, the model is offering the next value of each time series or, what is the same, the predicted value of each parameter in the next evaluation of the elder.

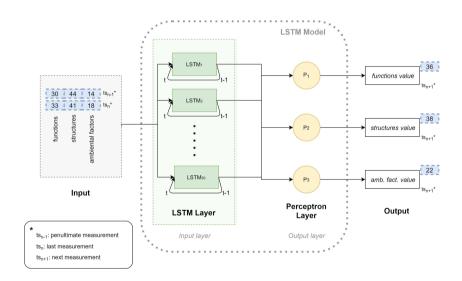


Fig. 2. Structure of the LSTM's model

Structure of the Neural Network. After defining the type of network used and its inputs and outputs, Fig. 2 shows the structure of the implemented neural network. This network is composed by only two layers: an LSTM layer as input and a simple perceptron layer as output.

The LSTM layer is the one that makes this model a RNN. When the problem to resolve is not too complex, the use of only one LSTM layer is the best option [17]. In this case, it is a stateless LSTM layer, which does not hold memory from

one batch to another. This type of LSTM's configuration is chosen because in the training dataset the fragments of the time series of all the elderly people are combined, in order to improve the generalization of the model, to predict the evolution of an elderly person based on the evolution of others. If it were a stateful LSTM, the neurons of this layer would keep in memory the results obtained with the previous training fragments. This gives very good results when the training is based on only one time series (in this case, if only the three time series of one elder were used to train the model). This layer is composed of 50 neurons with relu activation. The number of neurons has been adjusted based on the validation data. The activation function used has been selected because it offers better results in terms of learning, but it has the problem that it can flatten the volatility of the time series. In this case, by using few values as input, flattening the volatility is not a problem. Finally, this network takes 6 parameters as inputs (two measurements of each of the three time series of evolution).

The next layer is a simple perceptron layer, as used in MLP neural networks. This layer is used to transform the output of the 50 LSTM neurons of the previous layer into the 3 numerical values to be predicted. As activation, a linear function f(x) = x is used, so that it returns as output the value obtained directly by each neuron. This is a regression problem, where it is necessary to calculate continuous values and not to classify them into discrete values.

Training Parameters. To train the model, it is necessary to define another set of parameters. First, the loss function to evaluate if the model is learning and the degree of it. In this case, the Mean Square Error (MSE) function has been used, one of the most used loss function for regression problems. The optimization function is another of the parameters to be defined. It has been evaluated the choice of Adam or RMSprop, two of the most used ones. Although both are based on Stochastic Gradient Descent, the Adam function is better than RMSprop in terms of performance. Therefore, Adam will be used, together with a learning rate of 0.0002, adjusted based on the loss and accuracy function. And, finally, the number of epochs to train, which has been fixed at 400. The reason behind choosing these values of learning rate and number of epochs will be discussed in Sect. 4.

To conclude this section, it is important to mention that the value of some of the parameters discussed have been adjusted according to the data employed to the validation. The use of a different dataset would imply that parameters such as the number of layers and neurons should be adjusted. The learning rate and the epochs would also have to be adjusted again if data changes.

4 Validation

In order to validate the solution presented in this article, a validation phase has been carried out. Data about the accuracy of the system and the quality of the training has been collected using a dataset from the MIAPe platform.

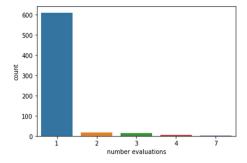


Fig. 3. Graphic related to the number of evaluations per elderly

4.1 Case Study

The case study used for the validation is the same introduced along this paper. The data of the elderly's functional profile collected by the MIAPe platform have been used. This functional profile is composed by five indicators, calculated from three measures that are evaluated by the elderly carers through the *Elderly Nursing Core Set (ENCS)* form.

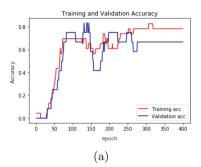
In total, MIAPe stores the data of approximately 1300 patients. Of these, 647 have at least one functional profile assessment. There are 720 functional profile assessments belonging to these 647 different elderlies. Therefore, it can be deduced that most of the elderly have only one assessment, so their data will not be optimal to the proposal of this paper. To check this, the distribution of the number of assessments per elderly can be seen in Fig. 3. Only 22 ageing people have 3 or more evaluations (minimum number of evaluations required for their evolution to be used on the training of the proposed system).

4.2 Results and Discussion

With the data collected from the case study, the model developed in the proposal has been evaluated. For this purpose, the accuracy obtained (Fig. 4a) and the format of the loss function (Fig. 4b), which evaluates the learning of the model, have been measured. This way, with the data represented on the two charts of Fig. 4, a series of conclusions can be extracted.

Thanks to the accuracy chart, it can be seen that the model is trained without overfitting, except in the last few epochs. If the loss chart is looked for those last epochs, it can be seen that this overfitting occurs at the moment the model starts to learn the training data "by memory", achieving lower losses than with the validation set (as opposed to before the overfitting). Having a model with too many epochs can lead to such a situation. Especially in cases where there are problems with the data. In this case, they are insufficient.

In order to situate the magnitude of the above statement, it is necessary to indicate that the dataset only contains data from 22 elderly people, which with their data allow the generation of 35 records from three evaluations.



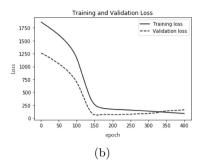


Fig. 4. Results of training with case study's data for (a) accuracy and for (b) loss.

Of these 35 records, 23 are used for training and 12 for validation. Any model of Machine Learning needs more data to be able to train correctly. In particular, Deep Learning models, such as this neural network, need even more data to train.

In addition to testing the final combination that gave the results shown in the figure above, other configurations were also tested, which allowed the exploration of how the results varied according to the number of layers, the activation function and other parameters that are commented on below.

First, it has been tried to modify the structure of the model. The first thing that has been adjusted is the number of LSTM layers. A configuration with two layers has been tested. However, it increased the complexity of the model, reaching an overfitting situation earlier and causing a worse training. In the LSTM RNN it is common to use one LSTM layer for simpler problems and two LSTM layers for more complex problems [17]. Configurations with more LSTM layers are not usually common, so they were discarded. As next step, the number of neurons in the LSTM layer has been adjusted. Different configurations have been tested. From 20 neurons per layer to 100. Finally, 50 neurons were chosen, as the results did not change much. Furthermore, the use of 100 neurons generates a model with unnecessary complexity (at least with the current amount of data) and therefore more susceptible to overfitting.

With regard to the learning rate, an effort has been made to adjust it based on the accuracy and loss function through the epochs. Although the value chosen is the one that gave the best results, a learning rate totally optimal and that generate a correct learning has never been achieved. This is clearly due to the amount of data because, by looking at the Fig. 4b, it can be seen that the loss function starts with a very small decrease (as if the learning rate was low) and in the subsequent epochs it decreases suddenly (as if the learning rate was high). Thanks to this, it is known that, with the current data, it will never be possible to obtain a learning rate that leads to correct learning.

Focusing now on the number of epochs, it has not been possible to determine an appropriate number because of insufficient data. A high number has been set to show the oscillation that occurs in the accuracy of successive epochs and how the loss function decreases. For the batch size, the default value of keras (32 samples) has been left, because, for the amount of data available, adjusting the batch size will not bring any benefit. When the amount of data will be greater, the batch size should be adjusted on the basis that if it is very low there will be noise in the loss function (depending on the bias of the data also) and if it is very high the model will not learn correctly.

As discussed in the process of adjusting the most training parameters, there are several indicators that show that the amount of data is small. Another indicator that has been found is that, although the training and validation sets are always split in the same way, the results that are obtained if the model is trained several times vary for each of these trainings.

It is also important to remember that the actual model is trying to determine the next evaluation based on only 2 evaluations. Therefore, obtaining a high probability of success is difficult (and even less if there are more different patients). If there would be enough data to be able to train a model that predicts based on more assessments, the accuracy would probably increase.

5 Future Works

Having defined everything that has been done so far, it is easy to see that the main future work is to obtain sufficient data to validate the proposal set out in this article.

However, by the time this happens, two lines of research have already been identified for continue working and improving the current proposal.

Determining Using Groups of Patients with Similar Evolution. When the number of different patients with evaluations increase, integrate the data of very different patients, with very different evolution, would make the model need a lot of data to learn correctly and could still decrease its performance. To solve this, the development of a system that, by applying other patient characteristics (e.g. age, weight or gender), allows the generation of groups with similar evolution is proposed. In this way, patients would be classified in these groups and an independent model would be generated for each group.

Automatic Model Adjustment and Learning. The proposed prediction model is used in a dynamic environment, where the amount of data is constantly growing (new patients and new assessments). Because of this there will be certain situations when the network parameters will have to be adjusted to adapt the model to the new complexity of the problem. Being able to automate this process would help to always maintain a model that offers high-quality predictions.

6 Conclusions

This paper proposes the development of a deep learning model that, by using time series forecasting, allows the analysis of the evolution of the functional profile of ageing people. In this way, automated predictions will be offered of how the functional profile of an elderly person will advance in the near future, based on their evolution to date and that of patients with a similar more advanced evolution.

This solution brings benefits to the proactivity of preventive medicine, helping health professionals to create diagnoses for patients by having a vision of how expect the patient will evolve in the near future. In addition to the functional profile of the elderly, a solution of this type can be extended to the analysis of any progressive capacity losses or pathology, which can be analysed using the evolution presented by the patient.

In order to validate the proposed model, it has been used the data of the functional profile of the elderly stored in the *Multidimensional Integrated Assessment Platform for elderly (MIAPe)*, developed by members of the research team to which the authors of this article belong. However, the amount of data available is still too small to affirm with complete certainty the validity of the proposed model.

In this way, a series of future improvements have been proposed which would improve the results obtained by the proposal, when sufficient data are available to evaluate it.

Acknowledgements. This work was supported by the project 0499_4IE_PLUS_4_E funded by the Interreg V-A España-Portugal 2014–2020 program, by the project RTI2018-094591-B-I00 (MCIU/AEI/FEDER, UE), by the FPU19/03965 grant, by the Department of Economy and Infrastructure of the Government of Extremadura (GR18112, IB18030), and by the European Regional Development Fund.

References

- Wang, Y., Zhou, X., Noulas, A., Mascolo, C., Xie, X., Chen, E.: Predicting the spatio-temporal evolution of chronic diseases in population with human mobility data. In: IJCAI International Joint Conference on Artificial Intelligence, July 2018, pp. 3578–3584. International Joint Conferences on Artificial Intelligence (2018). https://doi.org/10.24963/ijcai.2018/497
- 2. Flicker, C., Ferris, S.H., Reisberg, B.: Mild cognitive impairment in the elderly. Neurology 41(7), 1006–1006 (1991). https://doi.org/10.1212/WNL.41.7. 1006. https://n.neurology.org/content/41/7/1006
- 3. Jacobs, J.M., Maaravi, Y., Cohen, A., Bursztyn, M., Ein-Mor, E., Stessman, J.: Changing profile of health and function from age 70 to 85 years. Gerontology 58(4), 313–321 (2012). https://doi.org/10.1159/000335238. https://www.karger.com/Article/FullText/335238
- Yu, C.S., Lin, Y.J., Lin, C.H., Lin, S.Y., Wu, J.L., Chang, S.S.: Development of an online health care assessment for preventive medicine: a machine learning approach. J. Med. Internet Res. 22(6) (2020). https://doi.org/10.2196/18585
- 5. Sabra, S., Malik, K.M., Afzal, M., Sabeeh, V., Charaf Eddine, A.: A hybrid knowledge and ensemble classification approach for prediction of venous thromboembolism. Expert Syst. **37** (2020). https://doi.org/10.1111/exsy.12388

- Bhavya, S., Pillai, A.S.: Prediction models in healthcare using deep learning. In: Advances in Intelligent Systems and Computing, AISC, vol. 1182, pp. 195–204. Springer (2019). https://doi.org/10.1007/978-3-030-49345-5_21. https://link.springer.com/chapter/10.1007/978-3-030-49345-521
- Moguel, E., Berrocal, J., Murillo, J.M., Garca-Alonso, J., Mendes, D., Fonseca, C., Lopes, M..: Enriched elderly virtual profiles by means of a multidimensional integrated assessment platform. Procedia Comput. Sci. 138, pp. 56–63 (2018). https://doi.org/10.1016/j.procs.2018.10.009
- 8. Shi, H.Y., Wang, S.Z., Yang, X.J., Lin, L., Hu, J.Y.: Preventive medicine curriculum system in training program of clinical medicine in the era of Healthy China. Zhonghua liu xing bing xue za zhi = Zhonghua liuxingbingxue zazhi 41(7), 1155–1159 (2020). https://doi.org/10.3760/cma.j.cn112338-20200104-00009
- Liu, Y., Jin, G.F., Wang, J.M., Xia, Y.K., Shen, H.B., Wang, C.Q., Hu, Z.B.: Thoughts on the reform of preventive medicine education in the context of new medicine. Zhonghua yu fang yi xue za zhi [Chin. J. Prev. Med.] 54, E030 (2020). https://doi.org/10.3760/cma.j.cn112150-20200328-00461
- $10.\ \ Wei,\ W.W.S.:\ Oxford\ Handbooks\ Online\ Time\ Series\ Analysis,\ vol.\ 2,\ March\ 2013.$ $https://doi.org/10.1093/oxfordhb/9780199934898.013.0022.\quad https://www.oxford\ handbooks.com/view/10.1093/oxfordhb/9780199934898.001.0001/oxfordhb-9780199934898-e-022$
- Ramos, M.M.P., Del Alamo, C.L., Zapana, R.A.: Forecasting of meteorological weather time series through a feature vector based on correlation. In: Lecture Notes in Computer Science (Including Subseries Lecture Notes in Artificial Intelligence and Lecture Notes in Bioinformatics), LNCS, vol. 11678, pp. 542–553. Springer, September 2019. https://doi.org/10.1007/978-3-030-29888-3_44
- Tomar, A., Gupta, N.: Prediction for the spread of COVID-19 in India and effectiveness of preventive measures. Sci. Total Environ. 728 (2020). https://doi.org/10.1016/j.scitotenv.2020.138762
- Hirschfeld, W.J.: Forecasting and chronic illness. Bull. Math. Biophys. 33(3), 425–437 (1971)
- Rojo, J., Flores-Martin, D., Garcia-Alonso, J., Murillo, J.M., Berrocal, J.: Automating the interactions among IoT devices using neural networks. In: 2020 IEEE International Conference on Pervasive Computing and Communications Workshops (PerCom Workshops), pp. 1–6 (2020)
- Rojo, J., Hernandez, J., Murillo, J.M.: A personal health trajectory API: addressing problems in health institution-oriented systems. In: Bielikova, M., Mikkonen, T., Pautasso, C. (eds.) Web Engineering, pp. 519–524. Springer, Cham (2020)
- Goes, M., Lopes, M., Oliveira, H., Marôco, J., Fonseca, C., Santos, M., Caeiro, J.: Psychometric qualities of a core set to ascertain the functional profile of Portuguese elderly citizens. In: García-Alonso, J., Fonseca, C. (eds.) Gerontechnology, pp. 314– 329. Springer, Cham (2020)
- Reimers, N., Gurevych, I.: Optimal Hyperparameters for Deep LSTM-Networks for Sequence Labeling Tasks, July 2017. http://arxiv.org/abs/1707.06799



The Role of the Blockchain Technology in the Elderly Care Solutions: A Systematic Mapping Study

Edgar Dulce^{1,2(\boxtimes)} and Julio Hurtado^{2(\boxtimes)}

 Universidad Nacional Abierta, Pasto, Colombia edgar.dulce@unad.edu.co
 Universidad del Cauca, Popayán, Colombia ahurtado@unicauca.edu.co https://www.unad.edu.co

Abstract. The incorporation of technology in the improvement of health care for the elderly is identified as a potential strategy that maximizes the effectiveness of the provision of health services, generating a higher quality of life for older adults. However, an important health general concern is the security and data privacy. Thus, blockchain technologies are an opportunity for supporting them in this kind of solutions. However, due to lack of an unified knowledge about how blockchain could be applied, we present a systematic mapping study (SMS), in order to understand from primary studies as blockchain technology is supporting care solutions for the elderly. We selected Springer, ACM Digital Library, Scopus, IEEE Explore, and Direct of Science databases, which are consistent with the discipline of study. Among the main findings are different types of Blockchain that are being applied in many ways to positively support aspects of the healthcare solutions, such as in the registration, consultation and transmission of sensitive data, time banks, smart home sensor, wireless Body Area Networks (WBAN), user login, Wireless Sensor Network (WSN), Ambient Assisted Living (AAL), telemedicine in solutions combined with IoT or supported cognitive, physical therapy and others.

Keywords: Blockchain \cdot Elderly \cdot Systematic mapping studies \cdot SMS \cdot Health

1 Introduction

Globally, the proportion of the population aged 80 and over is projected to increase more than threefold between 2017 and 2050 [6]. Ageing societies will face more complicated and costly demands for improved, or even sustained welfare. These challenges will require major changes including new technologies and social innovations in elderly care.

Blockchain technologies has generated interest from various academic and industrial settings, and its applications have been studied in financial environments (where it started) and growing in many areas of ICT. In this paper, we addressed how blockchain technologies has been applied for to supporting solutions related to the care of the elderly through a literature review using the systematic mapping method proposed by Petersen et al. [16]. Our research shows that there is an increasing amount of research into blockchain-based solutions that can be used to address elder care. Likewise, the literature shows that it is evidenced that many health technologies and areas are supported by blockchain to improve the care of the elderly, as can be seen in the results section. The rest of the paper is organized as follows. Section 2 introduces the definitions and basic concepts of the study. Section 3 describes the methodology used. Section 4 presents our findings. Discussion and conclusions are presented in Sect. 5 and Sect. 6 respectively.

2 Background

Blockchain applications have been studied in financial environments (where it started) as well as other growing areas of ICT, evidenced in [2], who carried out a systematic literature review, yielding a total of 209 high-level articles related to Blockchain. The public World Economic Forum in 2015 [25], that by 2025, 10% of the world's gross domestic product will be stored using Blockchain. The term was initially introduced by Satoshi Nakamoto in an article about Bitcoin [15]. Now considered as a general purpose technology, used in different industries and use cases, such as identity management, contracts, supply chain, insurance, healthcare, voting, among others. Basically, Blockchain consists of a technology capable of building an open and distributed database, with a distributed ledger as core which is collaboratively immutable [26]. The ledger is composed of interlocking data structures called blocks (hence its name blockchain), arranged chronologically and correlatively [15]. Each block contains a timestamp, a hash pointing to the previous block and data of each transaction [7]. The generation or obtaining of new blocks to advance in the construction of the chain, is achieved through the use of mathematical functions of data correspondence or algorithms that have been previously designed and contractually predetermined by the chain managers. In this way, each time an algorithmic function is applied to the data to be recorded in the chain, a new hash is output that serves as a fingerprint uniquely associated with such data [2]. It is not possible to reproduce the information without the participation of all its nodes and it can be transmitted confidentially without a trusted third party. The technological component in Blockchain is quite disruptive [13] it can be shaped in different ways by the actors and needs of each sector where it is implemented [26].

Over the next 20 years there will be a demographic shift from predominantly younger to older populations [14]. The number of patients with chronic diseases in the world has increased from 118 million to 149 million in the last 25 years, while the number will increase to 171 million in the next 10 years [1]. Current

models of care and pathways need to be transformed to become more citizencentered and to support greater community resilience and sustainability. This will require different approaches to information technology innovation oriented to improve elderly quality of life as they age, in order to reduce the onset of frailty as they age [14]. There is a need to evolve from predominantly disease-focused care delivery to socially oriented care with increased attention to quality of life and social support [19]. However, low-efficiency conventional medical and healthcare systems cannot provide timely and efficient medical services to the public [4]. Measuring, tracking and promoting well-being can be useful for multiple stakeholders involved in disease prevention and health promotion. Cities and governments are placing increasing emphasis on well-being in public policy and urban planning. This is consistent with the paradigm shift that has taken place in public health: from a focus on morbidity and mortality to a focus on health and well-being.

3 Description of the Research Protocol

We selected the methodology of Petersen et al. [16] for conducting the SMS. The purpose of the study is to explore the field of blockchain technology in the care of the elderly. The SMS allowed us to identify and classify research topics in blockchain technology related to the care of the elderly solutions. Also, different facets of the schema can be combined to answer more specific research questions. A SMS is divided into several steps, namely defining the research questions, conducting the search, searching for relevant articles, writing keywords using abstracts, and data extraction.

3.1 Research Questions

The first step in a SMS is to define the research questions to be answered by the study. For searching related primary studies, the following research questions were defined: **RQ1**: In what way is blockchain technology being used for the care of the elderly solutions? **RQ2**: What security solution does blockchain offer in this type of solutions for the care of the elderly solutions? **RQ3**: What type of blockchain (private, public, other) do the authors use to support the care of the elderly solutions?

3.2 Conducting the Search

The second step was to search and gather all research papers related to blockchain technology in relation to the care of the elderly solutions, based on a specific search string build from the research context and the research questions. We chose the search string (blockchain) AND ("old age" OR elderly OR "older people" OR "older adults" OR "senior citizens"), because it relates blockchain technology with various synonyms used in the care of the elderly. Having identified the keywords for the searching task, we selected the

relevant electronic databases to carry out the search, the analysis of the results of [5], who provide a list of important databases in the field of Computer Science and Engineering. Then, to focus the search, this list was narrowed, obtaining the databases that cover the most important conferences and journals in the field of technology. We selected five scientific databases for conducting our search: Springer, ACM Digital Library, Scopus, IEEE Explore, and Direct of Science.

We used a bubble plot to report the frequencies, shown in Fig. 1, in which you can see the total number of papers categorized by each of the databases.

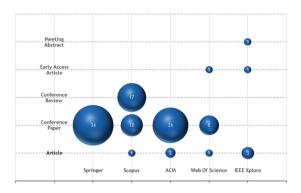


Fig. 1. Visualization of the number of papers obtained, by type in databases

3.3 Searching for Relevant Papers

Table 1 summaries the inclusion (I) and exclusion (E) criteria defined to add or eliminate relevant/irrelevant papers to the analysis

| Inclusion | Exclusion |
|---|---|
| I1: Papers published in the last five (5) years (2016–2020) | E1: Technical reports, abstracts, surveys (gray literature) secondary studies (SMS) |
| I2: If several papers are related to the same study, only the most recent one is selected | E2: Papers in languages other than English or Spanish |
| I3: If a paper describes more than one study, each study is evaluated individually | E3: Papers that do not present studies related to blockchain, elderly or synonyms |
| I4: If there are short and full versions of the same study, we select full | E4: Papers type Article (Journal), Conference Paper and Early Access Article |

Table 1. Inclusion and exclusion criteria

3.4 Keywording Using Abstract

With the inclusion and exclusion criteria been defined, the next stage is finding the relevant papers through abstracts is keywording. For this stage, we used the process defined by Petersen et al. [16]. The titles and abstracts (and sometimes the introduction and conclusions), were revised to identify those considered irrelevant to the topics studied. After applying these criteria, the final selection of papers was carefully read, and the data contained therein was extracted, analyzed and categorized. The final set of papers and data analysis are presented in the results section.

3.5 Data Extraction

The papers were analyzed and classified according to categories created to separate the research contributions of each paper (Results section). The data extracted from the papers were stored and subjected to qualitative and quantitative analysis. This analysis aimed to find evidence to answer the research questions defined in the Conducting the Search section. To organize the findings and document the data extraction process, a spreadsheet was used¹, which also allowed other statistical analyzes to be carried out, such as determining the number of publications per year, by place, and by type, among other analyzes.

4 Results

The aim of this paper is to know about the current uses of blockchain-based technology in the care of the elderly, describing different initiatives and discussing their social implications and future perspectives. Figure 3 shows the process indicated in Sect. 3, in the **Description of the research protocol**. Initially, when searching the selected databases, 122 papers were obtained. Of these, it was identified that 12 of them are stored in more than one database, therefore, duplicates are also eliminated, leaving only one copy of each paper in the records. Thus, for the next step, 110 papers remained to be analyzed. Next, the inclusion and exclusion criteria (I1 + E1 + E2) are applied in the 110 papers, including those published in the last five (5) years and, excluding records that do not correspond to published papers, conference or chapters of book, and those written in languages other than English or Spanish, leaving 105 articles. We applied the inclusion and exclusion criteria (I2 + I3 + I4 + E3 + E4) to the 105 papers, reading their title and abstract, identifying 14 relevant works with the topic, the 14 papers that were used as evidence to answer our RQ. The list of these documents appears in the References section at the end of this document. For the review and analysis of the complete documents, and to avoid bias on the part of the researcher, we was supported by an expert external to the research. Next, we are giving an overview of the classification of the final 14 papers, detailing some characteristics to expand their description (Fig. 2).

¹ Supplementary material for data processing: https://bit.ly/31c9ZZA.

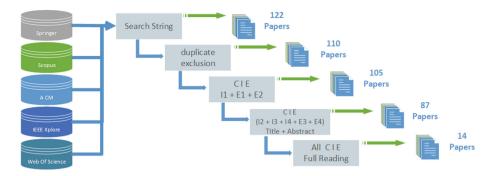


Fig. 2. Article filtering process overview, adopted [18]

Figure 3(a) shows the number of papers by type of publication (Journal Article, Conference Paper and Early Access Article) versus the database from which they were obtained. In this sense, the number of Conference Papers (9 papers) are the most frequent, followed by Article of journals (3 Articles) and finally, Early Access Articles (2 papers).

This result highlights the importance of conferences for the dissemination of research on the topic of blockchain in relation to the care of the elderly.

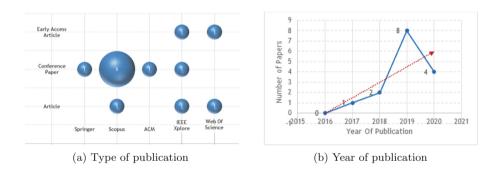


Fig. 3. Number of papers by type and year

Observing the frequency of publications, it was found that 93% of the studies on the subject were published in the last three years as shown the Fig. 3(b). This gradually increasing trend indicates the growing importance and potential of the research topic. As can be seen, the trend is increasing, in addition the revision was carried out with a few months to finish the year 2020.

To respond to **RQ1:** in what way is blockchain technology being used for the care of the elderly solutions?, a classification scheme was carried out, which was studied by Kötteritzsch and Weyers [12], that groups different aspects on which it is possible to relate categories and their characteristics that help to classify the systems, challenges and trends for the future in research with

older people (Fig. 4). These categories were extracted from the content of the reviewed contributions and incrementally subjoined. The most basic category, type of contribution, includes systems, services and studies. The application context covers a range of topics, within this category "intervention" includes measurements for care, prevention and rehabilitation; "presence" includes virtual and actual presence. Systems also use different means of adaptation. Finally, the literature includes systems, studies, and services in certain stages (status). The results analyzed were classified in the final 14 papers, which illustrate the work on blockchain technology in the support of the elderly. Taking into account to Mohtari et al. [14], the role of helpers or volunteers is going to gain greater importance every day and their services are essential for the elderly, according to figures from EPTA [6], Mokhtari et al. [14], people with disabilities or who require the help of a third to have a harmonious life. Taking into account the Status category of Fig. 4, 9 of the 14 final papers develop prototypes and proofs of concept, which shows the need to investigate and delve much more into functional proposals in the field of blockchain.

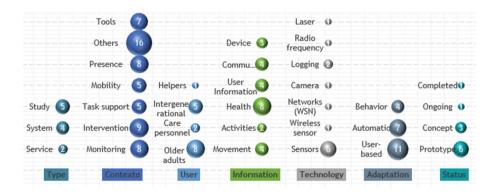


Fig. 4. Classification categories and characteristics found in the final papers.

To address the answer to the research question, RQ2: What security solution does blockchain offer in this type of solutions for the care of the elderly solutions? the properties offered by blockchain in each of the selected papers were analyzed, evidencing the way in which it is integrated into solutions for the elderly. For summary purposes, the 10 most common characteristics are shown in Fig. 5(a). These characteristics were classified according to ISO 27001, which is an international information security standard that aims to ensure the confidentiality, integrity and availability of the information of an organization and the systems and applications that treat it. Likewise, the above confirms the great potential that blockchain has in the field of information security. In Fig. 5(a), of bubbles, we can see how many papers (size of the bubble) took into account a characteristic of computer security, which is intrinsic to blockchain. One of the most outstanding characteristics of Fig. 5(a) is that blockchain technology is used in its vast majority in solutions for the assurance and storage of

personal or sensitive data, in this field, in the analyzed projects blockchain is used for: management of personal information storage [14,17,20], store data in various distributed data sources [3,17,19], store events that occurred in the system to generate traceability [8,21], store data anonymously [9], store data from vital signs and ensure data exchange through smart contracts [11], therapeutic data privacy, ownership, generation, storage, and sharing [10], multi-levels of privacy and data security [24], blockchain storage to protect patient privacy and provide access control [27]. One of the strengths of blockchain is to guarantee traceability, which is a cross-cutting feature of the CIA, which helps to guarantee data privacy, auditing and monitoring of transactions [19,21,24].

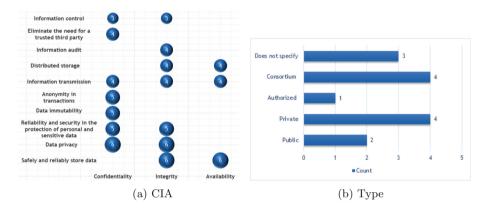


Fig. 5. Purposes of using blockchain in care of the elderly and Type of blockchain

According to the research question RQ3: What type of blockchain (private, public, other) do the authors use to support the care of the elderly solutions? Fig. 5(b) shows a summary of the different types of blockchain used in each of the 14 papers analyzed. There is no bias for using one type or another, some authors mention that this depends on the situation and type of solution offered, for example, in some cases where public data is handled, a blockchain of this type would be the best option, or in the case of projects that have different types of data protections, you can select between a private, authorized blockchain, and if several entities are involved in the project, by a consortium blockchain.

5 Discussion

The vast majority (9 of the 14) of the papers selected were part of academic events, showing a positive result, since in these events novel and general interest studies are published. On the other hand, we can see that the final 14 papers come from institutions represented in 17 countries, with participation from the 5 continents, this indicates that blockchain in relation to the care of the elderly is being investigated around the world.

5.1 Elderly Needs

The population over 60 years of age is growing and as predicted by [6], it tends to triple in the next 30 years. The foregoing raises concern in many areas of interest for the elderly society. To answer the QR1. The results show that there are many characteristics and categories in which blockchain is being taken into account for the care of the elderly. In Fig. 4 you can see 7 categories in which the different types of solutions aimed at providing services that support the care of the elderly can be framed, these are: type, context, user, information, technology, adaptation and status. The papers were analyzed, depending on the contributions in each category, ranging from the support of physical or cognitive activities [10,14], help coping with impairments and care support [14,21,22]. Most approaches focus on accident management by monitoring [20], the healthcare status [17], or predicting behavior [19]. A high number of monitoring systems leads to an increased usage of sensors [9], wireless Body Area networks (WBAN) [17], radio frequency tracking, predict intention and activities [24,27]. Ambient Assisted Living (AAL) [11], chronic disease monitoring through telemedicine [3]. Another major theme is digitally supported cognitive or physical therapy [10]. While most of the contributions present prototypes (6), some products for individual support were already in the market (1), and some had not yet exceeded a conceptual phase (3). Others present ongoing or completed studies. All of these contributions share the goal of supporting older adults in one or more aspects of everyday life and improve the quality of life.

5.2 Blockchain for the Care Elderly Solutions

As a result of the selection process of the final papers, it can be clearly evidenced that blockchain related to the care of the elderly is being investigated from multiple perspectives and offering a number of solutions to improve the quality of life of the elderly. To respond to **RQ2**, it is no stranger to the object of study, that blockchain is analyzed as a technology that provides security and that blockchain offers many security alternatives oriented to the care of the elderly. The foregoing is evidenced in the classification of Fig. 5(a), where it shows that blockchain has many variables immersed that contribute to improving the computer security environment that directly impact confidentiality, integrity and availability, essential at the time of providing a service care and attention to the elderly. Likewise, the concern of the authors of the final papers is clear, to offer a security scheme in each of their results, since all 14 articles related aspects that show the use of blockchain to contribute to the improvement of a specific service aimed at caring for the elderly. Taking into account the above, as mentioned in [17,19], it is feasible to use blockchain for the management (storage, consultation, transfer and audit) of EMR Electronic Medical Records, which are structures used to transport patient data and achieve interoperability between different Health Information Systems (HIS) [7], which require a broad security ecosystem, such as that shown in Fig. 5(a), with them, patients will also have control of their own health data and can decide how it is used. Data sharing between healthcare stakeholders will be easier, better controlled, transparent and reliable. A broader vision is the need to generate reference software architectures to achieve the interoperability of the different types of data storage (databases, flat files or the cloud) with blockchain, and guarantee the communication of the different modules. Regarding QR3, in relation to the type of blockchain that the authors of the final papers stated to take into account for their studies, there is no inclination for a particular type. Moreover, it is seen in Fig. 5(b), that practically the 4 most common types of blockchain are being used, the authors conclude the type of blockchain directly depends on the context of use, the level of privacy and protection of the data required by the proposed solution. Each of the types of blockchain has its advantages and disadvantages, their main difference is the scope, access to transactions and the consensus mechanism they use. In [3,20] lean towards handling ethereum private blockchain, as an open source platform, compatible with many decentralized application frameworks, also for your proposed work due to homeowner's privacy information and the immutability of data transaction, auditability, integrity and authorization, also, it provides simplicity and modularity in developing Distributed Applications. In [19], a combination of a private blockchain is used to store the healthcare data and a consortium blockchain to store the pointers to that information. Hyperledger Fabric is used, which is an opensource platform that does not present or encourage mining [17]. In fact, it doesn't use computationally expensive consensus algorithms like the Proof of Work (PoW) and Proof of Stake (PoS) varieties at all. Likewise, the public blockchain is used, because the stored data is required to maintain free accessing [9].

6 Conclusions, Challenges and Future Work

Most of the current research about Blockchain technology for the care of the elderly focuses on issues such as storage, security and privacy of sensitive data and health care Fig. 5(a). Another important aspect to analyze is the combination of tools, services, blockchain and elderly, showing that 8 of the 14 final papers [3,9–11,20,23,24,27] described a solution based on IoT and blockchain, which aim to allow loved ones and Medical professionals monitor and care for a patient remotely, providing peace of mind and empowering the patient by allowing them to receive care in the comfort of their own home. We have also found a lack of any kind of architectural aspects or models for supporting the development of support systems for the elderly using blockchain, for instance security and interoperability.

Blockchain has many security features, including confidentiality, anonymity, decentralization of information, integrity, availability, non-repudiation and traceability, which make it an ideal technology to support services, systems and products, which in the field of Elderly care is required to provide quality of life to people. The other characteristics can be seen in Fig. 5(a). There is no common denominator for the type of blockchain used in the analyzed papers, although

taking into account the type of data that is handled in the proposed solutions, most of them preferring private blockchain, in which there is a greater control over the registration, transmission and consultation of data; in addition, there are different consensus mechanisms mentioned, which depend on the scope, types of data that are handled and the permissions granted for such data. On the other hand, there are solutions that, due to their complexity or design, integrate two different types of blockchain, taking advantage of the benefits of each of them.

There are many challenges surrounding Blockchain technology, one of them is the lack of architectures or mature models that allow providing clear elements for future developments that implement blockchain in support of the elderly. The use of software engineering practices in blockchain-based systems for improving sustainability is very slight. However, our mapping study did not find studies dedicated to software engineering issues, such as development process, requirement engineering, and quality assurance, for developing blockchain-based systems to support the care of the elderly. Also, scalability, performance, and latency issues must be addressed. Likewise, it is necessary to go deeper into proofs of concept and generation of practical products that implement blockchain within their solutions, although several solutions have been presented to the challenges and limitations, many of them are only brief suggestions of ideas and lack an evaluation concrete about its effectiveness.

References

- 8th EAI International Conference on Mobile Communication and Healthcare, MobiHealth 2019, vol. 320. LNICST (2020)
- Agbo, C., Mahmoud, Q., Eklund, J.: Blockchain technology in healthcare: a systematic review. Healthcare 7(2), 56 (2019)
- Cui, L., Yuan, K., Zhao, X., Mou, L.Y.D.: Construction of elderly mutual aid time bank based on blockchain. In: Proceedings - IEEE International Conference on Mobile Data Management, June 2019, pp. 462–466 (2019)
- D'Hauwers, R., van der Bank, J., Montakhabi, M.: Trust, transparency and security in the sharing economy: what is the role of the government? Technol. Innov. Manage. Rev. 10(5), 6–18 (2020)
- Dyba, T., Dingsoyr, T., Hanssen, G.K.: Applying systematic reviews to diverse study types: an experience report. In: 1st International Symposium on Empirical Software Engineering and Measurement (ESEM 2007), pp. 225–234 (2007)
- 6. EPTA: Technologies in care for older people. Technical report, EPTA (2019)
- Esposito, C., De Santis, A., Tortora, G., Chang, H., Choo, K.K.R.: Blockchain: a Panacea for healthcare cloud-based data security and privacy? IEEE Cloud Comput. 5(1), 31–37 (2018)
- 8. Fang, L., Wu, Y., Wu, C., Yu, Y.: A non-intrusive elderly home monitoring system. IEEE Internet Things J. 8, 2603–2614 (2020)
- 9. Grossmann, U., Horster, B., Khess, I.: IDAACS 2017
- Jita, H., Pieterse, V.: A framework to apply the internet of things for medical care in a home environment. In: CCIOT 2018, pp. 45–54. ACM, New York (2018)
- 11. Kordestani, H., Barkaoui, K., Zahran, W.: HapiChain: a blockchain-based framework for patient-centric telemedicine. In: IEEE (SeGAH), pp. 1–6. IEEE (2020)

- 12. Kötteritzsch, A., Weyers, B.: Assistive technologies for older adults in urban areas: a literature review. Cogn. Comput. 8(2), 299–317 (2016)
- 13. Mettler, M.: Blockchain technology in healthcare: The revolution starts here (2016)
- Mokhtari, M., de Marassé, A., Kodys, M., Aloulou, H.: Cities for all ages: Singapore use case. In: Stephanidis, C., Antona, M. (eds.) HCI International 2019.
 Late Breaking Posters. HCII 2019. Communications in Computer and Information Science, vol. 1088. Springer, Cham (2019)
- 15. Nakamoto, S.: Bitcoin: a peer-to-peer electronic cash system (2008)
- Petersen, K., Feldt, R., Mujtaba, S., Mattsson, M.: Systematic mapping studies in software engineering. In: Proceedings of the 12th International Conference on Evaluation and Assessment in Software Engineering (2008)
- 17. Abdur Rahman, M.D., et al.: Blockchain-based mobile edge computing framework for secure therapy applications. IEEE Access 6, 72469–72478 (2018)
- Revelo, O., Collazos, C., Jimenez, J.: El trabajo colaborativo como estrategia didáctica para la enseñanza/aprendizaje de la programación: una revisión sistemática de literatura. TecnoLógicas 21, 115–134 (2018)
- Rosa, M., Barraca, J.P., Rocha, N.P.: Blockchain structures to guarantee logging integrity of a digital platform to support community-dwelling older adults. Cluster Comput. 23(3), 1887–1898 (2020)
- Rosa, M., Barraca, J.P., Rocha, N.P.: Logging integrity with blockchain structures.
 In: Rocha, Á., Adeli, H., Reis, L., Costanzo, S. (eds.) Advances in Intelligent Systems and Computing, vol. 932, pp. 83–93. Springer, Cham (2019)
- Rosaa, M., et al.: A platform of services to support community-dwelling older adults integrating FHIR and complex security mechanisms. Procedia Comput. Sci. 160, 314–321 (2019)
- Rupasinghe, T., et al.: Towards a blockchain based fall prediction model for aged care. In: ACM International Conference Proceeding Series, pp. 1–10. Association for Computing Machinery, New York (2019)
- Tantidham, T., Aung, Y.N.: Emergency service for smart home system using ethereum blockchain: system and architecture. IEEE PerCom Workshops 2019, 888–893 (2019)
- Wang, J., Han, K., Alexandridis, A., Chen, Z., Zilic, Z., Pang, Y., Jeon, G., Piccialli,
 F.: A blockchain-based eHealthcare system interoperating with WBANs. Future Gener. Comput. Syst. 110, 675–685 (2020)
- World Economic Forum: Technology tipping points and societal impact. Technical report, WEF (2015)
- Yang, G., Li, C., Marstein, K.E: A blockchain-based architecture for securing electronic health record systems. Wiley (2019)
- Zheng, X., Vieira, A., Marcos, S.L., Aladro, Y., Ordieres-Meré, J.: Activity-aware essential tremor evaluation using deep learning method based on acceleration data. Parkinsonism Related Disord. 58, 17–22 (2019)



MoRES: A Mobile App to Help Elderly People Grasp and Comply with COVID-19 Restrictions

José Ramón Lozano-Pinilla $^{(\boxtimes)}$, Daniel García-Pérez $^{(\boxtimes)}$, and Cristina Vicente-Chicote $^{(\boxtimes)}$

Quercus Software Engineering Group, Universidad de Extremadura, Cáceres, Spain {joserralp,danielgp,cristinav}@unex.es

Abstract. This paper introduces MoRES: a monitoring framework aimed at helping elderly people to understand and comply with the new mobility restrictions associated to the COVID-19 pandemic. The MoRES framework provides elderly people with a mobile app allowing them to visualise how crowded a particular area is and which are the allowed and forbidden places, according to the restrictions imposed by the authorities at a national, regional and local level. Additional functionalities supporting politicians, health authorities and public security forces are also supported by the MoRES framework.

Keywords: Elderly people \cdot Mobility monitoring \cdot COVID-19 restrictions

1 Introduction

Since November 2019, all countries around the world are experiencing an exceptional situation due to the appearance of the Covid-19 virus. This virus has spread rapidly across all continents causing a global pandemic with a huge impact, not only on health and economy, but also on our way of life. Mobility has been significantly restricted, as has any activity involving social interaction. Similarly, online activities (tele-work, tele-education, tele-medicine, etc.) have been favoured over face-to-face ones.

The Covid-19 virus exhibits a high transmission rate and, although its lethality appears to be lower than that of other corona-type viruses, according to the World Health Organization (WHO) it has already killed more than 1.5 million people worldwide [1]. It is worth noting that the Covid-19 disease is not affecting all population equally. In fact, according to the Centers for Disease Control and Prevention (CDC) [2], 80% of Covid-19 deaths in the United States have occurred among people aged 65 and older. Similar percentages have been reported for elderly people worldwide.

Depending on the evolution of the virus transmission rate and the availability of medical facilities (in particular, intensive care units), the authorities of each

[©] The Author(s), under exclusive license to Springer Nature Switzerland AG 2021 J. García-Alonso and C. Fonseca (Eds.): IWoG 2020, LNBE, pp. 35–42, 2021. https://doi.org/10.1007/978-3-030-72567-9_4

country/region/town establish more or less strict restrictions to prevent the virus expansion. These range from limiting the opening hours and the capacity of certain establishments to closing others, or even the total confinement of (part of) the population. The measures set by the authorities at different levels are quite diverse, changing and sometimes even conflicting, which frequently generates confusion, even more in elderly people.

The use of Information and Communication Technologies (ICT) has demonstrated to be very useful both for getting data from the elderly [3] and for making information more accessible to them [4]. In this vein, this paper introduces MoRES (Mobility Monitoring and Recommender System): an ICT-based system aimed at helping to define, understand and comply with COVID-19 restrictions. This goal can be divided, in turn, into the following sub-goals:

- Provide citizens in general, and the elderly in particular, with an easy-to-use mobile app allowing them:
 - to visualise crowded places in order to avoid them;
 - to be informed about the allowed/forbidden places according to current national, regional and local regulations; and
 - to be informed about relevant news about the COVID-19 pandemic;
- Provide politicians and health authorities (at national, regional and local levels) with a web application allowing them:
 - to identify population mobility patterns;
 - to establish mobility restrictions in a consistent way; and
- Provide public security forces with a web application providing them with instant information about mobility in unauthorised places so that they can take action accordingly.

The rest of the paper is organised as follows. Section 2 outlines the architecture of the *MoRES* framework and describes the technologies and tools used to develop each of its components; Sect. 3 describes some of the tests carried out to validate both the individual components and the framework as a whole; Sect. 4 discusses related works; and, finally, Sect. 5 draws some conclusions and future works.

2 Design and Implementation of the *MoRES* Framework

As previously stated, the *MoRES* framework includes three apps aimed at covering the needs of three different user profiles: a mobile app for the general public, particularly targeted to elderly people, and two web apps supporting politicians/health authorities and public security forces, respectively. These three apps provide customised functionalities and views, targeted to each user profile, and share data with each other using a loose-coupling scheme based on a publish-subscribe middleware. Figure 1 outlines the main components of the *MoRES* framework and how they relate to each other. Each of these components is briefly described next.

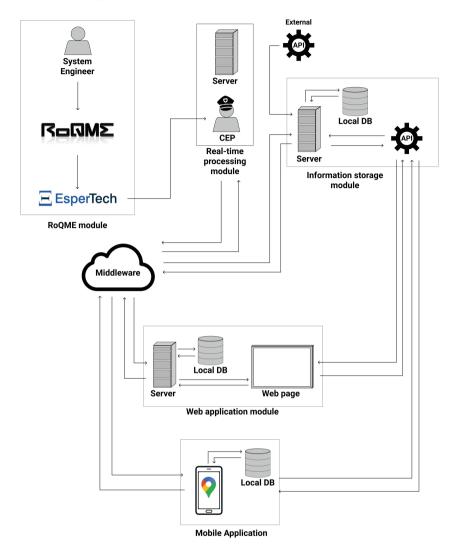


Fig. 1. Architecture of the *MoRES* framework.

Real-time processing module: this module is implemented as a server containing a Complex Event Processor (CEP), responsible for real-time processing the contextual information provided (through a publish-subscribe middleware) by the mobile app installed in the citizens' mobile devices. When relevant context patterns are identified (e.g., too crowded locations or several mobile devices close to a forbidden place), this module publishes the corresponding notifications for the users of the web applications (namely politicians, health authorities and public security forces) to be informed and take action when needed.

- Information storage module: this module stores all the relevant information exchanged by the different components through the middleware, allowing other components, e.g., to query the occupancy of a certain location on a given date. Components interested in retrieving these data must use the API provided with this module.
- Web app: this module is implemented as a web server aimed at providing customised information to different user roles. Only conveniently authenticated users can access the information stored in this module. Each user is assigned a role (national/regional/local authority or public security force) depending on which he/she will obtain different information and will be able to perform different actions. For instance, national authorities can set global restrictions. e.g., indicating the allowed/forbidden places nation-wide. Then, regional and local authorities can, in turn, define further restrictions for their area, but they cannot lift those defined by higher level authorities. This mechanism enforces restriction consistency. Besides, the web app displays general information about people mobility at a national, regional or local level, depending on the user role. Public security forces cannot define restrictions, but they can see real-time mobility data in their area, and are punctually notified whenever a strange mobility pattern occurs that may require their attention. Besides, they can use the web app to send patrols in response to any of these notifications. All the web app users can publish COVID-related news that will be displayed to the mobile app users of their area of influence.
- Mobile app: this application is available for the citizens to voluntary install it in their mobile devices. Once installed, it provides users with information about how crowded are nearby places (considering a 200-m radius area around their current position), restrictions applicable in their area (forbidden/allowed places) or news published by local, regional or national authorities that are relevant for them according to their current location (see Fig. 2).

Next, the technologies and tools used to implement each of the previous modules/apps is described.

- Databases. The MoRES framework gathers different types of databases.
 For instance, the SQLite [5] relational database was selected both for the mobile and web applications to store user-related information, while the MongoDB [6] non-relational database was selected for the information storage module.
- Middleware. The middleware selected as the central communication element among the different framework components was MQTT [7]: a publish-subscribe middleware considered the de facto standard for IoT messaging.
- Programming languages and tools. Many different programming languages and tools have been used to implement the different components of the MoRES framework, namely: Java/EsperTech [8] for the real-time processing module; Java/Android Studio [9] for the mobile app; Python and Flask [10] for the web app and Leaflet.js [11] and Jinja [12] for its front-end; and NodeJS [13] for the API of the information storage module.



Fig. 2. Main functionalities of the *MoRES* mobile app: nearby devices (left); nearby allowed/forbidden places (center); and (c) News (right).

The RoQME Toolchain. Some of the tools developed as part of the RoQME Toolchain [14,15], have been used to specify relevant context patterns and, from them, to generate the CEP rules to be fired by the real-time processing module when such patterns are identified in the data provided by the mobile app.

3 Tests Performed on the *MoRES* Framework

In order to check the correctness of both the individual components of the *MoRES* framework and the system as a whole, different tests were carried out.

Individual components were tested by feeding them (through the middleware) with simulated input data and checking, in a supervised way, if they behaved as expected. Tests on the different middleware subscribers were performed, e.g., using changing device locations to check whether the CEP module correctly identifies relevant situations (context patterns) or not. Similarly, several news items with different scopes (national, regional, local and urgent) were generated from the web app to check that only the mobile devices affected by those news (according to their location) received them.

In order to perform the integration tests, the Android Studio [9] mobile device simulator was used. Multiple instances of Android Studio were simultaneously launched to simulate several mobile devices. The location of some of these devices was modified to pretend that the people who were carrying them was moving through different areas of a town. Eventually, several of the moving devices where placed around a forbidden location to check if it was identified as a crowded place in the mobile app of the other users nearby, and if the corresponding notification arrived to the public security forces through the web app.

4 Related Works

Since the WHO declared COVID-19 a pandemic on 11 March 2020, a plethora of public and private initiatives have been developed to fight it on all fronts: from researching secure and effective vaccines and new medical treatments, to the development of new ICT-based solutions aimed at monitoring and preventing its spread. Among the later, some of the most relevant initiatives conducted world-wide, in Europe and in Spain are briefly reviewed next.

Firstly, it is worth highlighting the initiative jointly developed by the two tech giants, Google and Apple, around coronavirus contact tracing [16]. This initiative advocates for a privacy-sensitive decentralised approach to proximity tracking that relies on data processed locally on mobile devices, rather than being continually uploaded and held on a central server. Considering that more than 97% of current mobile devices use either Android (supported by Google and OHA) or iOS (supported by Apple), the impact of this initiative world-wide is huge. In fact, most of the mobile apps related with contact tracing, developed in different countries in the last few months, build on the Exposure Notification System jointly developed by Google and Apple.

Secondly, at a European level, it is worth mentioning the Recommendation adopted by the European Commission on the policy approach for eHealth mobile applications and how they should deal with data protection. According to this Recommendation, national contact tracing apps should be strictly voluntary, do not trace individual movements (location) but rather proximity among mobile devices (e.g., using Bluetooth), approved by national health authorities, privacy-preserving (personal data is securely encrypted) and dismantled as soon as no longer needed. Based on this Recommendation, European Countries have developed their own COVID-19 tracing apps [17], some of which are interoperable so that people can use them to be alerted wherever they are in Europe. Radar COVID [18], the mobile app supported by the Spanish national government, belongs to this group of Europe-wide interoperable contact tracing systems.

Finally, it is also worth mentioning some more modest initiatives carried out in Spain at a regional level, such as CoronaMadrid [19] or EPIdig [20], the former supported by the regional government of Madrid, and the later jointly developed by Ibermatica and Tecnalia: two tech companies based in the Basque country.

As described in this section, most of the ICT-based initiatives that have emerged in relation to the COVID-19 pandemic deal with contact tracing. However, the *MoRES* framework, presented in this paper, aims to cover two different issues, namely: (1) monitoring people mobility so that both citizens and authorities can identify excessively crowded places; and (2) support the definition of national/regional/local COVID-related restrictions in a consistent way, making them more graspable to people, particularly to the elderly. In this sense, *MoRES* in no way aspires to become an alternative to any of the previously mentioned mobile apps, but rather a complementary one.

5 Conclusions and Future Works

This paper has introduced MoRES: a mobility monitoring and recommender system aimed at helping citizens in general, and elderly people in particular, to better understand and comply with the COVID-related restrictions imposed by the authorities, keeping themselves safe by avoiding too crowded places. The architecture of the framework and the technologies and tools used to develop each of its main components have been described, and the links to previous projects and related works have been outlined.

Among the extensions and enhancements planned to be supported by the MoRES framework in the future, it is worth highlighting the following ones: (1) executing the different servers in a distributed way in order to improve both efficiency and fault tolerance; (2) integrating monitoring information obtained, e.g., from Smart Watches or other IoT devices, in order to provide end-users with additional functionalities and help them identify abnormal or harmful routines; (3) adding some "intelligent" features, e.g., allowing the mobile/web apps to adapt their behaviour according to the perceived situation, in line with some of our previous works on model-driven self-adaptive system development [21,22]; and (4) enabling end-users to privately enrich and manage their profile so that the mobile app could offer them more relevant information according to their age, health, mood, etc.

References

- World Health Organisation (WHO). WHO Coronavirus Disease (COVID-19) Dashboard. https://covid19.who.int/
- 2. USA Centers for Disease Control and Prevention (CDC). COVID-19 Death Data and Resources. Weekly Updates by Select Demographic and Geographic Characteristics. https://www.cdc.gov/nchs/nvss/vsrr/covid_weekly/index.htm
- Flores-Martín, D., Laso, S., Berrocal, J., Canal, C., Murillo, J.: Allowing IoT devices collaboration to help elderly in their daily lives. In: García-Alonso, J., Fonseca, C. (eds.) IWoG 2019, Communications in Computer and Information Science, vol. 1185 (2019). https://doi.org/10.1007/978-3-030-41494-8_11
- Jesús-Azabal, M., Rojo, J., Moguel, E., Flores-Martín, D., Berrocal, J., García-Alonso, J.: Voice assistant to remind pharmacologic treatment in elders. In: García-Alonso, J., Fonseca, C. (eds.) IWoG 2019, Communications in Computer and Information Science, vol. 1185 (2019). https://doi.org/10.1007/978-3-030-41494-8_12
- 5. SQLite. https://www.sqlite.org/
- 6. MongoDB. https://www.mongodb.com/
- 7. MQTT. https://mqtt.org/
- 8. EsperTech. https://www.espertech.com/
- 9. Android Studio. https://developer.android.com/studio
- 10. Flask. https://flask.palletsprojects.com/
- 11. Leaflet.js. https://leafletjs.com/
- 12. Jinja. https://jinja.palletsprojects.com/
- 13. NodeJS. https://nodejs.org/

- 14. Vicente-Chicote, C., Inglés-Romero, J.F., Martínez, J., Stampfer, D., Lotz, A., Lutz, M., Schlegel, C.: A component-based and model-driven approach to deal with non-functional properties through global QoS metrics. In: 5th International Workshop on Interplay of Model-Driven and Component-Based Software Engineering (ModComp 2018). Held in Conjunction with MODELS 2018, Denmark, Copenhagen, pp. 40–45 (2018). http://ceur-ws.org/Vol-2245/modcomp_paper_6.pdf
- 15. Vicente-Chicote, C., García-Pérez, D., García-Ojeda, P., Inglés-Romero, J.F., Romero-Garcés, A., Martínez, J.: Modeling and estimation of non-functional properties: leveraging the power of QoS metrics. In: Ferrández Vicente, J., Álvarez-Sánchez, J., de la Paz López, F., Toledo Moreo, J., Adeli, H. (eds.) From Bioinspired Systems and Biomedical Applications to Machine Learning. IWINAC 2019. Lecture Notes in Computer Science, vol. 11487 (2019). https://doi.org/10.1007/978-3-030-19651-6_37
- 16. Exposure Notifications Systems by Google and Apple. https://www.google.com/covid19/exposurenotifications
- 17. European Commission. Mobile contact tracing apps in EU Member States. https://ec.europa.eu/info/live-work-travel-eu/coronavirus-response/travel-during-coronavirus-pandemic/mobile-contact-tracing-apps-eu-member-states_en
- 18. Radar COVID. https://radarcovid.gob.es/
- 19. CoronaMadrid. https://coronavirus.comunidad.madrid/
- 20. EPIdig. https://ibermatica.com/covid-19/
- Inglés-Romero, J.F., Vicente-Chicote, C.: Towards a formal approach for prototyping and verifying self-adaptive systems. In: Franch, X., Soffer, P. (eds.) Advanced Information Systems Engineering Workshops. CAiSE 2013. Lecture Notes in Business Information Processing, vol. 148 (2013). https://doi.org/10.1007/978-3-642-38490-5_39
- Rodríguez-Gracia, D., Criado, J., Iribarne, L., Padilla, N., Vicente-Chicote, C.: Runtime adaptation of architectural models: an approach for adapting user interfaces. In: Abelló, A., Bellatreche, L., Benatallah, B. (eds.) Model and Data Engineering. MEDI 2012. Lecture Notes in Computer Science, vol. 7602 (2012). https://doi.org/10.1007/978-3-642-33609-6_4



Qualitative Research in Evaluation. An Usability Evaluation Protocol for the Assistant on Care and Health Offline (ACHO)

Borja Rivero Jiménez^(⊠), David Conde Caballero, J. Jesús-Azabal, Jerónimo Luengo-Polo, Jara Bonilla-Bermejo, and Lorenzo Mariano Juárez,

University of Extremadura, Cáceres, Spain brivero@unex.es

Abstract. One of the problems associated with ageing that most concerns health professionals is low therapeutic adherence. In recent years, technological developments have appeared that can increase therapeutic adherence. To do so, it is necessary to know their usability and the possibility of use that they may have. In the framework of the project "International Institute for Research and Innovation on Ageing" (4IE), we have developed the Assistant on Care and Health Offline (ACHO), a voice assistant that provides medical appointments and medication reminders for patients. In this text we present a usability evaluation protocol for this voice assistant. We will use a multidimensional and multidisciplinary analysis in the framework of the Living Lab for the usability evaluation. Our methodology for measuring results includes three phases and different quantitative and qualitative research tools. The application of this methodology will allow us to develop a better prototype, increasing ease of use and improving the user experience.

Keywords: Terapeutic adherence \cdot e-Health \cdot Living lab \cdot Voice assistant \cdot Anthropology

1 Introduction

Increased life expectancy of a population is associated with better health conditions, but also an increase in age-related diseases [1]. In this sense, elderly patients are particularly susceptible to the phenomenon of non-adherence to medication, which can be defined as the degree to which recommendations or frequency of medication intake are met [2]. Rates of non-adherence to medication are higher in the elderly than in the rest of the population [3,4].

In recent years there has been an increase in the use of technology applied to medical health services. Technological development has opened a field of possibilities for better therapeutic adherence in patients. Some studies have appeared on electronic reminders using audio [5] or audiovisual devices [6] that, through reminders, facilitate therapeutic adherence.

A voice assistant is a software agent that interacts through voice activation using an intelligent speaker device [7]. One of the first studies to investigate these voice assistants applied to the health of voice assistants responded inconsistently and incompletely to a variety of questions [8]. Further studies have considered certain safety risks for patients and consumers [9]. Further work and research is needed to improve these types of devices in terms of their application to health.

Research points to the importance of adapting technology to the user experience by involving the end user in the development of the technology itself. Thus, by making adaptations according to the needs of the elderly target group, considerable increases in performance and acceptance by older people using a specific technology can be observed [10]. The "Living Labs" concept dates from the 1990s, and refers to an approach to innovation which involves a group of researchers collaborating with target users as co-creators in the development and validation of new products [11]. In this text we explain the different phases of the protocol that we followed to carry out a usability evaluation of a voice assistant for the therapeutic adherence of elderly people.

2 Objectives

This protocol is being developed as part of a larger project, "International Institute for Research and Innovation on Ageing (4IE)". The aim of this project is to develop technologies to improve the quality of life of older people in rural environments.

In this text we explain the different phases of the protocol that we followed to carry out a usability evaluation of a voice assistant for the therapeutic adherence of elderly people [12,13]. We propose an exhaustive, cyclical and multidisciplinary evaluation [14], with the following objectives:

- 1. To validate the correct usability of the designed prototype by observing the particular characteristics of the elderly and the context in which they live.
- 2. To identify problems and to develop possible guidelines for improvement.
- 3. To analyse the usability.
- 4. To involve real end-users in the process of validating the usability of the prototype.

3 The Design of Assistant on Care and Health Offline (ACHO)

The field of e-Healthcare is striving to adapt technological advances to the care of the elderly. The aim is to promote the autonomy of the elderly and thus facilitate their independent live at home [15], including personalized assistance [16]. Within this field we can find technological solutions that range from apps for mobile devices, to smartbands or clothes or what has been called Smart Home:

advanced technological systems. e-Healthcare is in full expansion driven by some programmes such as the European Union's Active Assisted Living Programme - Technology designed to improve quality of life for older people (AAL) [17]. These are interdisciplinary networks that have focused on the possibilities offered by technology and are particularly interested in voice assistants. The device consists of a home conversation interface that allows users to request and save information, as well as to perform a series of actions among which those related to health and care of the elderly are beginning to be explored [18].

The Assistant on Care and Health Offline (ACHO) works along the same lines as the rest of the e-healthcare projects, providing a new option in the development of intelligent environments for assisted living among elderly people. It is part of the Institute for Research and Innovation on Ageing 4IE project [19]. It is an interdisciplinary research focused on the regions of Extremadura (Spain) and Alentejo (Portugal), which is interested in knowing and describing the different problems of the elderly men and women in the area. Based on the knowledge of the reality, the aim is to validate and developed technological solutions that enable the application of innovations and new forms of care that take into account the particular characteristics of the elderly and the context in which they live.

ACHO is a voice assistant based on Snips structure [20]. Is the first voice assistant that does not store information via cloud, but keeps it locally on the device. The terminal does not need to have an internet connection. Our project, therefore, brings together on the one hand the global trend to work in assisted living environments, while on the other it takes into account the important contextual fact that access to an internet connection is not always possible depending on the type of user and the area where he or she lives. This solves two possible problems that could arise. In rural contexts such as we work in, Internet can be difficult to access due to the lack of an adequate infrastructure. And, very important: we work with older people who do not always have Internet services.

The ACHO app for smarthphone will allow the interaction between the health professional and the device in order to provide the health data that need to be remembered. The result is the participation of health professionals in a kind of "new forms of care". Some of its initial features are as follows:

- 1. Specification of the patient's profile. The basic information of the patient will be specified in the application along with details of the medical prescriptions and appointments always made by the health professional. This data will be stored in the application's internal database. The stored information, such as patient profiles, medical appointments and prescriptions, will only be accessible by the application.
- 2. Synchronisation with the voice assistant In this process the application will generate a temporary file with the information of the prescriptions. This file will be transmitted via Bluetooth with the voice assistant, which will process it and set up the corresponding reminders. The synchronisation process has been designed to avoid any possible loss of information or compromise of data security.

4 ACHO Evaluation Protocol

Scientific literature has described a good number of methodologies and tools used to ensure the quality of usability of a service [21,22]. Evaluating the usability and user experience of technology stands out as an essential step if it is to be significantly effective and meet its objectives [23], even more so when talking about older people due to the special characteristics of this age group. A number of previous products very similar to ours have not been accepted because they did not take into account this kind of issues54, so it is especially important to look for empirical evidence on how to improve the usability of different devices55.

Our multi-method approach is following some experiences that have already proved positive with devices very similar to the one proposed here [24–26]. The type of study - descriptive observation -, constitutes a usability analysis in several phases following the available evidence that advocates cyclical processes of analysis, prototyping, testing and refinement of the mechanisms of interaction with the user [23,24]. In this sense, it is important to emphasise that the passage from one phase to another is totally limiting, being impossible to access the subsequent phase without having satisfactorily overcome the previous one.

The work in this phase focuses on what is known as Living Lab [27], consisting of the strong involvement of end users in all phases of the development of prototypes. In our opinion, this method allows a more realistic validation of the environmental and holistic factors of the user, something for which the involvement of the anthropologists of the research team and their ability to interact with the users even in their own homes is fundamental. As Bevan et al. point out, the introduction of user-centred methods ensures that 'real products can be used by real people to perform their tasks in the real world' [28].

4.1 Methodology

Researchers, at the end of the evaluation process, must report the experience through the completion of different tools in order to assess various aspects of usability. Three tools have been selected.

Firstly, the System Usability Scale (SUS) [29]. It was chosen because it is in the public domain and can be freely used [30] and because it has shown great robustness and solidity in its results [24]. It is an economical tool, very simple to use and capable of being adapted for use in different situations such as the evaluation of software interfaces, web pages and applications, mobile phones, landlines, modems or voice systems (Fig. 1).

In addition to this assessment measure, two other scales recently validated by members of the Institute of Electronics and Telematics Engineering of Aveiro (Portugal) will be used to bring more consistency to the process [16]. These are the ICF-US I Scale and the ICF-US II Subscale [26]. The ICF-US I Scale allows the identification of general usability problems. The ICF-US II Scale allows the identification of possible barriers and/or facilitators, as well as identifying more specifically those elements that may require further work to improve the device.

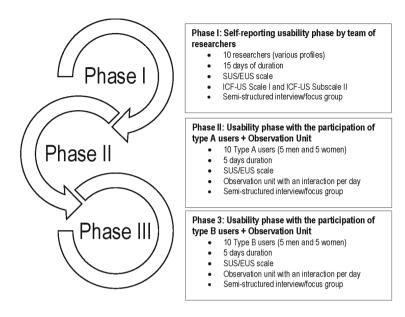


Fig. 1. Diagram of the research protocol

Previous evidence shows very positive experiences in its use, due to its use independently of the specific characteristics of the products being evaluated [24,25].

Similarly, all researchers face a semi-structured individual interview conducted by the team anthropologists. The researchers are asked to write down their impressions in a notebook. The aspects evaluated in this phase are:

- Positive or negative evaluation of the number of reminders made by the device.
- Evaluation of the way in which it is carried out: voice, tone...
- Evaluation of the name of the drug, which must be individualized.
- Feedback on consumption
- Existence of detected problems: Message saturation, message errors...
- Other subjective elements they may consider important.

4.2 Timing

The phases that we have decided to include in the design of the validation process are

- 1. Phase I: Self-reported usability phase by the research team, complemented by semi-structured interviews and/or Focus Groups.
- 2. Phase II: Usability phase with the participation of type A users + Observation Unit regarding "critical incidents" [31,32], complemented with semi-structured interviews and/or Focus Groups.

3. Phase III: Usability phase with the participation of type B users + Observation Unit regarding "critical incidents", complemented with semi-structured interviews and/or Focus Groups.

As in the initial stages of the project in which we carried out the ethnography, each and every one of the participants in the usability assessment sign an informed consent form after the actions to be carried out are made explicit. The data collection is anonymised and the participants receive all the information generated in the study. Quantitative data is stored and analysed using SPSS (Statistical Package for Social Sciences) version 22. Qualitative data is stored and categorised in the Dedalo Patform Intangible Heritage Management programme.

Phase I: Self-reported Usability by Research Team + Semi-structured Interviews. The first phase of the evaluation or analytical phase aims to determine whether our product is sustainable in terms of interface and functions. To this end, a total of 10 researchers from various knowledge profiles at the International Institute of Ageing - both Spanish and Portuguese - are evaluating the usability of the device over a period of 15 days. The researchers have been given a series of tasks through a script that they carry out at least three times a day, thus simulating the normal pattern of taking breakfast/lunch/dinner medication.

Phase 1 or the analytical phase is only overcome if

- A score on the SUS/EUS Scale above 68 is obtained in the final average of all users. This is the limit established in the scientific literature to determine the correct usability of a product [29].
- A score on the ICF-US I Scale higher than 10 is obtained in the final average of all users. This is the limit established in the scientific literature to determine the existence of a correct usability of a product [33].
- The results obtained in the ICF-US Scale II are analyzed.
- All the semi-structured interviews are carried out.
- The improvements suggested by the analysis of the instruments used are incorporated into the device. In this sense, the design changes can reduce certain errors and facilitate the usability and acceptance of the user [34,35].
 A new validation cycle is not ruled out once the necessary improvements have been incorporated.

Phase II: Usability with the Participation of Type a Users + Observation Unit. In the second phase of the evaluation, information is collected on the usability and satisfaction of real users with a physical implementation of the prototype in real but controlled contexts. It is therefore an empirical model. The participants in this phase are what we have called TYPE A users: people over 65 years of age from rural areas without cognitive and/or sensory impairments, selected on a non-random basis after recommendation of suitability by professionals from the Extremadura Health System in the selected locality. The selected sample must have the capacity to detect and report possible failures,

"critical incidents" and/or problems in the interaction with the prototype. At least 10 people are selected, possibly 5 men and 5 women in different age ranges from 65 years old.

Users will be trained on the actions to be carried out beforehand, and are accompanied in at least 1 of the three daily interactions foreseen by what we have called Observation Units. These are researchers who observe and evaluate the process of use and interaction in the user's context, which allows us to collect significant information to understand what changes need to be made in the environmental factor so that it can be better adapted to its users and its functionality can be improved [35]. In addition, the Observation Units are responsible for recording so-called "critical incidents" [36], that is, all situations that deviate from normality. Although there is no structure or standardised procedure for recording "critical incidents", their use has been described in the scientific literature as "very appropriate" [25,26].

These same researchers, at the end of the stipulated period of time, conduct a semi-structured interview in the same sense as indicated in Phase I, while helping people to report on usability through the SUS Scale - in this case selected because it is easier to administer. As in the previous phase, the possibility of holding Focus Groups with various users is not ruled out if the information collected is not considered sufficient. The estimated time of implementation is 5 days.

Phase 2 is considered to have been passed only if

- A score on the SUS/EUS Scale above 68 is obtained in the final average of all users. This is the limit established in the scientific literature to determine the existence of correct usability of a product.
- All semi-structured interviews are conducted.
- The improvements suggested from the analysis of the empirical evidence generated are incorporated into the device. In this sense, the design changes can reduce certain errors and facilitate the usability and acceptance of the user. A new validation cycle is not ruled out once the necessary improvements have been incorporated.

Phase III:Usability with the Participation of Type B Users + Observation Unit. Finally, the third phase of the evaluation of the pilot test aims to assess usability under normal, uncontrolled operating conditions. The so-called TYPE B users are people over 65 years old from rural areas with the only inclusion criterion of having non-critical medication according to the recommendations of the professionals of the Extremadura Health System in the selected locality.

The users, previously trained on the actions to be carried out and the objectives to be pursued, are accompanied in all the daily interactions planned by Observation Units. These researchers conduct a semi-structured interview in the same way as in the previous cases and help people to report on usability through the SUS Scale. As in the previous phases, the possibility of holding focus groups with various users is not ruled out if the information collected is not considered

sufficient. The estimated time of implementation is 5 days. Through the analysis of all the empirical material generated, we intend to measure the usability and functionality attributes of the prototype.

Phase 3 and therefore the evaluation of the usability of our prototype is considered to have been overcome only if:

- A score on the SUS/EUS Scale above 68 is obtained in the final average of all users. This is the limit established in the scientific literature to determine the existence of correct usability of a product.
- All semi-structured interviews are conducted.
- The improvements suggested from the analysis of the empirical evidence generated are incorporated into the device. In this sense, the design changes can reduce certain errors and facilitate the usability and acceptance of the user. A new validation cycle is not ruled out once the necessary improvements have been incorporated.

At the end of the validation cycle proposed here, the possibility of incorporating new functionalities is assessed, in which case the validation process would be the same as that indicated here. If this is not the case, the next phase would include an assessment of the safety of the use of the prototype with respect to the reminder when taking medicines.

5 Conclusions

This evaluation protocol will provide us in the coming months with results that will give us a reliable evaluation of the Assistant on Care and Heatlh Offline (ACHO). The evaluation of the usability of health technologies is essential, especially for those technologies that will be used by older people. To counteract certain difficulties in evaluation, we want to have technology evaluation tools that allow us to know the reality of use in their context. In future publications we will offer the concrete results and the difficulties encountered in the evaluation of this voice assistant.

Acknowledgment. This work was supported by the 4IE+ project (0499_4IE_4_PLUS_4_E) funded by the Interreg V-A España-Portugal (POCTEP) 2014–2020 program.

References

- 1. WHO: World report on ageing and health. Technical report, World Health Organization, Geneva, Switzerland (2015). https://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811_eng.pdf;jsessionid=182A9CD45B7035C521 E9DC1A8BCDE127?sequence=1
- Pisano González, M.M., González Pisano, A.: La modificación de los hábitos y la adherencia terapéutica, clave para el control de la enfermedad crónica. Enfermería Clínica 24(1), 59–66 (2014). https://doi.org/10.1016/j.enfcli.2013.10.006

- Smith, D., Lovell, J., Weller, C., Kennedy, B., Winbolt, M., Young, C., Ibrahim, J.: A systematic review of medication non-adherence in persons with dementia or cognitive impairment. PloS One 12(2), e0170651 (2017). https://doi.org/10.1371/ journal.pone.0170651
- Haynes, R.B., Ackloo, E., Sahota, N., McDonald, H.P., Yao, X.: Interventions for enhancing medication adherence. Cochrane Database Syst. Rev. (2), CD000011 (2008). https://doi.org/10.1002/14651858.CD000011.pub3
- Andrade, A.S.A., et al.: A programmable prompting device improves adherence to highly active antiretroviral therapy in HIV-infected subjects with memory impairment. Clin. Infect. Dis. Official Publ. Infect. Dis. Soc. Am. 41(6), 875–882 (2005). https://doi.org/10.1086/432877
- Christensen, A., et al.: The impact of an electronic monitoring and reminder device on patient compliance with antihypertensive therapy: a randomized controlled trial. J. Hypertension 28(1), 194–200 (2010). https://doi.org/10.1097/HJH. 0b013e328331b718
- Chung, A.E., Griffin, A.C., Selezneva, D., Gotz, D.: Health and fitness apps for hands-free voice-activated assistants: content analysis. JMIR mHealth uHealth 6(9), e174 (2018). https://doi.org/10.2196/mhealth.9705
- 8. Miner, A.S., Milstein, A., Schueller, S., Hegde, R., Mangurian, C., Linos, E.: Smartphone-based conversational agents and responses to questions about mental health, interpersonal violence, and physical health. JAMA Intern. Med. **176**(5), 619–625 (2016). https://doi.org/10.1001/jamainternmed.2016.0400
- Alagha, E.C., Helbing, R.R.: Evaluating the quality of voice assistants' responses to consumer health questions about vaccines: an exploratory comparison of Alexa, Google Assistant and Siri. BMJ Health Care Inform. 26(1) (2019). https://doi. org/10.1136/bmjhci-2019-100075
- Thilo, F.J., Bilger, S., Halfens, R.J., Schols, J.M., Hahn, S.: Involvement of the end user: exploration of older people's needs and preferences for a wearable fall detection device - a qualitative descriptive study. Patient Prefer. Adherence 11, 11–22 (2017). https://doi.org/10.2147/PPA.S119177
- 11. Almirall, E., Wareham, J.: Living labs: arbiters of mid- and ground-level innovation. Technol. Anal. Strateg. Manage. **23**(1), 87–102 (2011). https://doi.org/10.1080/09537325.2011.537110
- Jesús-Azabal, M., Rojo, J., Moguel, E., Flores-Martin, D., Berrocal, J., García-Alonso, J., Murillo, J.M.: Voice Assistant to Remind Pharmacologic Treatment in Elders. In: García-Alonso, J., Fonseca, C. (eds.) Gerontechnology. IWOG 2020, pp. 123–133. Springer, Cham (2020)
- Moguel, E., Jesus Azabal, M., Flores-martin, D., Berrocal, J., García-Alonso, J., Murillo, J.M.: Asistente de voz para el recordatorio de tratamiento farmacológico. In: Jornadas de Ingeniería del Software y Bases de Datos (JISBD). Cáceres (2019). hdl.handle.net/11705/JISBD/2019/078
- 14. Hoppe, A.: Technological stress-mental strain of younger and older users if technology fails. In: Wichert, R., Eberhardt, B. (eds.) Ambient Assisted Living, pp. 17–29. Springer, Heidelberg (2011)
- Ennis, A., Rafferty, J., Synnott, J., Cleland, I., Nugent, C., Selby, A., McIlroy, S., Berthelot, A., Masci, G.: A smart cabinet and voice assistant to support independence in older adults. In: International Conference on Ubiquitous Computing and Ambient Intelligence, pp. 466–472 (2017). https://doi.org/10.1007/978-3-319-67585-5_47
- European Commission: Shaping Europes digital future. Technical report, Brussels (2020)

- 17. The international classification of functioning, disability and health as a conceptual model for the evaluation of environmental factors. Procedia Comput. Sci. 14, 293–300 (2012). https://doi.org/10.1016/j.procs.2012.10.033
- Pradhan, A., Mehta, K., Findlater, L.: "Accessibility came by accident": use of voice-controlled intelligent personal assistants by people with disabilities. In: Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems CHI 2018, pp. 1–13. ACM Press, New York (2018). https://doi.org/10.1145/3173574.3174033
- Garcia-Alonso, J., Berrocal, J., Rivero Jiménez, B., Conde Caballero, D., Mariano Juárez, L., Murillo, J.M., Mendes, D., Fonseca, C., Lopes, M., Perez-Vereda, A., Canal, C.: Instituto Internacional de Investigación e Innovación del Envejecimiento. In: Jornadas de Ingenieria del Software y Bases de Datos, JISBD 2018 (2018)
- Coucke, A., Saade, A., Ball, A., Bluche, T., Caulier, A., Leroy, D., Doumouro, C., Gisselbrecht, T., Caltagirone, F., Lavril, T., Primet, M., Dureau, J.: Snips voice platform: an embedded spoken language understanding system for private-by-design voice interfaces. CoRR abs/1805.10190 (2018). http://arxiv.org/abs/1805.10190
- Martins, A.I., Queirós, A., Rocha, N.P., Santos, B.S.: Avaliação de usabilidade: uma revisão sistemática da literatura. RISTI-Rev Ibérica Sist E Tecnol Informação, pp. 31–43 (2013)
- Best, M.L., Smyth, T.N.: Global/Local Usability: Locally Contextualized Usability in the Global South BT Global Usability, pp. 9–22. Springer, London (2011). https://doi.org/10.1007/978-0-85729-304-6_2
- Martins, A., Queirós, A., da Rocha, N.: Usability evaluation of products and services: a systematic review. In: E-Soc (2013)
- 24. Martins, A.I., Rosa, A.F., Queirós, A., Silva, A., Rocha, N.P.: European Portuguese validation of the system usability scale (SUS). Procedia Comput. Sci. **67**, 293–300 (2015). https://doi.org/10.1016/j.procs.2015.09.273
- 25. Jegundo, A.L., Dantas, C., Quintas, J., Dutra, J., Almeida, A.L., Caravau, H., Rosa, A.F., Martins, A.I., Queirós, A., Rocha, N.P.: Usability evaluation of a virtual assistive companion. In: World Conference on Information Systems and Technologies, pp. 706–715 (2019)
- 26. Martins, A.I., Queirós, A., Silva, A.G., Rocha, N.P.: ICF based usability scale: evaluating usability according to the evaluators' perspective about the users' performance. In: Proceedings of the 7th International Conference on Software Development and Technologies for Enhancing Accessibility and Fighting Info-exclusion, pp. 378–383 (2016)
- 27. Dekker, R., Franco Contreras, J., Meijer, A.: The living lab as a methodology for public administration research: a systematic literature review of its applications in the social sciences. Int. J. Public Adm. 43(14), 1207–1217 (2020). https://doi.org/10.1080/01900692.2019.1668410
- Bevan, N.: European usability support centres: support for a more usable information society. In: European Telematics: Advancing the Information Society. Proceedings of TAP Annual Concertation Meeting, pp. 50–65 (1998)
- Brooke, J.: Others: SUS-a quick and dirty usability scale. Usability Eval. Ind. 189(194), 4–7 (1996)
- 30. Sauro, J.: A Practical Guide to the System Usability Scale: Background, Benchmarks & Best Practices. LLC, Denver (2011)
- Ivory, M.Y., Hearst, M.A.: The state of the art in automating usability evaluation of user interfaces. ACM Comput. Surv. (2001). https://doi.org/10.1145/503112. 503114

- 32. Tsiourti, C., Ben Moussa, M., Quintas, J., Loke, B., Jochem, I., Lopes, J.A., Konstantas, D.: A virtual assistive companion for older adults: design implications for a real-world application. In: Bi, Y., Kapoor, S., Bhatia, R. (eds.) Proceedings of SAI Intelligent Systems Conference (IntelliSys) 2016. IntelliSys 2016. LNNS (2018). https://doi.org/10.1007/978-3-319-56994-9_69
- 33. Martins, A.I., Queirós, A., Rocha, N.P.: Validation of a usability assessment instrument according to the evaluators' perspective about the users' performance. Univers. Access Inf. Soc. 19(3), 515–525 (2020). https://doi.org/10.1007/s10209-019-00659-w
- Kalimullah, K., Sushmitha, D.: Influence of design elements in mobile applications on user experience of elderly people. Procedia Comput. Sci. 113, 352–359 (2017). https://doi.org/10.1016/j.procs.2017.08.344
- 35. Holden, R.J., Campbell, N.L., Abebe, E., Clark, D.O., Ferguson, D., Bodke, K., Boustani, M.A., Callahan, C.M.: Usability and feasibility of consumer-facing technology to reduce unsafe medication use by older adults. Res. Soc. Adm. Pharm. RSAP 16(1), 54–61 (2020). https://doi.org/10.1016/j.sapharm.2019.02.011
- 36. Gitlin, L.N.: The role of social science research in understanding technology use among older adults. Self-care in later life, pp. 142–169 (1998)





A Self-sustainable DTN Solution for Isolation Monitoring in Remote Areas

Manuel Jesús-Azabal^(⊠), Javier Berrocal-Olmeda, José García-Alonso, and Jaime Galán-Jiménez

Quercus Software Engineering Group, Universidad de Extremadura, Avda. Universidad S/N, 10003 Cáceres, Spain {manuel,jberolm,jgaralo,jaime}@unex.es

Abstract. Global population is facing a widespread ageing. In next decades, the increasing percentage of people over sixty-five will be significant, which will impact society in several ways. The health system will be one of the sectors specially involved, exploiting the technology as a perfect allied. However, a big percentage of adults live in rural areas where almost 40% of inhabitants are seniors and technological infrastructure is often insufficient. Thus, factors like isolation, loneliness and lack of eHealth solutions conform a difficult context for this population sector. In this paper, a solution to provide isolation monitoring to elders living alone in places with lack of Internet connectivity is proposed. The proposed architecture allows the detection of emergencies in elderly's homes through presence patterns monitoring. Thus, potential home accidents or health emergencies can be detected. Furthermore, this model has been validated through simulations with the analysis of the required energy consumption, delivery probability and latency, obtaining a significant good performance.

Keywords: Elder healthcare \cdot Opportunistic networks \cdot Rural areas \cdot Internet of Things \cdot The ONE simulator \cdot Sustainable network

1 Introduction

The global population is experiencing a widespread ageing and European countries reflect this context. Nowadays, around 30% of population is over 65 years old while, in next decades, it is estimated that the percentage increases up to 50% [1]. Moreover, this situation affects regions irregularly. This way, rural areas face intensely the population ageing since almost half of inhabitants are seniors [2]. Rural areas involve a very concrete context for third age people. Elders face factors like solitude and isolation which affect actively on health and the way the inhabitants interact with the place. Thus, these aspects become problematic with a potential impact on health, involving a risk for cares and attention. Therefore, assistance can become fatal in seniors who live alone, especially when they are under clinical treatments. Nevertheless, this exposed context brings a suitable

scenario for technological solutions, especially those centred on monitoring and telemedicine.

Many technological projects provide monitoring tools and communication systems for elder [3], in many cases centered on a concrete illness [4]. Thus, health emergencies can be detected and response time is potentially decreased. However, the deployment of these solutions in isolated rural areas become hard for several reasons, specially the absence of Internet infrastructure in many of these places [5]. In spite of the communication technologies have experienced an exponential growth in the last years, there are still regions where the impact of these progresses is eminently low. Only in Spain, more than 80% of people have access to high-speed Internet [6]. Nevertheless, these figures mainly congregate on the principal urban cores like Barcelona, Madrid or Basque Country while other areas like Extremadura or Galicia represent the lowest values at dissemination of these technologies. Factors like the geographical difficulties and the lack of interests of network companies due to the low benefits, exacerbate the situation, becoming a challenge for telemedicine solutions and health monitoring systems [5]. In addition, the lack of Internet also affects the local business of the region. These enterprises have to face a significant competitive disadvantage with regard to the connected businesses, resulting into a big technological gap which impacts on quality services and performance [7]. As a response to the exposed context in isolated areas, alternative communication models are required. Thus, Delay Tolerant Networks (DTN) are a very suitable communication technology, providing a reliable mechanism to information transmission without Internet.

DTN is a technology based on short-radio communication which allow information broadcasting using physical proximity. The functioning rooted in moving nodes provides an Internet-agnostic operation, making use of low-energy interfaces to transmit packets. The possibilities DTN brings to isolated rural areas are notable. Following the context previously exposed, this communication model enables the deployment of eHealth solutions, as well as transmission platforms for local enterprises. This way, DTN provides a solid basis for implementations and proposals. In this paper, a DTN-based solution is proposed. Taking into account the limitations of rural scenarios and the relevance of telemedicine and telecomunications for the population, a platform for health monitoring of elders and data transmission for enterprises is explained and analyzed. This way, the proposal consists on a distributed communication system for sending data about the presence of elders in their homes. Thus, sensors located along the house provide information of the presence habits of the senior, enabling the detection of abnormal absences or unusual behaviour. Besides, local livestocks and farms are provided with sensors to monitor performance exploitation. As a result, these obtained data are transmitted through the DTN architecture, connecting eventually the area with the Internet through the gateway node. In order to perform this, intermediate nodes are key elements in the model. This way, throwboxes are devices located at roads which receive, store and forward information with encounters. Due to its autonomous nature, throwboxes are fed with a solar panel.

Therefore, energy consumption turns an important issue in the solution, since the operations of the devices suppose power use.

In this work, the solution is evaluated on a simulation, studying the performance of the router algorithm used to broadcast the data and analyzing the energy consumption model following the work J.Galán et al. [8]. The paper is organized as follows. Firstly, Sect. 2 consists of a short overview of similar approaches to communication in isolated villages. Secondly, Sect. 3 details the proposal and the different entities involved in the solution. Then, Sect. 4 analyzes the obtained results and Sect. 5 draws some conclusions about the work.

2 Related Work

The absence of Internet in isolated areas has motivated the deployment and research of alternative telecommunication solutions. DTN are one of the most representative models for information contexts where Internet coverage is absent. This technology makes use of low-energy wireless interfaces [9] and physical proximity to broadcast messages from a sender entity to a destination. During this process, it is common the use of intermediate nodes which are in distributing it along the scenario, following the store-carry-and-forward method. This functioning is based on receiving the information, storing it and, when a new contact is made, broadcasting the data. As a result, information can be transmitted without requiring a constant external connection, basing the working on autonomous collaborative nodes.

Many projects address the lack of Internet infrastructure with solutions based on DTN. This communication model finds on hostile-communication contexts the opportunity of providing a transmission mechanism. Situations like spatial or maritime communication, natural disasters, isolated regions or battlefield zones are contexts for this technology [10]. In this case, proposals like [11–14] or [15] are specially relevant.

The project [11] proposes a solid approach to DTN applied for asynchronous communications making use of mobile vehicles. This solution tries to provide Internet connection to remote and isolated areas, offering multiple non-real time services. In contrast with this proposal, our work is centred on providing an emergency detection tool for elders, focusing the traffic flow on broadcasting the presence data of the seniors.

In a more concrete use case, the work [12] proposes the use of DTN to provide communication for reindeer herders in Swedish Lapland. This work suggest the transmission of Email, Files and Web Services, highlighting the sustainability of the architecture. In contrast with the presented paper, the work [12] finds the solution quite different, not only due to the nomadic nature of the scenario but also on any practical simulation of the project.

In the case of [13] and [14], the energy consumption also plays a key role in the project. The first work proposes a wireless coverage in low-income areas through the deployment of Unmanned Aerial Vehicles (UAVs) fed with batteries and solar panels. This way, one of the key points of the work is defining the most

optimal paths for the UAVs. The second project follows the same line, centred on the optimization of the movement algorithm. This two proposals are quite relevant for the remote areas without Internet coverage but the deployment of drones and the geographical peculiarities make difficult relocate the solution in many places.

On the other hand, the article [15] also makes use of UAVs to provide a DTN communication network but specially for places where a natural disaster has happened. As a result, the project provides a mechanism for data delivery which is evaluated in simulations, obtaining favourable results.

In this work, the use of DTN goes further and provides a reliable mechanism for the transmission of health-related information from seniors. Moreover, the architecture is also deployed to provide communication to local exploitations like livestocks or hives. Thus, using the SACAR OCVN algorithm proposed in [16], a sustainable architecture is developed to detect possible emergencies at elderly's home and broadcast performance data from industries. Taking into account the objective of the system, the reliability of the system must be absolute. Therefore, a deep set of simulations are made in The ONE [17] to analyze the impact of the architecture at telecommunications. Next section describes the complete working of the proposal.

3 DTN Solution for Isolation Monitoring in Remote Areas

The proposed solution is a communication architecture based on DTN to provide reliable connection for eHealth solutions in rural isolated areas. This way, the system provides the detection of possible emergencies related with seniors. Furthermore, the communication platform provides local business with the transmission of performance data from livestocks or agriculture exploitation. As a result, the proposed network enables reliable communications in isolated areas.

The communication architecture provides a mechanism to broadcast the health information from seniors to gateways which transmit the data to the Internet. The detection of vital sights of seniors who live alone is key for the emergency prevention. Many seniors who live alone risks of getting ill or having a home accident, becoming hard to ask for attention or help. This paper proposes the installation of presence sensors in the elderly's home, enabling the detection of mobility patterns and absences. Thus, it is possible to identify when the elderly is not detected at home during a long term, breaking his presence pattern.

The sensors situated at the elderly's home communicate with a center unit which process the data and broadcast it following the DTN philosophy and using the PeaaS mechanisms. Moreover, local exploitations and livestocks are provided with sensors which monitor the production and performance. For example, in the case of a hive exploitation, sensors detect the boxes weight, providing reliable data about the production level. In the same way as the presence data of seniors, the information is broadcasted through the DTN network based on PeeaS.

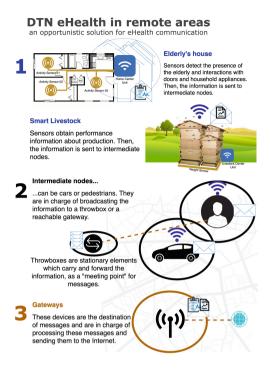


Fig. 1. Rural scenario overview.

SACAR is the algorithm used in the paper [16]. This mechanism is the DTN router in charge of broadcasting the obtained data into the network and gateways. The information is transmitted using PeeaS, guiding the transmissions into an interest-based system. The implementation of PeeaS provides a virtual profile for each node. The information kept in the profile defines the role that the element plays in the scenario. Thus, the Goal attribute declares the interest that the node have, while the Skill parameter specifies the performable actions. As a result, the Goal and Skill attributes provide the mechanism to identify which nodes are able to satisfy the interests. Thus, SACAR decides the intermediate nodes through the common interests.

The proposal involves three different node types which are in charge of operating different roles in the scenario, as it can be seen in Fig. 1. Firstly, the sender node are the elderly's home and the livestocks. These elements generates the information to be broadcasted into the network. The communication units installed in the places identify possible intermediate nodes interested on carrying the data and share it. Secondly, intermediate nodes plays a key role in the DTN solution. Taking into account the mobility nature of these elements, intermediate nodes serve as mules for the data, carrying the transmitted messages from the sender entities to the gateway destinations. Depending on the interests defined on the virtual profile, the nodes will carry the presence information or the performance data. Thus, this kind of nodes fit with devices like pedestrian's smartphones, passing cars or throwboxes. These last elements are

devices installed in roads and meeting points which store and broadcast data. Following a sustainable solution, throwboxes are fed with solar energy. Finally, destination nodes are gateways installed in zones with Internet coverage. Thus, the messages obtained are transmitted into the cloud, providing notifications for the health data and communication silk for the performance reports. As a conclusion, the system architecture combines SACAR and eHealth utilities.

This solution is evaluated using The One on a scenario that represents a rural area in which the population is mainly elderly people living alone. In the next section we draw the simulation details and survey the obtained results.

4 Experimental Results

This section describes the simulation process followed to obtain the performance results of the proposal and the set of parameters contempled for the study case. Thus, two subsections are defined: the simulated scenario and the performance tests.

4.1 Simulated Scenario

The simulation specified in The ONE represents one of the many villages which fill the rural areas of Extremadura. The little town counts on several urban and rural streets which communicate the two main places of the zone, the urban core and the industries. Thus, the roads link the places, providing throwboxes in strategic points for messages interchange. Figure 2 shows the graphic simulation aspect.



Fig. 2. Nuñomoral simulated in The ONE.

The simulation process is done in several executions under the same conditions, defining a set of environmental variables which represent an ordinary traffic flow (see Table 1). Thus, the village is represented in a $A=81000 \quad m^2$ scenario where multiple nodes are positioned. There are N=146 nodes in simulation, where $N_d=3$ are destinations, $N_s=80$ are senders and $N_i=66$ are intermediate. Inside this last group, three kind of behaviour can be found: $N_{sh}=34$

nodes interested on carrying health information, $N_{ip}=13$ nodes interested on carrying performance reports, $N_{ia}=13$ nodes interested in both and $N_{pn}=6$ nodes without interests. Furthermore, $N_{it}=3$ corresponds to the throwboxes installed along the roads. These devices count with an additional field where the solar energy that feed them is specified. This value is obtained from the hourly dataset from PWatts [18]. All these elements in simulation interact during a simulated time of $T=28800\,\mathrm{s}$ with a message generation interval of $\omega=3600\,\mathrm{s}$. The message generation interval is a parameter which specifies the waiting time before sender nodes generate new content on the network. This way, the message size is set to $M_{size}=300~\mathrm{kB}$. As a result, the execution under these conditions provides the performance evaluation of the solution.

4.2 Performance Evaluation

The simulation process is done in several executions under the same conditions. For the performance evaluation, three main variables have been considered: delivery probability, latency and energy consumed by the throwboxes. Taking into account the sustainable nature of the solution, the energy consumption defines one of the most relevant variables of the execution. Since throwboxes make use of solar panel to feed the batteries, the message processing and the encounters become imperative tasks which consume this resource. Thus, a multidimensional evaluation is made about the system simulation.

| Table 1. | Environmental | variables is | n the si | imulated | scenario. |
|----------|---------------|--------------|----------|----------|-----------|
| | | | | | |

| Parameter | Value |
|------------|---------------|
| A | $81000 [m^2]$ |
| N | 146 |
| N_s | 3 |
| N_{sh} | 34 |
| N_{ip} | 13 |
| N_{ia} | 13 |
| N_{pn} | 6 |
| N_i | 66 |
| N_{it} | 3 |
| N_g | 80 |
| T | 28000 [s] |
| ω | {3600} [s] |
| M_{size} | {300} [kB] |

The energy consumed (β in μAh) by the throwboxes is calculated every hour during the simulation. This way, the operations performed by the device

affect the battery consumption: number of stored messages (M_{stored}) , number of sent messages (M_{sent}) and contacts with other mobile nodes (C). When two nodes encounters, the virtual profiles are shared between them, so this process is considered as a send/stored operation. Based on the work presented in [19], the corresponding consumption for each action is assigned, defining the formula 1 to determine the β consumed in a concrete hour. The consumption reference values correspond to the concrete size of the messages $(M_{size} = 300 \, \text{kB})$.

- $-\zeta$ as energy consumed when a node contacts with another ($\zeta = 29.47 \,\mu\text{Ah}$)
- $-\delta$ as energy consumed when a message is sent ($\delta = 22.91 \,\mu\text{Ah}$)
- $-\epsilon$ as energy consumed when a message is stored ($\epsilon = 6.56 \,\mu\text{Ah}$)

$$\beta_t = \zeta \times C_t + \epsilon \times M_{sent} + \delta \times M_{stored} \tag{1}$$

Taking this into account, the battery of the device in a concrete time (ϖ in μ Ah) will be the result of associating the current battery level ($\varpi_{current}$) with the energy captured throw the solar panel ($\varpi_{captured}$) and the consumed battery (β_t). Thus, the interactions of the throwboxes with the surrounding nodes will impact notably on the battery evolution. This way, the value of ϖ follows the Formula 2.

$$\varpi_t = (\varpi_{current} + \varpi_{captured}) - \beta_t \tag{2}$$

Through the implementation of a custom report for The ONE, the execution of the simulation provides the evolution of the energy consumption in each throwbox. Thus, it is necessary to specify the energy captured by the solar panel during each hour of the simulation. Using the public dataset of Cáceres, Extremadura from the web PWatts [18], the energy capted in each simulation hour is specified for throwboxes. Assuming a panel surface of panel of $0.455\,\mathrm{m}^2$, the energy capted depends actively of the geoposition and the hour. Moreover, the report provides details about the battery evolution which allow the representation of three dimensions: i) the impact of storing and sending messages in battery (Fig. 3), ii) the impact of encounters in battery (Fig. 4) and iii) the relation between the energy capted and the battery of the throwboxes (Fig. 5). Throwboxes are represented in figures with format "T" and the corresponding number, followed by the variable which defines.

Figure 5 reflects the inherent relation between the obtained energy from the solar panel and the battery level. Therefore, the way the throwboxes are fed in a sustainable way through solar energy manifests the independence of these devices to work in an autonomous way.

As can be seen in Fig. 4, the energy consumed in each hour is actively related with the encounters the throwboxes have experienced. Taking into account the process of recognition and communication that every node opens when a encounter is made, the consumption is significant. On the other hand, Fig. 5 manifests the relation between the message traffic and the battery. The messages sent and store imapet on the battery of the throwbox. As a result, the

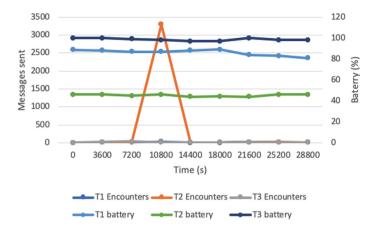


Fig. 3. Messages sent and battery consumed.

throwboxes denote a good and sustainable performance, manifesting the autonomy of this devices.

In addition to these results, the simulation is also studied under the consideration of reliability. Moreover, the delivery probability result becomes a key part of the reports since it reflects the percentage of messages correctly received at destination. Taking into account the sensible information transmitted through the network, it is imperative to guarantee the presence information from elderly's home and performance reports from industries are correctly broadcasted to the Internet. This way, the global results of the simulation were favourable, with a 99.69% of delivery probability, a latency average of 2178.44s and an overhead of 4195.64.

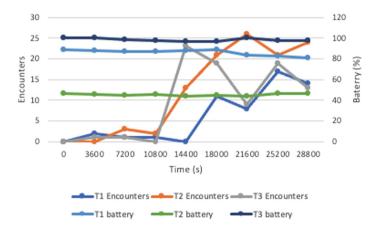


Fig. 4. Impact of the encounters on battery.

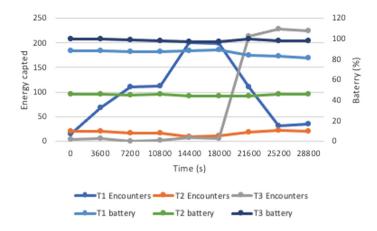


Fig. 5. Impact of the energy obtained in battery.

The performance evolution of the simulation shows a successful behaviour in all studied aspects. The energy consumed by the static intermediate nodes shows the sustainability of the proposal and the autonomous working of the architecture. Therefore, the good performance at connectivity and delivery probability provides the needed reliability to become useful at DTN eHealth.

5 Conclusion

The global population is facing a widespread ageing. The increasing average age in Europe elicits mechanisms and politics to deal with this evolution which implies a big challenge for society. Many sectors of society are specially involved in this demographic change but health is the one which faces the most relevant one. The care of third age population implies an important necessity which finds in technology a perfect allied. Possibilities like digital patient recipies, monitorization or telemedicine reflect some possibilities to improve the day-to-day of seniors. However, these systems are not applicable in some remote places where there is not Internet infrastructure. Many rural areas lack infrastructures to connect to the Internet. The geographical situation and the lack of interest from telecommunication companies disgorge into the absence of mechanism to provide a reliable connection to the cloud. This context blocks the deployment of eHealth solutions for these areas where the elder people represent a high percentage of the population. Thus, in addition to the deficiencies inherent to the ageing, the solitude of seniors who live alone in these rural areas induce potential health risks and emergencies. As a response to this contexts, alternative technologies like DTN provides mechanisms to transmit messages without requiring an Internet connection.

The work presented in this paper extends the proposal of [16] and [20]. The first project brought the original implementation of the routing algorithm SACAR OCVN, evaluating the performance in different scenarios and setting the

base of the work line. However, the test simulations involved simple scenarios were energy consumption was not considered. Besides, in the case of the second work, even tough a more complex scenario was brought, power consumption was not studied. Taking this into account, the present article explores deeply the possibilities of the algorithm while analyzes the consumption patterns of devices.

Taking this into account, this paper applies the original algorithm to simulate a communication architecture which provides a presence monitorization to seniors and a reliable service for industrial performance reports. Thus, the work enables the prevention and detection of emergencies in elderly's home through presence sensors which identify anomalous patterns in user habits. Additionally, the communication architecture serves as a reliable transmission mechanism to sensors located on exploitations, livestocks or hives, serving the data to the cloud processing. Thus, the intermediate elements serve as mule for the information, providing a link between the sender and the destination node.

The solution has been evaluated on The ONE, defining a representative rural area and studying variables like the delivery probability, latency and energy consumption. The throwboxes used as static intermediate devices in the communication architecture are fed with energy provided by solar panels installed in top of the element. Thus, the energy consumed is analyzed and crossed with the message processing done during the simulation. Therefore, the consumption model of the throwboxes is defined, studying the evolution of the battery during the simulation and relating the values with the operations performed in the execution. The obtained results reflect several interesting points regarding the power management, highlighting the impact of the encounters in battery and how the obtention of energy from the solar panel is more evident when interactions are none. As a result, the algorithm provides a reliable mechanism for eHealth monitoring and data transmission in regions without Internet infrastructure, requiring a cheap and sustainable infrastructure which operates autonomously. This way, emergency detection at elders' home can be detected while local livestocks are able to improve the performance, idenpendently of the Internet coverage.

Acknowledgment. This work has been partially funded by the 4IE+ project (0499-4IE-PLUS-4-E) funded by the Interreg V-A Espańa-Portugal (POCTEP) 2014-2020 program, by the Spanish Ministry of Science, Innovation and Universities (RTI2018-094591-B-I00), by the Department of Economy and Infrastructure of the Government of Extremadura (GR18112, IB18030), and by the European Regional Development Fund.

References

- Bloom, D.E., Chatterji, S., Kowal, P., Lloyd-Sherlock, P., McKee, M., Rechel, B., Rosenberg, L., Smith, J.P.: Macroeconomic implications of population ageing and selected policy responses. Lancet 385(9968), 649–657 (2015)
- European Commission (EC). Population structure and ageing: statistics explained.
 From July 2019 European population data extraction, p. 2 (2019)

- Atmojo, J.T., Sudaryanto, W.T., Widiyanto, A., Ernawati, A.D., Arradini, D.: Telemedicine, cost effectiveness, and patients satisfaction: a systematic review. J. Health Policy Manage. 5(2), 103–107 (2020)
- Sekhon, H., Sekhon, K., Launay, C., Afililo, M., Innocente, N., Vahia, I., Rej, S., Beauchet, O.: Telemedicine and the rural dementia population: a systematic review. Maturitas 143, 105–114 (2020)
- Goins, R.T., Kategile, U., Dudley, K.C.: Telemedicine, rural elderly, and policy issues. J. Aging Soc. Policy 13(4), 53–71 (2002)
- El 81% de la población española dispone de cobertura de Internet a más de 100
 Mbps Ministerio de Asuntos Económicos y Transformación Digital (es)
- Poon, S., Swatman, P.M.: Small business use of the internet. Int. Mark. Rev. 14, 385–402 (1997)
- 8. Galán-Jiménez, J.: Minimization of energy consumption in IP/SDN hybrid networks using genetic algorithms. In: 2017 Sustainable Internet and ICT for Sustainability (SustainIT), pp. 1–5 (2017)
- Vicente, A.B., Jimenez, J.G., Cervero, A.G.: Characterization of energy consumption of a 802.11g device. IEEE Lat. Am. Trans. 13(8), 2495–2499 (2015)
- Datta, S., Madria, S.: Efficient photo crowdsourcing with evolving POIs under delay-tolerant network environment. Pervasive Mob. Comput. 67, 101187 (2020)
- Pentland, A., Fletcher, R., Hasson, A.: DakNet: rethinking connectivity in developing nations. Computer 37(1), 78–83 (2004)
- Doria, A., Uden, M., Pandey, D.P.: Providing connectivity to the Saami nomadic community. In: International Conference on Open Collaborative Design for Sustainable Innovation: 01/12/2002–02/12/2002 (2002)
- Amorosi, L., Chiaraviglio, L., Galán-Jiménez, J.: Optimal energy management of UAV-based cellular networks powered by solar panels and batteries: formulation and solutions. IEEE Access 7, 53698–53717 (2019)
- Galán-Jiménez, J., Chiaraviglio, L., Amorosi, L., Blefari-Melazzi, N.: Multi-period mission planning of UAVs for 5G coverage in rural areas: a heuristic approach. In: 2018 9th International Conference on the Network of the Future (NOF), pp. 52–59 (2018)
- Xiong, X., Liu, M., Zhang, Y., Zhang, N., Chen, G., Fu, M., Cheng, Z.: The effect of region-based message selective delivery strategy on post-disaster emergency network. J. Phys. Conf. Ser. 1486, 022005 (2020)
- Galán-Jiménez, J., Berrocal, J., Garcia-Alonso, J., Azabal, M.J.: A novel routing scheme for creating opportunistic context-virtual networks in IoT scenarios. Sensors 19(8), 1875 (2019)
- 17. Keränen, A., Ott, J., Kärkkäinen, T.: The ONE simulator for DTN protocol evaluation. In: Proceedings of the 2nd International Conference on Simulation Tools and Techniques, p. 55. ICST (Institute for Computer Sciences, Social-Informatics and Telecommunications (2009)
- 18. PVWatts Calculator. https://pvwatts.nrel.gov/. Accessed 14 Oct 2020
- Berrocal, J., Garcia-Alonso, J., Vicente-Chicote, C., Hernández, J., Mikkonen, T., Canal, C., Murillo, J.M.: Early analysis of resource consumption patterns in mobile applications. Pervasive Mob. Comput. 35, 32–50 (2017)
- Jesús-Azabal, M., Berrocal, J., García-Alonso, J., Soares, V.N.G.J., Galán-Jiménez, J.: An opportunistic routing solution to monitor isolated elderly people in rural areas. In: International Workshop on Gerontechnology, pp. 195–203. Springer (2019)



Training Proposal Technology for the Elderly with Changes in Self Care and for Their Caregiver: Rehabilitation Nursing Care Contributions

César Fonseca¹(⋈), Liliana Barbas²(⋈), Patrícia Martins³, Rogério Ferrinho⁴, José Garcia-Alonso⁵, Lara Guedes de Pinho¹, and Inês Cardoso¹

¹ University de Évora, Comprehensive Health Research Center, POCTEP 0499_4IE_PLUS_4_E, Évora, Portugal

² Santarém District Hospital, Santarém, Portugal

Abstract. Objective: Identify the rehabilitation nursing interventions that can contribute to the training of the elderly person with self-care changes and to the training of their caregiver. Methodology: Systematic Literature Review, for which research was done at EBSCO selecting the Cinahl and Medline databases. The PRISMA recommendations were followed, and 11 studies were selected. Results: Training for self-care is one of the sensible results of Rehabilitation Nursing care, and in the selected studies the most identified were physical capacity, cognitive function, patient safety, and health literacy. Interventions for both the person and the caregiver are mentioned, and teaching is the basis of them. Conclusions: The training of the person and the caregiver must be objectives of the intervention of the nurse throughout the rehabilitation process, with a view to the continuity of care and achieving health gains. Professional practice implications: The caregiver should be seen not only as a relative of the elderly patient, but also as a target of care, as he or she also goes through a situation of wear and tear and vulnerability.

Keywords: Rehabilitation nursing · Training · Informal care · Self-care

1 Introduction

According to INE data, in Portugal in the last 40 years the population aged 65 and over has doubled and could increase from 2.1 to 2.8 million people between 2015 and 2080, representing about one third of the population. Thus, the aging index will rise from 147 to 317 elderly per 100 young people [1]. This is a situation that cuts across other developed countries, and Europe is currently the continent with the highest percentage of people over 60, corresponding to about 25% of its population [2].

The global aging of the population has been reflected in an increase in the number of elderly people living with chronic health problems, associated with a decline in their

UCC of Cartaxo, ACES Lezíria, ARS Lisboa and Vale do Tejo, Santarém, Portugal
 Polytechnic Institute of Beja, POCTEP 0499_4IE_PLUS_4_E, Beja, Portugal

⁵ University of Extremadura, POCTEP 0499_4IE_PLUS_4_E, Cáceres, Spain

[©] The Author(s), under exclusive license to Springer Nature Switzerland AG 2021 J. García-Alonso and C. Fonseca (Eds.): IWoG 2020, LNBE, pp. 69–80, 2021.

functionality, greater fragility and dependency [3]. Because chronic diseases can have consequences on the physical performance and social roles of the elderly person, leading to a functional decline and a greater risk of institutionalization, hospitalization due to acute illness and the need for care by others [2].

The person and the caregiver, when going through a situation of illness and/or dependence, and the implications it entails, also go through a process of transition that generates changes in family dynamics, particularly with regard to changes in social life, dysfunction of roles, and financial burden [4]. This situation often results in an overload of the informal caregiver, who from one moment to the next finds him/herself confined to taking care of his/her dependent family member, without having any training or support in his/her new function [5].

The Rehabilitation Nurse at the time of his intervention is therefore faced not only with the needs of the target person of his care, but also with the needs that the care-giver/family member presents. Thus, the family and other caregivers should also be included in the rehabilitation nurse's intervention plan, teaching and advising about their needs [5]. This is the only way they can be partners in the care of the dependent family member, guaranteeing the continuity of care and their permanence at home. Having this in mind, the need arose to carry out an SLR on the current state of knowledge regarding rehabilitation nursing interventions that can train not only the elderly person with changes in self-care, but also the caregiver, thus being possible to develop coping strategies that are facilitators in the management of their care [6, 7].

The Fonseca Self Care Model [8], which has as essential components the Orem's Self-Care Theory; and the continuum of functionality proposed by ICF, and which is composed of the description of the functional level, through which it is possible to determine the deficit of self-care, and the need for nursing care, is a model that allows the systematization of care. Through this, it is possible to develop an intervention plan, based not only on the needs of self-care, but also on the functional capacities and knowledge of the patient and, in the conditions and context of the same, including the caregiver. To this end, in addition to partially and fully compensatory interventions, an educational support system based on the therapeutic relationship nurse-patient/care may be implemented in order to obtain results sensitive to rehabilitation nursing care contributing to its quality.

According to Doran & Pringle [9] the sensitive outcomes of nursing care can be defined as all those that are relevant, based on the domain and nursing intervention, and for which there is empirical evidence that relates nursing interventions to outcomes. Thus, the authors identified some of the following sensitive nursing care outcomes: functional status, self-care, symptom management, patient safety, patient satisfaction, psychological changes, and health care utilization.

Donabedian [10] in his theory defended that, for the quality of care to be measured, indicators must be developed that can evaluate it quantitatively. For this, it is necessary to consider three dimensions: structure, process and results. According to the theory developed by this author, it is possible to make a systematic evaluation of care through the use of indicators, which allow the quantitative and qualitative representation of results and thus evaluate quality. The indicators, besides allowing the evaluation of quality, allow the evaluation of health gains and the identification of opportunities for improvement [11].

Therefore, given the morbidity and mortality and greater dependence on self-care to which people are subjected due to changes resulting from the aging process, given the importance that the caregiver may have in continuing to provide care to the person with changes in self-care, and the need to involve the caregiver in the rehabilitation process and train him/her to promote their empowerment and continuity of care, it was determined as an objective for the achievement of this SLR: identify the interventions of the rehabilitation nurse that can contribute to the training of the person with changes in self-care and to the training of their caregiver.

2 Materials and Methods

2.1 Materials: Concepts

Due to the aging process and/or acuteness due to chronic illness, the person is often subject to a loss of autonomy and a greater dependence on self-care, and there is a need for home care to be provided by family members or other caregivers. Dependency arises as a condition in which people who, for reasons linked to lack or loss of physical, psychic or intellectual capacity, during "a more or less prolonged period, need help from another person or equipment, to perform certain self-care activities," appear [12].

Self-care is defined as the practice of activities that favor the improvement and maturation of people, which are initiated and performed within spaces of time, for their own benefit and with the purpose of preserving life and healthy functioning and to give continuity to personal development and well-being [13].

In order to promote self-care, it is necessary to develop rehabilitation nursing interventions that can train not only the dependent elderly person, but also the caregiver. Capacity building/empowerment is understood as the process of promoting and strengthening people's ability to meet their own needs, solve their problems, and mobilize the necessary resources in order to feel they control their own lives Gibson [14].

2.2 Methodology

In this study we chose to use as methodology the systematic literature review (SLR), which according to the Cochrane Handbook "attempts to collate all empirical evidence that fits pre-specified eligibility criteria in order to answer a specific research question. It uses explicit, systematic methods that are selected with a view to minimizing bias, thus providing more reliable findings from which conclusions can be drawn and decisions made" [15]. In order to ensure the consistency, transparency and integrity of this SLR, PRISMA recommendations were followed (Fig. 1) [16].

After defining the subject to be addressed, the formulation of the problem was constructed through a starting point based on the PICO methodology. The FINER criteria (Feasibility, Interesting, Novel, Ethical, Relevant) were also taken into account in order to develop a good research question. That is, to be viable, interesting, original, to respect the ethical principles and be relevant to the nursing practice [17]. Thus, the following starting question was raised: "Which Rehabilitation Nursing Interventions (Context) can contribute to the Capacity Building (Outcomes) of the Person with self-care

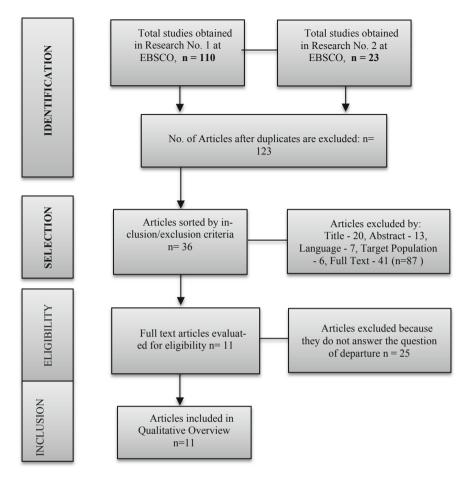


Fig. 1. Flow diagram that describes the process followed in the realization of the SLR, according to PRISMA recommendations [16].

alterations (Population) and to the capacity building (Outcomes) of his/her caregiver (Population)?".

For this study, two English language surveys were conducted on the EBSCO platform during September 2019, and the Cinahl Complete and Medline Complete databases were selected. In the first survey the following descriptors were used: "Nursing", "Nursing Care", "Nursing Intervention", "Health selfcare", "Selfcare", "Patient Education", "Rehabilitation", "Nursing Rehabilitation", "Blood pressure", "Stroke", "Neurology", "Cerebrovascular disorders", and "Cardiovascular diseases". And, in a second survey, the descriptor "Caregivers" was added to the previous ones. The Bolean operators "AND" and "OR" were also used in the combination of the various surveys. And all the descriptors were extracted from the vocabulary "Medical Subjects Heading" (MeSH) [18].

The inclusion criteria were: articles analyzed by experts, with full text and publication date between January 2014 and September 2019. Duplicate articles were excluded, which were not in English or Portuguese, which did not answer the starting question, and which did not contain the identified target population - i.e., studies with nurses, with people with self-care alterations, and which also included the informal caregiver.

The classification of the levels of evidence of the selected studies was made according to Melnyk & Fineout-Overholt [19], in order to guarantee their reliability and eligibility, as well as the quality of the results and conclusions.

3 Results and Discussions and Conclusions

3.1 Discussion of Results

Following the PRISMA flowchart, we were able to select 11 of the 133 studies initially identified. The following table (Table 1) presents the selected studies.

Table 1. Characterization of studies included in the SLR.

| Study description/level of evidence | Objectives | Results |
|---|---|---|
| "Caregiver-mediated exercises with e-health support for early supported discharge after stroke (CARE4STROKE): study protocol for a randomized controlled trial" [20] Methodology: Study with Control Group Level of evidence: IV Participants: 66 stroke patients | To evaluate the effects and the cost-benefit ratio, in terms of mobility and length of stay, of an exercise program after a stroke, mediated by the caregiver and together with the health services | There was an increase in the functionality of patients and a greater number of early rises, with a consequent reduction in costs |
| "Nursing Interventions to the Patient with Stroke in Rehabilitation" [6] Methodology: Integrative Literature Review Level of evidence: I Participants: Not applicable | To present the knowledge produced about the Nursing interventions directed to stroke patients in rehabilitation | A greater number of nursing interventions targeted to the patient were identified, namely motor and functional rehabilitation. The educational interventions are directed both to the patient and the caregiver. And the managerial interventions are related to the coordination of care |
| "Nursing roles and functions addressing relatives during in-hospital rehabilitation following stroke" [7] Methodology: Randomized Control Study Level of evidence: II Participants: 19 Nurses | Describe the role and functions of nurses for caregivers during rehabilitation care of stroke patients in a hospital | The nurses recognized that they direct the care to both patients and caregivers, and that they support the relationship between them. But family members are affected by the patient's situation, presenting needs that take second place. After structural analysis, four focuses of intervention emerged: changes in the life of the caregiver; shared life after the stroke; non-cooperative relatives; and lack of time for relatives |

 Table 1. (continued)

| Study description/level of evidence | Objectives | Results |
|---|---|---|
| "An ICF – Based Model for Implementing and Standardizing Multidisciplinary Obesity Rehabilitation Programs within the Healthcare System" [21] Methodology: Control Study Level of evidence: III Participants: 51 patients | Develop an individual rehabilitation project based on CIF, for obese patients with comorbidities integrated in Rehab-CYCLE to standardize rehabilitation programs | The proposed model offers the following advantages: (1) Standardizes rehabilitation procedures; (2) facilitates communication between hospital, patient, relatives and caregivers; (3) addresses organizational issues; (4) can serve as a reference for professionals involved in the rehabilitation of morbidly obese patients. |
| "Effects of Mobility-Enhancing Nursing Intervention in Patients with MS and Stroke: Randomised Controlled Trial" [22] Methodology: Randomized Control Study Level of evidence: II Participants: 140 patients with stroke, multiple sclerosis or brain problems | To investigate the effect of a new nursing intervention (Mobility Enhancing Nursing Intervention - MFP) developed to improve the results of rehabilitation | There has been an increase in the functionality of patients and an improvement in their quality of life, which indicates that specialist rehabilitation nursing care should be part of rehabilitation programs |
| "Gender Analysis in the Outcomes of a Lifestyle Intervention Amon Patients Who Had an Open Heart Surgery" [23] Methodology: Randomized Control Study Level of evidence: II Participants: 500 patients undergoing open heart surgery after discharge from hospital | To evaluate gender differences in the results of a lifestyle intervention study (diet, smoking cessation and exercise) in patients undergoing open heart surgery | Nursing intervention in the lifestyle of patients after heart surgery showed benefits in men, who stopped smoking faster, reduced the risk of cardiovascular events and returned to work. In women no significant results were found |
| "Implementation and Feasibility of the stroke nursing guideline in the care of patients with stroke: a mixed methods study" [24] Methodology: Retrospective Cohort Study Level of evidence: IV Participants: 78 patients and 33 nurses and nursing auxiliaries | Determine the implementation and feasibility of the Stroke Nursing Guideline (SNG) in terms of changes in the documentation and use of the guideline in the care of stroke patients in neurology and rehabilitation wards; and identify barriers and facilitators, and how nurses and nursing auxiliaries view its implementation | The nursing team considered the SNG viable and its implementation was successful. The SNG promotes care, with greater consistency and more rigor in functional exercises than before. It also promotes pain control, patient education, discharge planning and reduces post-stroke depression levels |
| "Strengthening the role and functions of nursing staff in inpatient stroke rehabilitation: developing a complex intervention using the Behaviour Change Wheel" [25] Methodology: Cohort Study Level of evidence: IV Participants: 12 nurses and 10 patients | Describe the development of a nursing intervention that aims to optimize the interaction in the rehabilitation of patients with stroke, strengthening the role and functions of the nursing team | A 24/7 educational rehabilitation intervention was developed. Following the Medical Research Council and Behavior Change Wheel's models some resources were consumed, but it was possible to develop a practical and well-structured intervention, based on theory and evidence |

 Table 1. (continued)

| Study description/level of evidence | Objectives | Results |
|--|--|--|
| "Systematic scoping review of frameworks used to develop rehabilitation interventions for older adults" [26] Methodology: Systematic Literature Review Level of evidence: I Participants: Not applicable | -Verify if the development structures are being used in research on elderly in rehabilitation; - Document which programs are being used; - Explore how these programs are used, what methods and details | Included 35 studies with participants with various medical conditions (dementia, heart, stroke, falls, # femur, Diabetes Mellitus (DM), Parkinson's, Breast Cancer, Depression, Chronic problems, osteoarthritis, leg ulcer, cervical pain, and foot problems). The type interventions that can be developed are: support, cognitive, physical activities, nursing, fall prevention and occupational therapy. The Medical Research Council structure is more popular to develop rehabilitation interventions for the elderly |
| "The effects of increased therapy time on cognition and mood in frail patients with stroke who rehabilitate on rehabilitation units of nursing homes in the Netherlands: a protocol of a comparative study" [27] Methodology: Study with Control Group Level of evidence: IV Participants: 138 participants with stroke | To investigate whether increased therapy time has a positive effect on cognition, mood (depression and anxiety), and life activities of the stroke patient | The implementation of interventions according to the Clinical Nursing Rehabilitation Stroke Guideline has increased the time spent on therapeutic activities, without the need for extra therapies; the role of the nurse can become more therapeutic; and the increase in therapy time has had positive effects on cognition, mood and life activities |
| "Ward-based interventions for patients with hemispatial neglect in stroke rehabilitation: a systematic literature review" [28] Methodology: Systematic Literature Review Level of evidence: I Participants: Not applicable | Identify rehabilitation interventions that can integrate a nursing program for patients with hemi-spatial neglect after strokes in the right hemisphere of the brain | Among 41 original studies, 11 interventions were identified: vibration against neck injury; emotional stimulation; family participation and training intensity; training for limb stimulation; mental imaging training; mirror therapy; music therapy; alternate ocular occlusion; smooth movement training with the eyes; virtual reality and computer-based training; visual scanning training |

Vloothuis et al. [20] developed a study on the CARE4STROKE program in which patients and caregivers were accompanied by rehabilitation specialists, with the support of an application with videos. They chose a set of exercises and the caregiver was instructed and mediated the therapeutic exercises that the patient had to do. After discharge, the objective was that the program would continue at home. At the end of the program there was a significant improvement in mobility with gains in strength, walking ability, balance, achievement of ADL's, gains in the psychosocial field (decreased anxiety and depression, increased self-efficacy, decreased fatigue), and improved quality of life.

Corroborating the idea that the caregiver should be an integral part of the rehabilitation process Cavalcante et al. [6], they point out that the interventions that the nurse directs to him are mainly educational. In relation to the patient, functional and motor

rehabilitation stands out, as well as the importance of teaching. And, Booth et al. [26] in their systematic review of the literature on rehabilitation interventions in elderly adults also reported: cognitive interventions, physical activities, fall prevention, occupational therapy, and post stroke care.

Aadal et al. [7] found that although the care is directed both to the patient and the caregiver and the relationship between them, the caregiver's needs are still left in the background. This should not happen, because according to the authors the caregivers are essential partners in the care and when they face their family member's illness situation, they also see their life changed, and often run out of time for themselves and without the support of other people.

The study by Imhof, Suter-Riederer & Kesselrin [22], conducted in Switzerland, shows that specialized rehabilitation nursing intervention should be an effective part of rehabilitation programs. By developing a nursing intervention program for gains in mobility, to improve patient safety, develop sensory skills, promote mobility and functionality, and reduce fatigue of caregivers, they have achieved gains in functionality and quality of life of the patient. It is an intervention based on the assumption that learning occurs from movement. Thus, tactile and kinesthetic stimulation was used in the process of mobilization and in the realization of ADL's, in order to promote brain reorganization through the perception of the environment. The intervention was done several times a day and in a perspective to personalize the care to the patient, to negotiate based on the results and to include the relatives - recognizing once again the importance of caregivers.

Regarding the guidelines as structural elements of care, Bjartmarz, Jónsdóttir & Hafstensdóttir [24] found that the Stroke Nursing Guideline (SNG) is useful and promotes the consistency of nursing care. With its contribution the components of rehabilitation nursing were defined and integrated in the daily routine of care being considered key elements, besides contributing to the practice based on evidence. SNG includes recommendations on mobility, daily living activities, falls, depression, pain and patient and family education and discharge planning. Patients also become more active during the day, occupying a large part of it in activities, and reducing bed time. As for the family, he was around half of the day with the patients, which proved to be a reason for encouragement and support. The teachings about stroke to the patient and caregiver allowed to increase the knowledge, to increase the patient's satisfaction and to reduce the levels of depression.

Reinforcing the importance of guidelines for evidence-based practice, Huijben-Schoenmakers et al. [27] developed a study in which they proved that rehabilitation nursing intervention according to the Clinical Nursing Rehabilitation Stroke Guideline and with the addition of another 50 min of therapeutic activity (exercises) per day had positive effects on cognition, mood and ADL's. In order to ascertain the gains, global cognitive functions, executive functions, speech fluency, verbal and nonverbal memory, cognitive functions combined with memory, levels of anxiety and depression, mood and functional independence in ADL's were evaluated. The type of exercise was adapted to the objectives for the patient and all had a map with the planning of exercises.

Still regarding the stroke patient, in SLR of Klinke et al. [28] the objective was to identify rehabilitation interventions that could be part of a nursing care program for patients with neglect hemisphere after stroke in the right hemisphere. The authors emphasize the importance of diagnosing neglect, since most cases are not detected. For

this, it is necessary to make a correct assessment of the patient by the multidisciplinary team, taking into account: the degree of cognitive impairment, orientation and motor skills, physical impairment such as paralysis and hemianopsy, and spasticity. Computer activities such as listening to music, playing, and developing activities that result in positive reinforcement can be an important stimulus. It is also important that the patient remains active in ADL's and is stimulated for them. The authors also reinforce the importance of the family in caring for and looking after the patient.

Brunani et al. [21] when developing a rehabilitation program according to the ICF for patients with obesity demonstrated that these for the comorbidities (DM, HTA, Heart disease, muscle and joint alterations) and limitations they present, need a holistic and multidisciplinary intervention. Because they have limitations as in body functions (neuromuscular, movement function, pain and cardiovascular function), and in activities and participation (self-care, day-to-day activities, relationships) and report few environmental facilitators (support). The rehabilitation gains in these patients are the promotion of self-care and long-term lifestyle changes. This model has allowed the standardization of rehabilitation procedures from the ICF, facilitates communication between the hospital, the patient, family members and caregivers, and can serve as a reference for other professionals.

In the study of Kadda et al. [23], 500 patients undergoing open heart surgery received intervention related to lifestyles (diet, smoking session and exercise). One of the interventions concerned physical exercise, and it was recommended that the duration be gradually increased, as well as the frequency and intensity, for a greater adherence and lower risk, according to the patient's age and capacity. It was also recommended that the aerobic activity be in addition to the ADL's. The results showed that only in men an intensive intervention on lifestyles can reduce the risk of non-fatal cardiovascular events. It also helps in smoking cessation and rapid return to work. The fact that no significant results were found in women may have to do with the higher levels of depression and anxiety that they present.

Loft et al. [25] developed an intervention based on the model of the Medical Research Council (MRC), seeking to understand the behavior of the nursing team and its influence on their roles and functions in rehabilitation. The Behavior Change Wheel's (BCW) was also used, and trained and motivated nurses in order to promote their participation in the rehabilitation process of patients. After analyzing the data collected and conducting a literature review, it was concluded that nurses can play an important role in the education and training of patient needs, as well as in exercise training instruction. Their intervention should be based on the following functions: education, persuasion, modeling, encouragement, training, capacity building, and environment restructuring.

The Rehabilitation Nurse should thus recognize the importance of the caregiver as a provider of care in the home and the need to involve him/her in the care plan and train him/her to solve problems related to the family member and learn how to deal with them in order to reduce complications and better manage care. In addition, empowering the patient through teaching is also important to promote their autonomy and adaptation to their limitations by including them in their own care plan.

Thus, seeking to contribute to the improvement and quality of specialized care in rehabilitation nursing and in order to answer the starting question of this SLR, in the various studies analyzed it was possible to identify interventions, related to the outcome variables of the rehabilitation nursing care described by Carretas [29], namely:

functional status, physical capacity, cognitive function, professional-user relationship, symptom control, safety/adverse occurrences, training for self-care, user satisfaction, psychological support, use of health services, human resources, protective factors, health literacy and therapeutic compliance.

3.2 Implications in Professional Practice

The caregiver, as an essential partner in providing care, should also be the target of the rehabilitation nurse. For often their needs are forgotten and the caregiver goes through a process of wear and tear and vulnerability. The non-recognition of signs and symptoms of depression and anxiety can be a gap in rehabilitation care, preventing its continuation.

Given that we live in an era where technology is of paramount importance, software development with rehabilitation programs can be an attractive and simple method to promote continuity of care.

There are still few studies on the interventions of the rehabilitation nurse, so it is necessary to document the clinical practice and the results obtained in the intervention directed to the person and caregiver.

3.3 Conclusion

A considerable number of studies demonstrate that the start of the rehabilitation process must be early and that the intensity and repeatability of the various interventions included in the care plan is fundamental to achieving positive results in the functionality of the elderly person, as well as a greater number of early discharges and cost reduction [20, 24, 27].

The involvement of the caregiver in the patient's rehabilitation process, mentioned in most of the studies reviewed, reveals its importance not only as a support and encouraging element, but also as a partner in providing care [6, 7, 20, 22, 24, 28]. The teaching of the same by the rehabilitation nurse, with a view to his/her empowerment, can be an important contribution to an early discharge and to promoting the continuity of care at home [20]. It is necessary to change the paradigm of patient focused care and include the caregiver in the care plan, providing time for the same [24]. Because of this, their involvement in the rehabilitation of the patient and the social support offered to them can be essential for the promotion of the quality of life of both [20, 22].

With regard to rehabilitation care directed at the patient, the importance of making a correct assessment of the patient's motor and neurological function was reinforced, with a view to obtaining a correct diagnosis and developing an individualized care plan [24]. For this, its involvement is extremely important, promoting care negotiation, and the determination of achievable goals [22]. Nurses must maximize their contribution to rehabilitation and reinforce the importance of this area of specialization, by integrating exercise training into simple daily activities, aiming at increasing mobility and promoting self-care; and increase the intensity and duration of the rehabilitation process [24, 27]. The training of the person and the caregiver must, therefore, be objectives of the nurse's intervention in the entire rehabilitation process, with the objective of ensuring continuity of care and promoting the person's functional capacity [20]. The systematization of interventions by sensitive indicators of rehabilitation nursing care and the guidance

of care based on the Self-Care Model, when promoting the quality of life of the person/caregiver, can be important actions to obtain health gains. Because evidence-based clinical practice allows the development of a structural basis for the excellence of care and for the improvement of the quality of the professional practice of the Rehabilitation Nurse.

References

- Direção Instituto Nacional de Estatistíca [INE]: Projeções de População Residente 2015– 2080. Destaque, informação à comunicação social. INE, I. P., Lisboa, Portugal (2017)
- Organização Mundial de Saúde [OMS]: Resumo: Relatório Mundial de Envelhecimento e Saúde. OMS, Genebra (2015)
- Slatyer, S., Aoun, S., Hill, K., Walsh, D., Whitty, D., Toye, C.: Caregivers' experiences of a home support program after the hospital discharge of an older family member: a qualitative analysis. BMC Health Serv. Res. 1–10 (2019). https://doi.org/10.1186/s12913-019-4042-0
- Rocha, S., Avila, M., Bocchi, S.: Influência do Cuidador Informal na Reabilitação do Idoso em Pós-operatório de Fratura do Fêmur Proximal. Revista Gaúcha de Enfermagem, 1–9 (2016). https://doi.org/10.1590/1983-1447.2016.01.51069
- Graça, T., Bocchi, S., Fusco, S., Avila, M.: A Experiência do Cuidador Informal à Luz da Teoria Geral de Enfermagem. Online Braz. J. Nurs. 355–365 (2018). https://doi.org/10.17665/ 1676-4285.20175649
- Cavalcante, T., Nemer, A., Moreira, R., Ferreira, J.: Nursing interventions to the pacient with stroke in rehabilitation. J. Nurs. UFPE Online, 1430–1436 (2018) https://doi.org/10.5205/ 1981-8963-v12i5a230533p1430-1436-2018
- Aadal, L., Angel, S., Langhorn, L., Pedersen, B., Dreyer, P.: Nursing roles and functions addressing relatives during in-hospital rehabilitation following stroke. Care needs and involvement. Scand. J. Caring Sci., 871–879 (2018). https://doi.org/10.1111/scs.12518
- Jiménez, B.R., Caballero, D.C., González, B.M., García-Alonso, J., Fonseca, C., Juárez, L.M.: Los enfoques culturales en la alimentación de personas mayores rurales. Una necesidad multidimensional para la agenda del cuidado. INDEX DE ENFERMERÍA 28(3), 125 (2019). (SCImago Journal Rank SJR: 8 H Index. Quartiles: Q4. SCOPUS INDEX)
- 9. Doran, D., Pringle, D.: Patient outcomes as accountability. In: Doran, D. (ed.) Nursing Outcomes: The State of the Science, 2nd edn., pp. 1–27. Jones and Bartlett, Sudbury (2011)
- Donabedian, A.: The Definition of Quality and Approaches to its Assessment: Explorations in Quality Assessment and Monitoring. Health Administration Press, Chicago (1980)
- 11. Ordem dos Enfermeiros [OE]: Core de Indicadores por Categoria de Enunciados Descritivos dos Padrões de Qualidade dos Cuidados de Enfermagem de Reabilitação (PQCER). Assembleia do Colégio da Especialidade de Enfermagem de Reabilitação, Porto (2015)
- Goes, M., Lopes, M.J., Oliveira, H., Fonseca, C., Marôco, J.: A nursing care intervention model for elderly people to ascertain general profiles of functionality and self care needs. Sci. Rep. 10, 1770 (2020). https://doi.org/10.1038/s41598-020-58596-1
- 13. Tomey, A., Alligood, M.: Teóricas de Enfermagem e a Sua Obra (Modelos e Teorias de Enfermagem), 5th edn. Lusociência, Loures (2004)
- 14. Gibson, C.: A concept analysis of empowerment. J. Adv. Nurs. 16, 354–361 (1991)
- 15. Higgins, J., Thomas, J., Chandler, J., Cumpston, M., Li, T., Page, M., Welch, V. (eds.): Cochrane Handbook for Systematic Reviews of Interventions, 2nd edn. Wiley, Chichester (2019)

- 16. Galvão, T., Pansani, T., Harrad, D.: Principais itens para relatar Revisões sistemáticas e Meta-análises: A recomendação PRISMA. Epidemiologia Serviços de Saúde, Brasília, pp. 335–342. Trad. Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G. The PRISMA group. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement (2015). https://doi.org/10.5123/S1679-49742015000200017
- Sousa, L., Marques, J., Firmino, C., Frade, F., Valentim, O., Antunes, A.: Modelos de Formulação da Questão de Investigação na Prática Baseada na Evidência. Revista Investigação em Enfermagem, 31–39 (2018)
- 18. National Institutes of Health [NIH]: Medical Subjects Heading [MeSH] 2019. U. S. National Library of Medicine (2019)
- Melnyk, B., Fineout-Overholt, E.: Box 1.3: rating system for the hierarchy of evidence for intervention/treatment questions. In: Evidence-Based Practice in Nursing & Healthcare: A Guide to Best Practice, 3rd edn, p. 11. Wolters Kluwer Health, Philadelphia (2015)
- Vloothuis, J., Mulder, M., Nijland, R., Konijnenbelt, M., Mulder, H., Herthog, C., Tulder, M., Kwakkel, G., Wegen, E. (2015). Caregiver-mediated exercises with e-health support for early supported discharge after stroke (CARE4STROKE): study protocol for a randomized controlled trial. BioMed. Central Neurol. 1–9 (2015). https://doi.org/10.1186/s12883-015-0440-z
- Brunani, A., Raggi, A., Sirtori, A., Berselli, M., Villa, V., Ceriani, F., Corti, S., Leonardi, M., Capodaglio, P.: ICF-OBESITY Group. An ICF – based model for implementing and standardizing multidisciplinary obesity rehabilitation programs within the healthcare system. Int. J. Environ. Res. Public Health, 6084–6091 (2015). https://doi.org/10.3390/ijerph120606084
- 22. Imhof, L., Suter-Riederer, S., Kesselring, J.: Effects of mobility-enhancing nursing intervention in patients with MS and stroke: randomised controlled trial. Int. Sch. Res. Not., 1–6 (2015). http://dx.doi.org/10.1155/2015/785497
- 23. Kadda, O., Manginas, A., Stavridis, G., Balanos, D., Kotiou, M., Panagiotakos, D.: Gender analysis in the outcomes of a lifestyle intervention amon patients who had an open heart surgery. Angiology, 66–74 (2016). https://doi.org/10.1177/0003319715577293
- 24. Bjartmarz, I., Jónsdóttir, H., Hafsteinsdóttir, T.: Implementation and Feasibility of the stroke nursing guideline in the care of patients with stroke: a mixed methods study. BioMed. Central Nurs. (2017). https://doi.org/10.1186/s12912-017-0262-y
- 25. Loft, M., Martinsen, B., Esbensen, B., Mathiesen, L., Iversen, H., Poulsen, I.: Strengthening the role and functions of nursing staff in inpatient stroke rehabilitation: developing a complex intervention using the behaviour change wheel. Int. J. Qual. Stud. Health Well-Being, 1–15 (2017). https://doi.org/10.1080/17482631.2017.1392218
- 26. Booth, V., Hood-Moore, V., Hancox, J., Logan, P., Robinson, K.: Systematic scoping review of frameworks used to develop rehabilitation interventions for older adults. BMJ Open, 1–10 (2019). https://doi.org/10.1136/bmjopen-2018-024185
- 27. Huijben-Schoenmakers, M., Rademaker, A., Rooden, P., Scherder, E.: The effects of increased therapy time on cognition and mood infrail patients with stroke who rehabilitate on rehabilitation units of nursing homes in the Netherlands: a protocol of a comparative study. BioMed. Central Geriatr. 14, 68 (2014). https://doi.org/10.1186/1471-2318-14-68
- 28. Klinke, M., Hafsteinsdóttir, T., Hjaltason, H., Jónsdóttir, H.: Ward-based interventions for patients with hemispatial neglect in stroke rehabilitation: a systematic literature review. Int. J. Nurs. Stud., 1375–1403 (2015). http://dx.doi.org/10.1016/j.ijnurstu.2015.04.004
- Moguel, E., Berrocal, J., Murillo, J.M., García-Alonso, J., Mendes, D., Fonseca, C., Lopes, M.: Enriched elderly virtual profiles by means of a multidimensional integrated assessment platform. In: Paper presented at the Procedia Computer Science (2018). https://doi.org/10. 1016/j.procs.2018.10.009



PSIQUE: A Computerised Neuropsychological Assessment App

Daniel Diaz¹(⋈), Steban Cadena¹, Juan Gil¹, Deisy Chaves^{1,2}, and Maria Trujillo¹

- Multimedia and Computer Vision Group, Universidad del Valle, Cali, Colombia {daniel.alejandro.diaz,steban.cadena,juan.felipe.gil,deisy.chaves, maria.trujillo}@correounivalle.edu.co
 - ² Group for Vision and Intelligent Systems, Universidad de León, León, Spain

Abstract. Dementia is a syndrome whose main risk factor is age and it is characterise by the deterioration of cognitive functions. Hence, tools to measure and evaluate these functions are vital during the diagnosis of dementia. Commonly, cognitive functions are evaluated using neuropsychological tests which are manually applied by a neuropsychologist and the results are scattered in paper-files. This is a error-prone and time-consuming process. Nowadays, several automatised batteries and computerised assessment are developed as an alternative to manual tests. However, most automatised batteries do not fill the requirements of interoperability among medical centres. Besides, medical centres should acquire various software tools for coping all needs. In addition, the lack of resources in health centres may be considered as a reason for not using computerised assessments. In this paper, we present a web application, called Psique, which grouped a set of automated neuropsychological tests based on the frequency of use in Centro Médico Imbanaco and Hospital Departamental Psiquiatrico Universitario del Valle, located in Cali, Colombia. Psique was evaluated in terms of usability and functionality by neuropsychologists with promising results.

Keywords: Neuropsychological tests \cdot Cognitive diseases \cdot Automatised batteries \cdot Computerised assessment \cdot Computerised neuropsychological tests

1 Introduction

Dementia is a syndrome that deteriorates the cognitive function of patients, such as memory, thinking, behaviour and the ability to perform everyday activities. This syndrome affects mainly elderly, being the 5–8% of the general population aged over 60 with dementia. Worldwide, around 50 million people have dementia, and it is projected that this number will grow in the next thirty years [14]. Tools for testing and identifying deterioration on cognitive functions are crucial for diagnosing dementia and realise a proper treatment and care to a person with dementia.

Neuropsychological tests are tools used to measure the performance of a subject's cognitive abilities, such as memory, attention and reasoning [6]. Additionally, they are considered a relevant topic [4] in the field of health due to applications in neuroscience, such as supporting of differential diagnosis for cognitive impairment diseases and following-up treatments; and, measuring changes that may occur in a brain during surgical procedures [4].

Usually, neuropsychological tests are manually applied and scored; using paper-pencil based methods and storing results in paper files. However, this methodology is inefficient, since the application and scoring of tests are time consuming and storing results on paper files do not allow to perform an efficient analysis of results. In addition, test results are susceptible to scoring errors due to human factors. Furthermore, since neuropsychological tests usually consist of booklets score sheets that are shown to a patient as a stimuli, applying those tests in an operating room become difficult.

Several approaches of automatic neuropsychological tests or computerised assessments are available in the market. Some of them automated and standardised traditional assessments – i.e. face-to-face evaluation with a patient—while others adapted traditional tests using strategies such as gamification, virtual reality or online evaluations. In some cases, the presence of neuropsychologists is reduced during the application or supervision of tests, offering alternatives such as remote neuropsychological evaluation [9–11]. These approaches offer several advantages, including the reduction of time during the test application and scoring [3,7,15], the reduction of imprecision in test results [8] by avoiding manual scoring, the transfer of results into a database for immediate or subsequent analysis [11]. However, some automated approaches require either a license or purchasing specific hardware or software developed for application.

In this paper, we present Psique, a web-based application which seeks to automate the scoring and application of neuropsychological tests. Likewise, Psique intends to avoid possible human errors that can be derived from manual scoring, and to create digital records that allow analysing results. Currently, Psique has six automated neuropsychological tests: the Weschler intelligence scales (WAIS and WISC), Zung Anxiety Scale, Rey's Complex Figure, Stroop colour and word and Wada test. The application was evaluated in terms of usability and functionality by neuropsychologists with promising results.

2 Psique

Psique is conceived as a user-oriented web application that automatise standardised tests, using low hardware requirements. Questionnaires, buttons and keyboard entries are used to collect patient's responses and a computer screen and a tablet with internet access to present the test stimuli. Two neuropsychologists are involved in the development process, for guiding user needs. Agile practices such as prioritisation and estimation of user stories, burn down chart, weekly meetings and project planning—are used for developing the application. Those practices allow the project to adapt [5] to the feedback continuously received from the deliveries by the neuropsychologists, which play the role of clients. Initially, a meeting was held with the clients, where the problem was identified and a set of neuropsychological tests to be automated were selected and prioritised. The main criterion for prioritising the development of tests is the frequency of use, in Centro Médico Imbanaco and Hospital Departamental Psiquiatrico Universitario del Valle, in Cali. Periodic meetings are also performed throughout the project, mainly before starting the development of a test, when an analysis of the chosen tests was required and for conducting requirements survey. The analysis of the chosen tests is performed to identify elements that can be automated and which elements have to be manually applied. Once the development process has begun, the meetings serve for reviewing progress and providing feedback, allowing the generation of ideas to improve or redefine the current requirements.

Currently, the application has implemented six tests: three tests that assess executive functions and attention—the WISC and the WAIS intelligent scales, the Stroop test—; the Rey's complex figure test that assess memory and visuospatial skill; and, two tests that assess language and memory—the Zung depression scale and the Wada test—. A summary of the tests and the automatised elements is presented in Table 1. In particular, the front-end or Psiqus's graphical interface was developed using Reactjs. The main menu gives access to each neuropsychological test developed as an independent module from the others, to make the application scalable. The back-end was developed using Nodejs and Graphql with PostgreSQL to manage the database. Psique's Back-end and Front-end were deployed using the free hostings Heroku and Firebase, respectively. Furthermore, we use Git versioning tools and Travis, a continuous integration tool, to build and automatically deploy each module in the hosting. The deployed application is used to evaluate the usability and functionality with end-users.

3 Results and Discussion

Clients evaluated the six developed tests through interviews that assess the user interface designs and app functionality. An important aspect considered by neuropsychologists during the evaluation was the simplicity of the interface, which must avoid elements that would distract the patient during the assessment, see Fig. 1. The presence of this kind of elements may add noise to the results and cause a misdiagnosis. To identify distract elements, the neuropsychologist examined the interface components of the automatised test and compared it against the manual application test. As result, clients expressed their satisfaction with the design of the Psique's user interface which elements do not generate distractions to the patient during the application of tests.

Psique functionality was tested by showing the logic of the application to the clients. After the evaluation, the clients recommended to include a chronometer to control the test application time and eliminate the automatic stimuli transition in the WAIS test. This aspect was addressed in the tests where the results are time-depending and whose stimuli had to be shown to the patient. A timer was run in second plane and a message was displayed when the time was over to avoid split the attention of the patient while the stimuli was shown.

| Test | Application age | Test elements applied manually | Automatised test elements |
|---------------------|--------------------------|--|---|
| Rey's figure | 6-89 [1] | Figure presented to the patient | Form to add a grade to the figure. Score calculation. |
| Stroop | 15–90 [2] | The neuropsychologist must select the last word said correctly by the patient | Word presentation. Store and count correctly spelled words. Score calculation. |
| Zung | 16-89 [16] | None | Form to answer each of the test items. Score calculation. |
| WISC-IV, WAIS-IV | 6–16 [12], 16–89 [13] | Stimuli orally or graphically presented by the specialist. Manual entry of patient answers | A chronometer starts when the subtest requires it. Forms to collect patient's answers. Score calculation. |
| WADA | | Selection of sub-test to be applied. Indication if patient's answer is | Stimuli presentation. Score calculation. Audio and video |

right or wrong for each

stimuli

Table 1. Summary of the automated elements in the neuropsychological tests.





streaming from patient

to neuropsychologists

device

 $\textbf{Fig. 1.} \ \ \text{User interface of Wada test in both patient (left) and neuropsychologist (right)} \ \ \text{devices.}$

Based on the evaluation results, we determined that the total automation of the tests may reduce Psique's precision, because these technological tools do not have sufficient precision to score some task correctly. For instance, in the Stroop test, we initially used a voice recogniser, which added a delay between collecting the answer and scoring whether the answer was right or wrong. It is not recommended to use technological tools that may add noise to the test results that are time dependent as the Stroop test.

In general, Psique is a successful approach for the automation of neuropsychological tests without using licence software or specialised hardware. However, methods for using the application during Magnetic Resonance Image scans need to be further investigated, since within the room with a magnetic resonator, any metal may affect the acquisition.

4 Final Remarks

We propose Psique, a web application, to automate six neuropsychological tests –Rey's Complex Figure, Test of colours and words - Stroop, Wada, Zung Anxiety Scale, WAIS IV and WISC IV intelligence scales – as a solution for medical centres with limited hardware and software resources.

The development of an application with neuropsychologists implied to learn a technical language for communication and spend large sessions understanding the mechanisms of tests. Moreover, working with end-users allows us to apply a user-centred methodology which helps us to understand the users' necessities (i.e. neuropsychologists and patients) and included these aspects in the application interface and functionality.

As Psique is currently on development stage changes on interface and functionality are expected, based on neuropsychologist evaluation allowing to improve the application to facilitate the usage with patients. In terms of design, development and testing of the application, user-centred methodologies will be implemented, not only to understand the users but also to get insights on aspects of the application that are related to the users. Those aspects can be evaluated using usability metrics to measure the effectiveness, efficiency and the satisfaction of the users with the application. Besides, a protocol for communication of data between medical centres and a data mart module will be integrated to support data analysis and decision making for diagnosis.

As future work, the test catalogue of the application will be increased by including five additional tests: the Boston test, the Wisconsin Card Sorting test, Evaluacion Neuropsicológica Infantil (ENI), the Token test, and Addenbrooke's Cognitive Examination III (ACEIII). Moreover, since results have shown that fully automated tests might hinder the application of neuropsychological tests with the tools used, such as the use of voice recogniser in the Stroop tests, we will evaluated machine learning techniques and image processing methods to improve the accuracy during the application of the tests.

References

- Rey complex figure test and recognition trial. https://www.parinc.com/Products/ Pkey/355
- 2. Stroop color and word test 2020. https://www.parinc.com/Products/Pkey/435
- Chan, K.L.M.: Automation in neurorehabilitation: needs addressed by clinicians.
 In: Intelligent Biomechatronics in Neurorehabilitation, pp. 209–224. Elsevier (2020)
- Crawford, J., Parker, D., McKinnley, W., McKinlay, W.: A Handbook of Neuropsychological Assessment. Taylor & Francis Group (1992)
- 5. Dingsøyr, T., Dybå, T., Moe, N.B.: Agile software development: an introduction and overview. In: Agile Software Development, pp. 1–13. Springer (2010)
- Harvey, P.D.: Clinical applications of neuropsychological assessment. Dialogues Clin. Neurosci. 14(1), 91 (2012)
- 7. Kane, R.L., Kay, G.G.: Computerized assessment in neuropsychology: a review of tests and test batteries. Neuropsychol. Rev. **3**(1), 1–117 (1992)
- 8. Kemp, A., Hatch, A., Williams, L.: Computerized neuropsychological assessments: Pros and cons. CNS Spectr. 14, 118–20 (2009)
- Rizzo, A., Wiederhold, B.K.: Virtual reality technology for psychological/neuropsychological/motor assessment and rehabilitation: applications and issues. In: IEEE Virtual Reality Conference (VR 2006), pp. 308–308. IEEE (2006)
- Rotaru, D.C., García-Herranz, S., Morán, M.F., Martínez-Ortiz, I., Fernández-Manjón, B., Díaz-Mardomingo, M.C.: Using game technology to automatize neuropsychological tests and research in active aging. In: Proceedings of the 4th EAI International Conference on Smart Objects and Technologies for Social Good, pp. 65–70 (2018)
- Schatz, P., Browndyke, J.: Applications of computer-based neuropsychological assessment. J. Head Trauma Rehabil. 17(5), 395–410 (2002)
- Wechsler, D.: WISC IV Manual de aplicación (Versión estandarizada). El Manual Moderno (2005)
- Wechsler, D.: WAIS IV Manual de aplicación y corrección. Pearson (2012). https://www.pearsonclinical.es/
- 14. WHO: Dementia (2020). https://www.who.int/news-room/fact-sheets/detail/dementia
- Woo, E.: Computerized neuropsychological assessments. CNS Spectr. 13(S16), 14– 17 (2008)
- (ZUNG), Z.S.R.D.S. https://betterworldhealthcare.com/zung-self-rating-depression-scale-zung/



Indicators Sensitive to Rehabilitation Nursing Care: A Functional and Technological Respiratory Rehabilitation Program for Elderly People

Anabela Silva¹(⊠), Susana Silva¹, César Fonseca², Inês Cardoso², Rogério Ferrinho³, Luís Sousa³, Lara Guedes de Pinho², and Manuel Lopes²

 Portalegre School of Health, Portalegre, Portugal
 University of Évora, Comprehensive Health Research Center, POCTEP 0499_4IE_PLUS_4_E, Évora, Portugal
 Polytechnic Institute of Beja, POCTEP 0499_4IE_PLUS_4_E, Beja, Portugal

Abstract. Chronic Obstructive Pulmonary Disease (COPD) is characterized by a series of persistent respiratory symptoms that limit airflow, causing morbidity and even mortality. The intervention of the Rehabilitation Nursing Specialist (RNS) is important to promote actions which ensure functional empowerment in self-care, preventing complications. Objective: Identify indicators sensitive to Rehabilitation Nursing (RN) care that promote health gains during intervention at the self-care level within technological respiratory rehabilitation (TRR) programs. Methodology: A systematic literature review (SLR) was carried out through research on the EBSCO-HOST scientific platform, the CINAHL Complete and MEDLINE Complete databases, using the Boolean operators "OR" and "AND" and using the PI[C]O method. Results: The results of RN are sensitive to the application of TRR plans regarding the self-care of the person with COPD, which demonstrate the importance of intervention and care of Rehabilitation Nursing. Conclusions: The results of RN are sensitive to the application of TRR plans regarding the self-care of the person with COPD, which demonstrate the importance of intervention and care of Rehabilitation Nursing.

Keywords: Rehabilitation Nursing · Self-care · Person · Program

1 Introduction

In the decades between 1980 and 1990, the first programs of RR as a non-pharmacological treatment [1] began, becoming an important recommendation for the treatment of COPD [2] being this a multidisciplinary approach with the aim of optimizing physical functioning, social and autonomy [3]. Currently recommended to all people with COPD according to the categories defined by GOLD [4], it is seen as a method to recover the physical, intellectual, emotional, social and professional capacity of the person [5]. This is a progressive and incurable lung disease [6], characterized by increased shortness of breath due to airflow obstruction [7], caused mainly by tobacco [8].

[©] The Author(s), under exclusive license to Springer Nature Switzerland AG 2021 J. García-Alonso and C. Fonseca (Eds.): IWoG 2020, LNBE, pp. 87–98, 2021. https://doi.org/10.1007/978-3-030-72567-9_9

The development of these programs is the responsibility of RNS, through which it promotes teaching, demonstration and training of techniques, promoting self-care and continuity of care in different contexts [9], identifying specific needs at the level of functionality [10] and the factors that facilitate or make it impossible to carry out ADL independently. Still able to make decisions [11], based on the realization, monitoring and evaluation of differentiated RN plans, based on the recognition of problems [12].

They address exercise plans aimed at education, psychological support, food counseling, and evaluation [7], with education being an important component for TRR, focused on improving knowledge of COPD and teachings related to smoking cessation, exercise, inhalation therapy techniques, and coping strategies [13], with the objective of empowering, informing, and supporting self-care [14] in the person. This makes the optimization of emotional capacity possible through the dominion over the disease, with moderately large and clinically significant improvements [7].

It acts on alveolar ventilation, ventilation-perfusion ratio and diffusion [15], decreasing dyspnea, increasing capacity for physical activity with improvement in quality of life [16].

The results of the programs also depend on the type, duration and effectiveness [17], which must be monitored and evaluated [9].

In this sense, it is important to have indicators that demonstrate the effectiveness of specialized health care with a structure aimed at improving the quality of care provided, as well as professional exercise [18], It is through care sensitive indicators that RNS evaluates health gains for training, independence and quality of life [9].

EBS being recognized as the key to improving the quality of care, thus ensuring the best results [19], which reflect the impact on the change to best practices, enabling the quality of care and results in the elderly, to whom we provide care [20].

2 Methodology

The RSL is a summary of evidence on a specific topic, which through a rigorous process identifies, evaluates and analyzes the various studies in order to answer a specific question [19], proving the need for the study and providing an explanation on issues related to the starting question [21]. It also consists of the analysis of articles with the purpose of obtaining information related to the starting question, determining methods, evaluating relationships between concepts, results and conclusions [22].

We intend to identify indicators sensitive to RN care [23] that promote health gains [13, 24], during the intervention at the level of self-care, within TRR programs, using systematic and explicit processes, with the objective of reducing the different types of bias, providing reliable results that support the conclusions and decisions [20].

After defining the issue to be addressed, the formulation of the problem emerged through a starting point, based on the PICO structure developed to answer health-related questions [25]. Based on this concept, the starting question arises "What are the sensitive indicators in RN obtained through an TRR program, at the level of self-care in people with respiratory disease (COPD)?", schematized in Fig. 1.

Following the criteria of FINER (Feasibility, Interesting, Novel, Ethical, Relevant) [26], which demarcate the quality of the research question as viable, interesting, original,

fulfilling the ethical principles and relevant to the practice, we conducted a research through the scientific search platform EBSCOhost, accessing the databases CINAHL Complete and MEDLINE Complete, carried out in September 2019.

The survey consisted of using the following descriptors according to the starting question: (pulmonary disease) (elderly); (chronic obstructive); (dyspnea); (pulmonary emphysema); (health self-care); (patient education); (rehabilitation nursing); (Nursing); (Nursing care) and (Nursing intervention) combined with the Boolean operators "OR" and "AND".

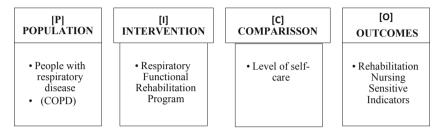


Fig. 1. Methodology PICO

The selection of studies was defined according to inclusion and exclusion criteria. Inclusion criteria include articles with TRR plans and self-care interventions in adult participants with COPD. The exclusion criteria were full text, publication date (2009–2019), written in English, and repeated in the databases.

After selecting the studies according to the inclusion/exclusion criteria, 93 articles were obtained, reading the title, abstract, methodology, results and conclusion, during the analysis and detailed reading those that did not answer the starting question were excluded, finding a duplicate. At the end of this selection, we obtained a result of eight articles for this SLR.

Moving on to the next phase, which consists in the evaluation of the quality of the studies, which must be adequate to the inclusion criteria [20], taking into account the rules of authorship, with the due citations and references of the authors, considering the principles of intellectual honesty as an ethical question [27].

3 Results

The results become more credible when the selected studies pass through inclusion and quality criteria [19], instituting validity and reliability [20]. In this sense, the classification of the eight articles in terms of quality and scientific evidence followed the system of classification of hierarchy of evidence [19], directed to questions about interventions and treatments. This consists of four levels of evidence: Level I (systematic review or meta-analysis of all relevant randomized controlled trials); Level II (well-designed controlled randomized controlled trials); Level V (systematic reviews of descriptive and qualitative studies); Level VI (single descriptive or qualitative studies) [19] in order to ensure eligibility, quality of results and conclusions, producing current knowledge for the subject under study (see Table 1).

Table 1. Characteristics and overview of selected articles.

| Article | Metadata | Objectives | Results/Conclusions |
|---------|--|--|--|
| 1 | Title: "Effects of modified pulmonary rehabilitation on patients with moderate to severe chronic obstructive pulmonary disease: A randomized controlled trail" Authors: Xu et al. Year: 2017 Methodology: Randomized Controlled Study Participants: People with COPD Level of evidence: II | To evaluate the effects of an adapted RR intervention plan on people with moderate to severe COPD (n = 125) for 12 weeks | The experimental group (n = 63) showed significant improvement, after a 6-min walk test, the control group (n = 62) showed no improvement; Pulmonary function without significant changes in both groups; Intervention plan, decreased dyspnea symptoms, increased exercise capacity and improved quality of life |
| 2 | Title: "The effect of home-based pulmonary rehabilitation on self - efficacy in chronic obstructive pulmonary disease patients" Authors: Khoshkesht et al. Year: 2015 Methodology: Randomized Controlled Study Participants: People with COPD Level of evidence: II | To investigate the effect of RR on the self-efficacy of people with mild to moderate COPD (n = 66), through weekly visits and telephone monitoring | Intervention group with high performance in self-efficacy relative to the control group (n = 32); Improved self-efficacy in the intervention group; Demonstrated the importance of self-efficacy in intervention planning, with a view to improving self-care; Effective program in improving self-efficacy; Nurses play an important role in education, implementation, encouragement and follow-up |
| 3 | Title: "Pulmonary rehabilitation for chronic obstructive pulmonar disease (Review)" Authors: McCarthy et al. Year: 2015 Methodology: Systematic review and meta-analysis of randomized clinical trials Participants: People with COPD Level of evidence: I | Compare the effects of RR versus general care on quality of life, health, functionality and exercise capacity | RR promotes relief of dyspnea and fatigue; Improvement of the emotional function and feeling of control over the disease; Improvement in the results of the 6-min walk test with great clinical significance in view of the effects of the program; Improvement of quality of life, functional capacity and exercise |

 Table 1. (continued)

| Article | Metadata | Objectives | Results/Conclusions |
|---------|--|---|--|
| 4 | Title: "Home or community-based pulmonary rehabilitation for individuals with chronic obstructive pulmonary disease: a systematic review and meta-analysis" Authors: Neves et al. Year: 2016 Methodology: Systematic review and meta-analysis of randomized clinical trials Participants: People with COPD from the GOLD 2 stage onwards Level of evidence: I | Investigate the effects of RR in the home or in the community in comparison with outpatient regime. (intervention defined over a period of 4 weeks) | Improvement of funci-onal capacity and quality of life; Decrease of the sensation of dyspnea; High potential in community programs with the use of fewe devices and resources with similar gains in functional capacity compared to other programs; Improvement of physical capacity |
| 5 | Title: "Meta-analysis of the Effect of a Pulmonary Rehabilitation Program on Respiratory Muscle Strength in Patients with Chronic Obstructive Pulmonary Disease" Authors: Lee and Kim Year: 2019 Methodology: Systematic review and meta-analysis of randomized clinical trials Participants: People with COPD Level of evidence: I | Analyze effect of RR programs on respiratory muscle strength | Significant improvement in inspiratory performance and expiratory muscle strength, without significant improvement in pulmonary function; Increase in maximum expiratory pressure; Strengthening of expiratory an inspiratory muscles with equal effectiveness through respiratory muscle training for symptom relief; Increased inspiratory muscle strength associated with improved exercise capacity, dyspnea and quality of life; Need to adapt the program individually, easily accessible to be performed by people autonomously |

 Table 1. (continued)

| Article | Metadata | Objectives | Results/Conclusions |
|---------|---|---|---|
| 6 | Title: "Clinical-effectiveness of self-management interventions in chronic obstructive pulmonary disease: An overview of reviews" Authors: Murphy et al. Year: 2017 Methodology: Systematic review Participants: People with COPD Level of evidence: V | Analyze the clinical effectiveness of interventions in COPD self-management, capacity building for disease control and symptoms (studies with education interventions, goals with targets, decision making) | Focus education on improving knowledge about the disease, directed at smoking cessation, exercise, inhalation techniques and "co-ping" strategies; Education decreases internal-mentals and gives significant gains to health; Effectiveness of RR programs in quality of life and health with improvement in exercise capacity; Telephone "Follow up" of the decrease in demand for health services |
| 7 | Title: "Effectiveness of a perioperative pulmonary rehabilitation program following coronary artery bypass graft surgery in patients with and without COPD" Authors: Chen et al. Year: 2018 Methodology: Qualitative Study (retrospective) Participants: Carriers and non-carriers of COPD after coronary artery bypass grafting Level of evidence: VI | Compare efficacy of RR in people undergoing coronary artery bypass grafting (n = 78), with (n = 40) and without (n = 38) COPD pathology | Interventions: smoking cessation; breathing exercises (3 times a day); muscle exercises (30 min a day); incentive spirometry (3 times a day); accessory maneuvers and postural drainage (1 week in the preoperative period and 2 weeks in the post-operative period); Improvement of maximum inspiratory and expiratory pressures, and respiratory rate found in both groups; Improvement of respiratory function between the 1st and 14th postoperative days in both groups; Improvement of pulmonary and muscular function in both groups; RR program reduces pulmonary complications and mortality in people with COPD |

Objectives Results/Conclusions

 Table 1. (continued)

| Article | Metadata | Objectives | Results/Coliciusions |
|---------|--|--|---|
| 8 | Title: "Facilitating education in pulmonary rehabilitation using the Living Well with COPD programme for pulmonary rehabilitation: a process evaluation" Authors: Cosgrove et al. Year: 2013 Methodology: Qualitative study Participants: People with primary diagnosis of COPD (n = 57) and professionals (n = 25) Level of evidence: VI | Adapting the self-management program, (Living Well with COPD) in rehabilitation care Effectively evaluate the process of an adapted program RFR intervention lasting 15 months in 11 hospitals, consisting of 6 weekly sessions of 30 to 45 min | Self-management program with good acceptance by people (62.3% participated in the sessions) and professionals, demonstrating effectiveness in the RR plan, both in hospital and community settings; Acquisition of knowledge and improvement in the perception of the disease; Sessions classified as good or excellent by people and health professionals; This type of program can be used in educational sessions with quality, consistent, equitable in RR both in the hospital and in the community |

4 Discussion

Article Metadata

Obtaining and monitoring health gains, and producing sensitive indicators, are priorities for continuous quality improvement in health [12]. To obtain results that integrate the indicators, it is important to adapt the intervention plans to the individual, allowing their capacity building for self-care [28], these being described in Table 2.

Table 2. Rehabilitation nursing care sensitive indicators identified.

| Indicators of results | Sensitive Indicators |
|------------------------|--|
| Functional state | Increase in exercise tolerance and capacity [7, 8, 13, 16, 17]; Improvement of functional capacity [8]; Improvement of physical fitness [8] |
| Respiratory indicators | Improvement of the inspiratory capacity [17]; Increase in expiratory muscle capacity [1, 17]; Improvement of maximum expiratory pressure [1–17]; Improvement of inspiratory muscle strength through physical exercise [1, 17]; Decrease of pulmonary hyperinflation [17]; Improvement of respiratory rate [1]; Improvement of pulmonary function [1, 29] |

 Table 2. (continued)

| Indicators of results | Sensitive Indicators |
|------------------------------------|---|
| Training for self-care | Improvement in self-efficacy through RR programs [28]; Training for self-care [28]; Improvement in autonomy [17]; Improved access to programs [17]; Better perception of people in relation to autonomy [29] |
| Professional/personal relationship | Improvement in implementation, incentive and follow-up [28];Improvement in meeting needs [17] |
| Symptom control | Relief from dyspnea [7, 8, 16, 17]; Decrease of tiredness [7]; Improvement of people's perception of the disease [7]; Increase in respiratory function programs with effectiveness [17] |
| Person's satisfaction | Improvement of emotional balance [7]; Confers gains in health [13]; Decrease of pulmonary complications [1]; High satisfaction of people regarding the program [29]; High participation in the programs [29] |
| Use of health services | Decreased need to use Non Invasive Ventilation [NIV] and OLD [8]; Improvement of health status [13]; Decrease in the need to use health services [13]; Increased efficiency of RR plans [29] |
| Training for knowledge | Improving health education [13, 28]; Improvement of knowledge about the disease [13, 29]; Additional educational sessions [29] |
| Therapeutic adherence | Increase in smoking cessation [13]; Improvement of inhalation techniques [13]; Increase in coping strategies [13]; Improvement of knowledge about therapy [29]; Implementation of strategies in the transition between education and exercise sessions [29] |
| Training for quality of life | - Improvement of quality of life [7, 8, 13, 16, 17] |
| | |

Table 2 shows that the improvement in functional capacity [8] resulting from TRR intervention plans is corroborated by several authors, verified through the increase in capacity for the exercise [7, 16, 17].

In the study [17], aerobic exercise is identified as an important component for RFR intervention plans, due to the strengthening of expiratory and inspiratory muscles, promoting significant improvement in inspiratory performance and expiratory muscle

strength, reflecting in the increase of maximum expiratory pressure and reducing pulmonary hyperinflation. Also another study analyzed, proves improvements in maximum inspiratory and expiratory pressure and respiratory rate, reflected in a general way, in the increase of respiratory muscle strength with improvement of pulmonary function, documented in the 2 groups of the study [1].

Regarding the functional evaluation, in which the measuring instrument was used, a 6-min gait test, significant improvement was observed in the experimental group [16], in another study with the same instrument a result of 43.93 m of walking tolerance [7] was demonstrated. It is also noted significant improvement of dyspnea [17] through the Borg Scale and mMRC questionnaire, at the end of 12 weeks of intervention [16], people have exercise tolerance.

Dyspnea is one of the symptoms of COPD that can be controlled through respiratory muscle training and physical exercise [30] and can be equally effective in relieving these symptoms [17], incorporated in an TRR intervention plan. The decrease of dyspnea as a relief condition [7, 8, 16, 17], as well as of fatigue, promotes a feeling of control in the person over the disease [7]. A study reveals that a program for the management of the disease has good acceptance by the participants, revealing a participation of 62.3% in the sessions, which were classified from good to excellent, demonstrating the self-efficacy of the program [29].

The effectiveness of the RFR, depends on the intervention program, which should be selected according to the needs of the person [17], aiming at its functionality and autonomy. Its implementation also includes encouragement and monitoring [28], based on a relationship of trust [31]. One of the studies concluded that an RFR program is effective in improving autonomy [28], and self-care, promoting the accessibility of the program to people to be carried out autonomously [17].

It also benefits the functional aspects of physical capacity [8], causing a reduction in pulmonary complications [1], and consequently reducing hospitalizations [13]. These aspects have influence on the improvement of the emotional function capacity [7], to meet the satisfaction of the person, because the anxiety associated with COPD [30], causes social isolation, motivated by disabilities caused by the disease itself.

The TRR Plan is efficient in both hospital and community settings [29], but community programs have high potential because they use fewer devices and resources [8], conferring significant health gains [13].

Telephone follow up is one of the strategies that gives results, reducing the need to resort to health services and home visits [13].

Education is considered an important component [13] in the intervention, in which RNS has an effective role in teaching [28]. However, education should be focused on improving the perception of the disease [13], to acquire knowledge [29] that alters life habits, effective administration of inhalation therapy and to train people for ADL. Therefore, educational sessions with quality, consistent and equitable, are important both in hospital and community settings [29].

Thus, by improving a person's perception of the aspects of the disease [29], it is possible to encourage therapeutic adherence, smoking cessation, improved exercise and coping strategies [13], and the quality of life improves significantly after completing

the program [8], an aspect confirmed through several studies [7, 8, 16, 17], leading to decreased mortality [1].

5 Conclusion

Nursing is a science that covers a universe of knowledge, rehabilitation is a branch of its specialty that incorporates an identity organized in methodologies, aiming at training the person for autonomy [17, 29]. For RNS to develop its competencies and increase its knowledge, it needs to develop projects in the practice of its care, based on scientific evidence to obtain results sensitive to nursing care [9, 13, 28, 29] in elderly people.

The results found in this study allow us to verify sensitive indicators of RN [23] for the application of TRR plans, referring to the self-care of the person with COPD [17, 28, 29] which demonstrate the importance of RN intervention and care. This study reinforces the importance of developing adapted programs, these with good acceptance [29], noting the improvement in functionality [7, 8, 13, 16, 17] in terms of physical exercise and mobility [8] and respiratory capacity [17], as well as in the control of symptoms aimed at empowerment of autonomy and self-care [17, 28].

Another aspect, important to emphasize in the results of the analysis of this SLR is the improvement of people's quality of life [7, 8, 13, 16, 17] in which it shows that although the disease presents itself in acute or chronic form it is possible to maintain stability and relief of symptoms, countering complications [7, 8, 16, 17].

Thus, it is possible to design and implement ER intervention programs, based on these sensitive indicators, suggesting, however, the continuity of scientific studies in this area with a view to the continuous improvement of nursing care.

References

- Chen, J., Liu, J., Liu, Y., Chen, Y., Tu, M., Yu, H., Lin, M., Lin, C., Liu S.: Effectiveness
 of a perioperative pulmonary rehabilitation program following coronary artery bypass graft
 surgery in patients with and without COPD. Int. J. 13, 1591–1597 (2018). https://doi.org/10.
 2147/COPD.S157967
- Mathar, H., Fastholm, P., Hansen, I., Larsen, N.: Why do patients with COPD decline rehabilitation. Scand. J. Caring Sci. 30(3), 432–441 (2016). https://doi.org/10.1111/scs.12268
- 3. Guo, S., Bruce, A.: Improving understanding of and adherence to pulmonary rehabilitation in patients with COPD: a qualitative inquiry of patient and health professional perspectives. Plos One **10**(9), 1–7 (2014). https://doi.org/10.1371/journal.pone.0110835
- 4. Direção Geral de Saúde: Orientação nº 014/2019 de 7 de agosto: Programas de Reabilitação Respiratória nos Cuidados de Saúde Primários. Direção Geral de Saúde, Lisboa (2019). https://www.dgs.pt/directrizes-da-dgs/orientacoes-e-circulares-informativas/orientacoo-n-0142019-de-07082019.aspx
- 5. Ordem dos Enfermeiros.: Guia Orientador de Boa Prática Reabilitação Respiratória, serie 1, n. °10. Edição: Ordem dos Enfermeiros-Conselho de Enfermagem e Mesa do Colégio de Enfermagem de Reabilitação (2018). https://www.ordemenfermeiros.pt/media/5441/gobp_r eabilita%C3%A7%C3%A3o-respirat%C3%B3ria_mceer_final-para-divulga%C3%A7%C3%A3o-site.pdf
- 6. COPD Foundation: What is COPD (2020). https://www.copdfoundation.org/What-is-COPD/Understanding-COPD/What-is-COPD.aspx

- 7. McCarthy, B., Casey, D., Devane, D., Murphy, K., Murphy, E., Lacasse, Y.: Pulmonary rehabilitation for chronic obstructive pulmonar disease (Review). Cochrane Database Syst. Rev. (2015). https://doi.org/10.1002/14651858.CD003793.pub3
- Neves, L., Reis, M., Gonçalves, T.: Home or community-based pulmonary rehabilitation for individuals with chronic obstructive pulmonary disease: a systematic review and metaanalysis. Caderno de Saúde Pública 32(6), 1–25 (2016). https://doi.org/10.1590/0102-311 X00085915
- Regulamento nº 392/2019 de 3 de maio. Regulamento das competências específicas do enfermeiro especialista em Enfermagem de Reabilitação. Diário da República, 2ª série, n.º 85, 13565–13568 (2019). https://dre.pt/web/guest/pesquisa/-/search/122216893/details/ normal?l=1
- 10. Nabais, A., Sá, M.: Intervenção do Enfermeiro na Promoção do Autocuidado na Pessoa com DPOC: uma Revisão Sistemática da Literatura. Investigação Qualitativa em Saúde: Atas 7º Congresso Ibero-americano em investigação qualitativa, 2, pp. 131–139 (2018). https://proceedings.ciaiq.org/index.php/ciaiq2018/article/view/1772/1725
- 11. Pontes, M.: Doença Crónica. In: Vieira e Sousa. 1ª edição. Cuidados de enfermagem de reabilitação à pessoa ao longo da vida, pp. 487–500. Lusodidacta, Loures (2016)
- 12. Ordem dos Enfermeiros: Assembleia do colégio da especialidade de Enfermagem de Reabilitação: Padrões de Qualidade Especializados em Enfermagem de Reabilitação. Colégio da Especialidade de Enfermagem de Reabilitação. Colégio da Especialidade de Enfermagem de Reabilitação, Lisboa (2018). https://www.ordemenfermeiros.pt/media/8141/ponto-4_regu lamento-dos-padr%C3%B5es-qualidade-ceer.pdf
- Murphy, L., Harrington, P., Taylor, S., Teljeur C., Smith, S., Pinnock, H., Ryan, M.: Clinical-effectiveness of self-management interventions in chronic obstructive pulmonary disease: an overview of reviews. Chron Respir. Dis. 14(3), 276–288 (2017). https://doi.org/10.1177/147 9972316687208
- 14. Murphy, K., Casey, D., Devane, D., Cooney, A., McCarthy, B., Mee, L., Nichulain, M., Murphy, A., Newell, J., O' Shea, E.: A cluster randomised controlled trial evaluating the effectiveness of a structured pulmonary rehabilitation education programme for improving the health status of people with chronic obstructive pulmonary disease (COPD): the PRINCE study protocol. BMC Pulm. Med. 11(4), 2–10 (2011). https://doi.org/10.1186/1471-2466-11-4
- Branco, P., Barata, S., Barbosa, J., Cantista, M., Lima, A., Maia, J.: Temas de Reabilitação
 Reabilitação Respiratórias. Medesign, Porto (2012). https://repositorio.chlc.min-saude.pt/ handle/10400.17/765
- Xu, J., He, S., Han, Y., Pan, J., Cao, L.: Effects of modified pulmonary rehabilitation on patients with moderate to severe chronic obstructive pulmonary disease: a randomized controlled trail. Int. J. Nurs. Sci. 4, 219–224 (2017)
- 17. Lee, E., Kim, M.: Meta-analysis of the effect of a pulmonary rehabilitation program on respiratory muscle strength in patients with chronic obstructive pulmonary disease. Asian Nurs. Res. 13, 1–10 (2019). https://doi.org/10.1016/j.anr.2018.11.005
- 18. Ordem dos Enfermeiros: Padrão documental dos Cuidados de Enfermagem na Especialidade de Enfermagem de Reabilitação. Porto: Ordem dos Enfermeiros, Assembleia do Colégio da Especialidade de Enfermagem de Reabilitação (2015). https://www.ordemenfermeiros.pt/arquivo/colegios/Documents/2015/MCEER_Assembleia/Core_Indicadores_por_Categoria_de_Enunciados_Descrit_PQCER.pdf
- 19. Melnyk, B.M., Fineout-Overholt, E.: Evidence-Based Practice in Nursing & Healthcare: A Guide to Best Practice (2ªedition). Lippincott Williams & Wilkins (2011)
- Apóstolo, J.: Síntese da evidência no contexto da translação da ciência. Escola Superior de Enfermagem de Coimbra, Coimbra (2017). https://www.researchgate.net/publication/322861 762_Sintese_da_evidencia_no_contexto_da_translacao_da_ciencia

- 21. Streubert, H., Carpenter, D.: Investigação qualitativa em enfermagem: Avançando o Imperativo Humanista (2ª edição). Lusociência, Loures (2002)
- 22. Fortin, M.: Fundamentos e etapas de processo de investigação. Lusodidata, Loures (2009)
- 23. Fonseca, C., Lopes, M., Mendes, D., Parreira, P., Mónico, L., Marques, C.: Psychometric properties of the elderly nursing core set. In: García-Alonso, J., Fonseca, C. (eds.) Gerontechnology. Communications in Computer and Information Science, vol. 1016, pp. 143–153. Springer, Cham (2019). https://doi.org/10.1007/978-3-030-16028-9_13
- 24. Soares, M., Ribeiro, S., Fonseca, C., Santos, V.: Ganhos sensíveis dos cuidados de Enfermagem de Reabilitação nas Pessoas Idosas com alteração da mobilidade. J. Aging Innov. 7(2), 159–176 (2018). https://journalofagingandinnovation.org/pt/volume-7-edicao-2-2/
- Davies, K.: Formulating the evidence based practice question: a review of the frameworks. Evid. Based Libr. Inf. Pract. 6(2), 75–80 (2011). https://doi.org/10.18438/B8WS5N
- 26. Sousa, L., Marques, J., Firmino, C., Frade, F., Valentim, O., Antunes, A.: Modelos de formulação da questão de investigação na prática baseada na evidência. Revista Investigação em Enfermagem, 31–39, maio 2018. https://www.researchgate.net/publication/325699143_MODELOS_DE_FORMULACAO_DA_QUESTAO_DE_INVESTIGACAO_NA_PRA_TICA_BASEADA_NA_EVIDENCIA
- 27. Nunes, L.: Considerações éticas a atender nos trabalhos de investigação académica de enfermagem. Departamento de Enfermagem ESSIPS, Setúbal (2013)
- 28. Khoshkesht, S., Zakerimoghadam, M., Ghiyasvandian, S., Kazemnejad, A., Hashemian, M.: The effect of home-based pulmonary rehabilitation on self-efficacy in chronic obstructive pulmonary disease patients. J. Pakistan Med. Assoc. 10(65), 1041–1046 (2015). https://search.ebscohost.com/login.aspx?direct=true&db=mdc&AN=26440829&lang=pt-pt&site=ehost-live
- Cosgrove, D., Macmahon, J., Bourbeau, J., Bradley, J., O'Neill, B.: Facilitating education in pulmonary rehabilitation using the Living Well with COPD programme for pulmonary rehabilitation: a process evaluation. BMC Pulm Med. 13(50), 1–10 (2013). https://doi.org/ 10.1186/1471-2466-13-50
- Global Initiative for Chronic Obstructive lung Disease: Report: Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonar disease (2020). https://goldcopd.org/gold-reports/
- 31. Lopes, M.: A relação Enfermeiro-Doente como intervenção terapêutica. Formasau, Coimbra (2006)



Experiences and Definitions of Loneliness. The Use of Technology for Anthropological Research

Borja Rivero Jiménez^(⊠), David Conde-Caballero, Jara Bonilla-Bermejo, Jerónimo Luengo-Polo, and Lorenzo Mariano Juárez,

University of Extremadura, Cáceres, Spain brivero@unex.es

Abstract. Ageing in Western societies results in various related problems. One of the most important is loneliness of the elderly. The research that has addressed loneliness has mostly been carried out from biomedical approaches, which have given priority to quantitative methodologies. We propose the research protocol for a study of ethnographic nature that is supported by technology to produce new empirical materials in loneliness research. The study will be carried out in two villages of Extremadura (Spain) with high ageing rates. We will be used traditional research tools from anthropological fieldwork, such as participant observation or interviews. For data collection through technological devices, we will be used Smart band, voice assistant and an app for location through bluetooth. These technological data will offer new insights into loneliness research and also new ways of representing it.

Keywords: Aging · Loneliness · Anthropology · Technology · Qualitative research

1 Introduction

Loneliness has emerged in recent years as one of the most pressing problems. Medias even published, before COVID19, that we are experiencing a "pandemic" or "epidemic" of loneliness [1,2]. Particularly worrying is loneliness among older people. The life experience of older people is framed by family and social relationships that, over time, may be limited or disappear[3,4]. A 2017 study in Madrid city shows that 6.8% of the city population had feelings of loneliness, rising to 14.2% of the population over 65 years old [5].

Western countries have the highest rates of ageing. For example Spain, where the Ageing Index has risen from 37.35 to 120.46 in the last 30 years (1978–2018), with a percentage of people over 65 of 19.43% [6]. This phenomenon is known as "second demographic transition" [7]. The implications of loneliness an ageing lead to it being considered as one of the great challenges of the present and future [8]. Variables such as poverty or rurality can increase loneliness very

significantly among older people. Extremadura, the region where we will carry out this research, has an ageing index of 144.3%.

[6] We do not have official data on loneliness, but following the National Institute of Statistics, we know that a total of 112,400 people lived alone in Extremadura in 2018, 1.2% more than the previous year, of which 42.8% were people over 65.

Loneliness has been described from different approaches. Many academic disciplines have launched in recent years to scrutinise its meanings and consequences [9]. The biomedical approaches, from health sciences or psychology and psychiatry, have placed themselves in a hegemonic position, extending to other disciplines their ways of measuring, observing and evaluating. A very important part of the loneliness research has been aimed at "diagnosing" rather than explaining [10]. The different scales developed to measure loneliness, such as the UCLA Loneliness Scale [11], the De Jong Gierveld Loneliness Scale [12], the Social and Emotional Loneliness Scale for Adults (SELSA) [13] or the Emotional Social Loneliness Scale (ESLI) [14], are examples of this hegemony of quantitative approaches. All these scales consist of a series of multiple choice questions, with fixed answers that are related to a numerical value. The sum of all these answers results in a number to establish more or less high levels of loneliness or social isolation.

This hegemonic methodological approach to measuring loneliness can certainly be reductionist [15]. In this way, the contributions that social sciences can make are left aside [16]. We defend the need for approaches that open the concept of loneliness and enrich the debate on causes, consequences and possible solutions. To this aim, we propose this protocol where, from the classic assumptions of ethnographic field work and with the help of technological devices, we aim to show other ways of measuring loneliness.

2 Objectives

This protocol will be part of the research developed by the "International Institute for Research and Innovation on Ageing" (4IE). The aim of this project is to understand the different health-related problems suffered by the elderly and to propose technological solutions that can improve their quality of life and avoid their institutionalisation [17]. The project gather a multidisciplinary team of computer engineers, nurses, anthropologists and sociologists. The fieldwork of anthropologists consists of analysing the situation and the different health problems of the elderly at different levels. The engineers, with these analyses and together with the anthropologists, propose technological solutions.

The aim of this paper is to propose the design of a protocol to measure loneliness among older people in rural contexts through different technological devices, such as smart bands or voice assistants. These devices can extend the data collection and complement the data obtained through the tools of ethnography. With all these materials we will create "maps of loneliness", offering definitions and experiences of loneliness of the older people participating in the study.

3 Protocol for Ethnographic Research on Loneliness with Technology

Ethnography is a methodology for social research that uses various qualitative techniques within a particular context and social group [18]. These techniques are used to collect empirical materials, which, after analysis and interpretation by the researcher, will provide information on social practices, rules or guidelines [19]. The fieldwork constitutes the primordial phase of ethnographic methodology. In the social sciences, it is understood as the period and mode of research used to collect data [20]. Since the first studies that started the discipline, anthropology has had fieldwork as the fundamental research technique for data collection.

For the fieldwork, anthropologists use various tools to collect information. There are techniques, such as informal interviews or participant observation, where data is usually not collected at the exact time, but later in a notebook or at the end of the day in the field diary [21,22]. Other techniques, such as indepth interviews or focus groups, do allow for instantaneous collection through voice recording [23].

In recent years, with the emergence of Internet and the introduction of the use of smartphones, the anthropologists are turning to technology to facilitate data collection in their research work. Anthropologist and engineers at 4IE developed an app, Feedelio, which served to collect different data with audiovisual resources of smartphones [24]. We want to go further with this research protocol, and answer this question: "What can technological devices such as smart bands or voice assistants measure in relation to loneliness?

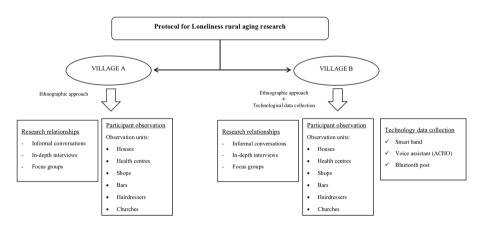


Fig. 1. Diagram of the research protocol

3.1 Research Techniques and Empirical Materials

The qualitative research presented is based on the traditional tools and assumptions of ethnographic fieldwork. In addition, we want to use technological devices

to expand the empirical materials collected. Table 1 presents an explanatory summary of the empirical materials that we hope to obtain.

Qualitative instruments such as participant observation, informal conversations or in-depth interviews will provide us with empirical materials related to the experiences, perceptions and definitions of the loneliness of the study participants. We will prepare an observation guide for the field work, in which we will collect data obtained from the analysis of the different observation units (homes, shops, bars, hairdressers). We will also collect notes in a field diary. In-depth interviews will follow a guide developed on the basis of key categories collected in informal conversations at field.

Technological tools will provide us with information related to the presence of people in space: the way people move, where they are during the day, how many people they meet and how much time they spend with other people.

We will use different technologies to do this. The smart bands will be able to offer us a guide to the different movements and encounters that people have throughout the day. These intelligent bands will be connected to an app developed following the architecture of the COVID Radar app in Spain [25]. The aim is to find out when people are close to each other.

A voice assistant will be used based on the prototype already developed in the work of 4IE, the Assistant on Care and Health Offline (ACHO) [26,27]. This prototype will be placed in participants' homes. The aim is to talk with people when they enter home and maintain interactions, with a qualitative approach, with questions such as "How are you?" or "How was your day?. The answers to these questions will be recorded and transcribed for analysis and relationship with rest of data. The aim is to "measure" how these social relationships are influenced.

For interactions in public spaces we will use a technology that has yet to be defined. This technology would have to be something like a permanent "bluetooth post". Through pairing with smart bands, this "post" could be connected when the participants in the study pass by, and thus be able to give us "maps" of people's different movements and know when they are in those public places and with whom they coincide. These devices will be placed in spaces such as squares, bars, shops, hairdressers or health centres.

This "automatic" and massive data collection will serve to complement the meaning analyses of the empirical materials collected through the qualitative methodology.

3.2 Sample

We will choose two towns in the region of Extremadura that respond to specific socio-demographic data. The profile of the population will be chosen with the idea that it responds to the typical characteristics of the rural context and the phenomenon to be studied. These socio-demographic characteristics will be: a population of no more than 100 inhabitants, with an ageing index of more than 30%, more than 35 km away from a population of more than 10,000 inhabitants and without a residential centre for the elderly.

| Research techniques | Empirical materials |
|-------------------------|--|
| Participant observation | Registration of the spaces of greatest interaction, practices on the process of interaction, how many people are in the spaces alone. Description of the processes of social interaction at public spaces |
| Informal conversations | Informal conversations, not recorded, to improve the guide of the in-depth interviews and provide other empirical materials |
| In-depth interviews | Narratives with answers from interviews according to the model of semi-structured interview worked. EMIC Opinions, beliefs, perceptions, descriptions and attitudes about loneliness and social isolation |
| Focus groups | Discussion of opinions, beliefs and perceptions about loneliness obtained from the interviews. Proposals for new categories of analysis |
| Smart band | Public presence. Participants' movements and meetings with other people in the village |
| Voice assistant | Private presence. How the person is, how much time they spend at home and if they are accompanied |
| Bluetooth post | Public presence. Maps of loneliness |

Table 1. Research techniques and empirical materials.

We will compare the results obtained in each of the villages. In village A, we will only use ethnographic research methods: field work with observation in the different units proposed, interviews and focus groups. In village B, to the qualitative method we will add the collection of data through the different technological devices. The proportion of men and women will be dictated by the characteristics of the local population. There will be no limitations in relation to the health status of the participants, as we are also interested in how certain health processes (such as mobility problems) can act as variables that significantly influence loneliness.

3.3 Ethical Considerations

All participants will sign a consent form informing them of the purpose of their participation in the study and the objectives of the research. They will also be informed that they may discontinue their participation at any time without consequences. The confidentiality of participants' personal data will be guaranteed throughout the research process. All data obtained through the smart band and voice assistants will be anonymous and only the interaction with ACHO will be recorded. The study will be conducted in accordance with the ethical principles outlined in the Declaration of Helsinki and the Belmont Report. This protocol will be submitted to the Bioethics Committee of the University of Extremadura for approval.

3.4 Timing

The study will be carried out for twelve months. This timing includes in addition to the fieldwork the literature review of scientific literature and the analysis of empirical data obtained. Table 2 shows the research protocol schedule.

Data collection with technological devices will be carried out during three weeks, in different times of the year, to avoid that there are elements that influence the distortion of the obtained data. For example, during the summer months, in most towns in Extremadura many people who have migrated to the cities and live and work abroad, return to spend their holidays. This leads to greater social activity.

| Activity | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 |
|----------------------------|---|---|---|---|---|---|---|---|---|----|----|----|
| Literature review | X | X | X | X | X | X | X | X | X | | | |
| Ethical considerations | X | X | | | | | | | | | | |
| Informal interviews | | | X | X | | | | | | | | |
| Participant observation | | | X | X | X | Χ | X | Χ | | | | |
| In-depth interviews | | | | X | X | Χ | | | | | | |
| Focus groups | | | | | X | Χ | X | | | | | |
| Technology data collection | | X | | | X | | | | X | | | |
| Data analysis | | | X | X | X | Χ | Χ | X | Χ | X | | |
| Publication of results | | | | | | | X | Χ | X | X | X | X |

Table 2. Timing of protocol research

3.5 Data Analysis

All interviews will be audio recorded. The interviews will be conducted by a team of three researchers with extensive experience in qualitative research and in-depth interviews. The audio recordings will be transcribed. The transcribed interviews will be analysed using the qualitative data analysis software ATLAS.ti. The smart band movement maps and the interactions collected by the voice assistants will also be anonymous.

The empirical material collected by the qualitative tools will be analysed using the method of constant comparison, inductive analysis and triangulation. The empirical material collected through the technological devices will also be used for this analysis. In addition, it will serve to generate "maps of loneliness" where it is graphically represented which are the spaces where loneliness is most present and how it influences on the basis of different categories, such as health or gender.

4 Conclusions

This protocol for ethnographic research on loneliness aims to complete the empirical materials collected with traditional qualitative techniques with data obtained through technological devices such as smartband or voice assistants. The data collected with these devices can offer us new ways of "measuring" loneliness, but also other views on definitions, experiences and meanings within a rural context such as the one in which we carry out our work. Variables such as gender, observed with the possibilities offered by technology, can offer us results that complete our analyses. Furthermore, we believe that these "maps of loneliness" will offer us new ways not only to interpret but also to publish our results.

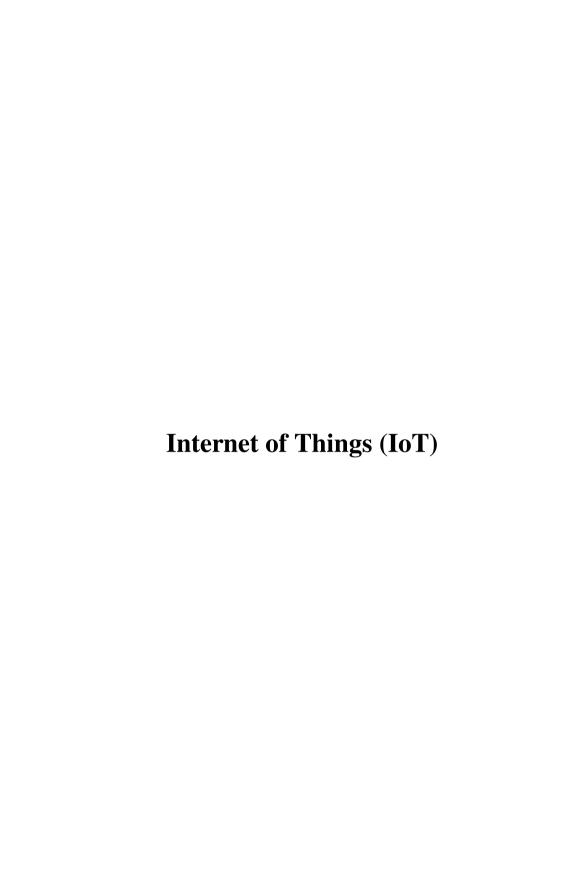
Acknowledgment. This work was supported by the 4IE+ project (0499_4IE_4_ PLUS_4_E) funded by the Interreg V-A España-Portugal (POCTEP) 2014–2020 program.

References

- La epidemia de la soledad ya supera a la obesidad como amenaza para la salud (2017). https://www.elmundo.es/sociedad/2017/09/21/59c2a0fb46163faa058b45f8.html
- An Epidemic of Loneliness in America? (2018). https://www.nytimes.com/2018/ 12/08/opinion/letters/loneliness-epidemic.html
- 3. Victor, C., Scambler, S., Bond, J.: The Social World of Older People. Understanding Loneliness and Social Isolation in Later Life. Open University Press/McGraw Hill Education, Maidenhead (United Kingdom) (2009)
- López Doblas, J., Díaz Conde, M.d.P.: El sentimiendo de soledad en la vejez. Revista Internacional de Sociología 76(1), 1–13 (2018). https://doi.org/10.3989/ris.2018.76.1.16.164
- 5. Hernán Montalbán, M.J., Rodríguez Moreno, S.I.: La Soledad no deseada en la ciudad de Madrid. Informe de Resultados. Technical report, Madrid (2017)
- 6. Instituto Nacional de Estadística de España (INE): Estadística del Padrón Continuo. Datos provisionales a 1 de enero de 2020 (2020). https://www.ine.es/dynt3/inebase/index.htm?type=pcaxis&path=/t20/e245/p04/provi&file=pcaxis&dh=0&capsel=0
- van de Kaa, D.J.: The idea of a second demographic transition in industrialized countries. In: Sixth Welfare Policy Seminar of the National Institute of Population and Social Security, Tokyo, p. 34 (2002)
- 8. Pikhartova, J., Bowling, A., Victor, C.: Is loneliness in later life a self-fulfilling prophecy? Aging Ment. Health $\bf 20(5)$, 543-549 (2016). https://doi.org/10.1080/13607863.2015.1023767
- Stein, J.Y., Tuval-Mashiach, R.: The social construction of loneliness: an integrative conceptualization. J. Constructivist Psychol. 28(3), 210–227 (2015). https://doi.org/10.1080/10720537.2014.911129

- Rivero Jiménez, B., Conde Caballero, D., Muñoz González, B., Mariano Juárez,
 L.: Technology and rural elderly loneliness. thinking about analog solutions for
 the community. In: Gerontechnology. IWOG 2019, CCIS, vol. 1185, pp. 307–313
 (2020). https://doi.org/10.1007/978-3-030-41494-8_30
- Russell, D.: UCLA loneliness scale (version 3) reliability, validity, and factor structure.
 J. Pers. Asses. 66, 20–40 (1996)
- de Jong-Gierveld, J., van Tilburg, T.: The De Jong Gierveld short scales for emotional and social loneliness: tested on data from 7 countries in the UN generations and gender surveys. Eur. J. Ageing 7(2), 121–130 (2010). https://doi.org/10.1007/s10433-010-0144-6
- DiTommaso, E., Spinner, B.: The development and initial validation of the Social and Emotional Loneliness Scale for Adults (SELSA). Pers. Individ. Differ. 14(1), 127–134 (1993). https://doi.org/10.1016/0191-8869(93)90182-3
- 14. Vicenzi, H., Grabosky, F.: Measuring the emotional/social aspects of loneliness and isolation. J. Soc. Behav. Pers. **2**(2), 257–270 (1987)
- Comelles, J., Perdiguero, E., Martínez Hernáez, A.: Topographies, folklore and medical anthropology in Spain. In: Saillant, F., Genest, S. (eds.) Medical Anthropology. Regional Perspective and Shared Concerns, pp. 103–122. Blackwell Publishing, Malden Oxford & Victoria (2007)
- 16. Rivero Jiménez, B., García Perales, N.M., Conde Caballero, D., Muñoz González, B., Calderón García, J.F., Mariano Juárez, L.: Loneliness among rural elderly: present and future public health challenges. In: Handbook of Research on Health Systems and Organizations for an Aging Society, pp. 48–61. IGI Global, Hershey (2020)
- 17. Garcia-Alonso, J., Berrocal, J., Rivero Jiménez, B., Conde Caballero, D., Mariano Juárez, L., Murillo, J.M., Mendes, D., Fonseca, C., Lopes, M., Perez-Vereda, A., Canal, C.: Instituto Internacional de Investigación e Innovación del Envejecimiento. In: Jornadas de Ingenieria del Software y Bases de Datos, JISBD 2018 (2018)
- 18. Hammersley, M., Atkinson, P.: Etnografía. Métodos de investigación, Barcelona (1994)
- 19. Kottak, C.P.: Antropología Cultural. McGraw-Hill, Madrid (2002)
- Velasco, H., Díaz de Rada, Á.: La lógica de la investigación etnográfica. Trotta, Madrid (2006)
- Strauss, A., Corbin, J.: Bases de la investigación cualitativa. Técnicas y procedimientos para desarrollar la teoría fundamentada. Universidad de Antioquia, Antioquia, Colombia (2002)
- Díaz de Rada, Á.: El taller del etnógrafo. Materiales y herramientas de investigación en Etnografía. Uivesidad Nacional de Educación a Distancia (UNeD), Madrid (2011)
- San Vicente Vicente, F.J.: Guía básica para el conocimiento de la investigación etnográfica, pp. 1–30 (2010)
- Rivero Jiménez, B., Jesús-Azabal, M., Conde Caballero, D., Muñoz González, B., Mariano Juárez, L.: Technology for anthropological research. Feedelio: an application for food and nutrition studies. In: García-Alonso, J., Fonseca, C. (eds.) Gerontechnology. IWOG 2020, CCIS, vol. 1185, pp. 134–139. Springer, Cham (2020). https://doi.org/10.1007/978-3-030-41494-8_13

- 25. Pérez, E.: Probamos Radar COVID: así funciona la aplicación de rastreode contactos que usaremos en España. https://www.xataka.com/aplicaciones/probamos-radar-covid-asi-funciona-aplicacion-rastreo-contactos-que-usaremos-espana
- 26. Moguel, E., Jesus Azabal, M., Flores-martin, D., Berrocal, J., García-Alonso, J., Murillo, J.M.: Asistente de voz para el recordatorio de tratamiento farmacológico. In: Jornadas de Ingeniería del Software y Bases de Datos (JISBD). Cáceres (2019). hdl.handle.net/11705/JISBD/2019/078
- 27. Jesús-Azabal, M., Rojo, J., Moguel, E., Flores-Martin, D., Berrocal, J., García-Alonso, J., Murillo, J.M.: Voice assistant to remind pharmacologic treatment in elders. In: García-Alonso, J., Fonseca, C. (eds.) Gerontechnology. IWOG 2020. pp. 123–133. Springer, Cham (2020)





Human Data Model: An Approach for IoT Applications Development for Elderly Healthcare

Niko Mäkitalo¹, Daniel Flores-Martin²(☒), Javier Berrocal², Juan M. Murillo², and Tommi Mikkonen¹,

¹ University of Helsinki, Helsinki, Finland {niko.makitalo,tommi.mikkonen}@helsinki.fi ² University of Extremadura, Badajoz, Spain {dfloresm,jberolm,juanmamu}@unex.es

Abstract. Nowadays, the number of devices connected to the Internet is growing at an unstoppable rate. This, added to the amount of information these devices produce, makes new techniques necessary to take advantage of their potential. New devices are continually being introduced in the daily life of people, and they are already producing an unprecedented amount of data related to people's well-being. However, taking advantage of such information to create innovative solutions heavily relies on manually gathering the needed information from several sources. In this paper, we present a Human Data Model to combine personal data, perform related computations, and proactively schedule computer-human interactions. The model's main aim is to improve the development of IoT applications by means of reusing the interactions detected in order to meet the sensation or abstractions inferred from the stored information.

Keywords: Internet of Things \cdot IoT \cdot Human Data Model \cdot People \cdot Well-being

1 Introduction and Motivations

Today, an increasing number of interoperating systems produces a flood of sensitive and intimate data. In the cyber world, human data is generated by our actions in social media and various types of cloud services. In the physical world, the data is now generated by the ever-growing amount of data pumps (wearables, sensors, mobile devices, etc.) next to us, on the network edges, where we and our devices are located.

To facilitate the daily life of elderly smart devices are developed. However, these devices also have some limitations and are not always useful if they are not combined with services that include the exchange and processing of the data they generate [1]. Also, the elderly may require frequent and immediate medical intervention, so it is necessary to know information about their routines

[©] The Author(s), under exclusive license to Springer Nature Switzerland AG 2021 J. García-Alonso and C. Fonseca (Eds.): IWoG 2020, LNBE, pp. 111–120, 2021. https://doi.org/10.1007/978-3-030-72567-9_11

and preferences [2]. This leads to remote health monitoring on an intelligent home platform allowing people to remain in their comfortable home environment rather than expensive and limited nursing homes or hospitals, ensuring maximum independence of the occupants [3,4]. This highlights the importance of smart devices and the information they produce in the elderly lives and how by processing their information, their day-to day life can be simplify and quality of life can be improved.

People use smart devices that continuously capture information. In this sense, the data provided by people posses plenty of potential for both new types of software applications as well as for improving conventional applications. Particularly important, said data is considered as data collectively gathered from our surroundings being directly related to our well-being from a smart healthcare perspective [5,6]. Nonetheless, by making use of this data with current approaches can be a complicated task. The access to this data and the usage requires that an IoT device sends the data to a smartphone, central devices, or a backend service. This setting has serious inconveniences, such as the Internet companies swamp personal data gathered from their customers is a privacy nightmare, and transferring the data to and from the cloud is intolerable for latency-sensitive systems [7]. It can only be fixed by reconsidering the way the data is utilized, calling for coordination between the Edge, the Fog, and the Cloud [8].

In this paper, we propose applying a new model based on people's data and wearable devices, Human Data Model (HDM) [9], in the context of the elderly. In addition, this model is complemented with an API that allows developers for accessing and interacting with it. The main objective of this model is to collect data concerning elderly lives and then processing the data into an actionable form. With this proposal it is also possible to build applications that proactively schedule computer-human interactions to allow the computing infrastructure to take the initiative to serve the users better.

The rest of the document is structured as follows. Section 2 shows the background of this work and some related work. Next, Sect. 3 details a use-case based on a elderly people to show the detected problem. In Sect. 4 we show our proposal HDM. Finally, in Sect. 5 the discussion and conclusions are detailed.

2 Background and Related Work

The rise of mobile and web apps have lead the way for digitization and define how people embrace technology [10]. While there are established approaches for mobile and web app development, there currently is no such approaches for developing solutions based on wearable devices.

Using Healthcare APIs, developers can integrate their healthcare applications with complex ecosystems that capture, store, and process data about people's health, e.g., Apple's HealthKit¹ with ResearchKit and CareKit provide an excellent opportunity to conduct studies and to build apps that leverage health

¹ https://developer.apple.com/health-fitness.

and wellness data. However, this approach still allows room for technological improvements. First, data processing and capture are separated, so data has to be sent from one device to another. Second, the approach does not offer solutions for connecting and leveraging different services for data processing. Finally, it is limited to Apple-compatible devices, but it also offers advantages, as the devices are homogenized and it is easier to exchange information among them.

The most direct alternative to Apple's HealthKit is Google Fit². Google Fit allows people to discover different types of sensors and devices from connected applications through the sensor APIs. This makes it easy to create an ecosystem where different devices or sensors can be used by users. These devices can collect data about people's activities, which is really useful to know their needs, preferences or interactions with other people. In addition, this data also serves to create a history of routines or activities of people so that they can know their progression. Google Fit allows developers to work with different types of manufacturers such as Adidas, Nike or Asus, among others, creating a relatively large ecosystem. As with Apple's HealthKit, Google Fit is subject to those manufacturers that support its integration. In terms of security, Google Fit cannot be used by a service that is certified as a medical device. This is because Google Fit should not be considered a medical service and therefore does not require security measures to protect user information.

The integration of these APIs can also be done with intelligent devices, that allow a versatile placement and provide flexibility and comfort to monitor elderly health status. Many of these devices can be worn or placed on clothing, or under the skin, and on almost any part of the body. These devices can detect a plethora of different variables, the number of steps, activity performed, etc. There are works devoted entirely to the analysis of these types of sensors for monitoring human activity such as [11], where many of the most relevant works on wearables for healthcare domain are analyzed. The authors reaffirm challenges yet in current solutions to be addressed such as energy consumption, privacy and security of information or standardization of protocols. Also, most of the systems analyzed require validation by healthcare personnel to certify that the devices effectively fulfill their function. Our proposal addresses many of these aspects, such as supporting a wide variety of devices regardless of communication protocols, that the devices are mainly low consumption, that users are the ones who have their data and are not in external sources and that the model is easy to use, both for developers and for users themselves. Also, Kim et al. provide in [12] an interesting review on the advances in wearable sensors where they also discuss their potential, alternatives or how invasive they are for people. This study result quite useful to highlight the potential that wearables have in the daily life of people and the limitations they have. The work [13] studies different types of sensors that can be used for monitoring health status from the biomedical-technological perspective. Here, the authors analyze wearable devices, sensors, wireless technology, and real-time tracking devices in the home and their application to physicians. Besides, they point out that these devices are

² https://developers.google.com/fit.

generally underused and should be further exploited through different systems that are capable of both managing them and relating them to each other.

The following section presents a use case detailing an ecosystem of different wearable devices, and how HDM can be used to improve the health care of an elderly person.

3 Use-Case: New Healthcare and Well-Being Services for Elderly People

Today, great efforts are being made to bring technology closer to older people. This is why older people are becoming increasingly familiar with intelligent devices, which enhance their quality of life and help them in their daily lives. The following use case shows the importance of this:

Helen is a 74-year-old woman. Recently, she incorporated smart devices that facilitate her daily life and monitor her activity. These devices are a bracelet that monitors her heart rate, slippers that track the number of steps taken during the day or the type of physical activity performed, and even pyjamas that allow her to detect movements while she is sleeping. The advantage of these devices is that they are perfectly integrated into Helen's clothing, so there is no disruption to her daily life nor usage barriers.

In addition, Helen takes part in physical sports activities in the company of other people, which are organised by an association in her neighbourhood. This helps her to stay active and meet new people. Also, the association is responsible for adapting people's exercises and activities, based on information collected from the different participants. This is why the information captured by the different sensors that Helen carries are useful, not only for monitoring her daily life, but also to find out more about her hobbies, interests and sensations. These sensations are stored locally on Helen's devices and are continuously synchronised with each other on her wearable cloud. In addition, some data may be accessible to third parties when connected to the Internet. Sensations can therefore be shared and synchronised with family, friends or health care experts, so that, Helen can be proactively advised to improve her quality of life.

In addition, introducing new smart health monitoring devices into Helen's environment is a simple process, since Helen's existing devices automatically detect when a new data source is available and, then, Helen simply grants access to that information. In addition, an application can be download onto her smart phone to access the data provided by the new source device or service. In terms of data privacy, Helen can decide what information is shared and with whom. Also, this information is processed and stored on her devices locally, so it does not travel to external servers.

This use case shows how one person, Helen, can improve her lifestyle by using wearables that allow her to interact with other people. However, the most important aspect is the processing of the information that these devices generate about Helen's routines. For this reason, the following section presents the HDM, a data model for the intelligent processing of information captured through wearables

that allows information to be easily exchanged with other devices and encourages developers to develop applications easily.

4 Human Data Model for Elderly and Wearable Technologies

The above scenario where elderly people, devices and services work as seamlessly as described above requires solutions that go beyond the current state of the art development approaches.

In this paper, we introduce HDM and its architecture. The motivation for HDM is to allow applications running on the devices around the elder's environment to anticipate the relevant sensations, and then to adapt the device behavior so that the environment can serve the elder in a more personalized way. In this sense, the HDM design follows some of the main principles of the User-Centred Design methodology as it is based on an explicit understanding of the users, environment conditions are driven and refined by a user-centred assessment and it addresses the entire user experience [14]. The Fig. 1 shows globally the concept of HDM and how, through data captured using different types of devices, applications or services can be used that take advantage of this data to obtain information from people's routines. By combining external services, intelligent devices, specific IoT devices or information from social networks, a data model of a person can be created. In order to enrich the model, contextual information such as location, date and time, climate or identify other people nearby through sensors located in the environment can be included. This model is then used by developers to create new IoT applications that are easy for people to use.

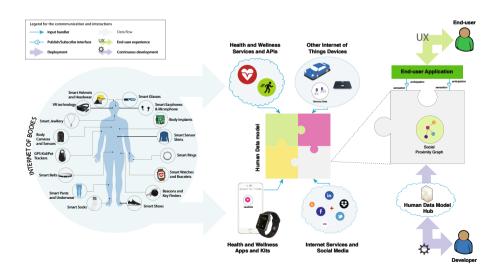


Fig. 1. Design of the Human Data Model.

In addition, Fig. 2 describes the HDM architecture and its different components. HDM collects the data related to our digital and physical elderly lives, and then refines this data into more abstract sensations. In addition, it offers an API for accessing and interacting with the now more meaningful data, but the abstractions can also be used for proactively scheduling computer-human interactions. The HDM is composed of three main layers: Unified Communication Layer, Human Data Model Instance Manager and Human Data Model Programming Interface. Each layer feeds on the sensations generated in the previous layer to perform its functions. The following paragraphs explain the HDM architecture (Fig. 2), from the Unified Communication Layer that is in charge of connecting with different types of devices; to the Instance Manager whose job is to ensure that each device can get its seed that allows it to be identified with its owner and related to other devices; and, finally, the Programming Interface that allows developers to create applications easily.

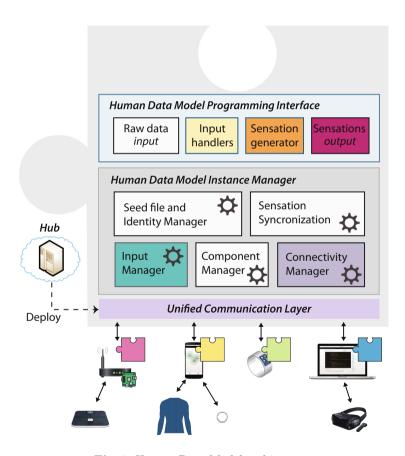


Fig. 2. Human Data Model architecture.

Regarding the first layer, the use of elements from both physical and cyber worlds such as smart devices, social networks, or any application that makes use of people's information, generates a large amount of raw data that allow to detect perceptions and sensations about people to generate a data model. In HDM this perception is enabled by collecting raw data from the physical and cyber worlds (*Unified Communication Layer*).

Once the perception are enabled, they are used as a feed to define people's data model in the second layer. As social relationships are also fundamental in how entities interact, we have defined how the relationships from the so-called "social world" can be reflected in the sensations. In the presented scenario, HDM allowed us to detect the *sensations* that took place in Helen's daily life, e.g., to help anticipating possible health problems and to help discovering routines that lead to healthier and better life quality. An example sensation in the above scenario could be describing that Helen's heart rate was a bit high in contrast to her typical heart rate after a heavy lunch while she was making some activity with her friends in the association. Such a sensation is intuitive and helps Helen to understand better her health condition and what kind of habits and choices may affect her health in a concrete way.

Different people have different needs that are in constantly changing and must be satisfied to facilitate their daily life [15]. Additionally, people use different devices. However, not all of their devices can process all types of data. For instance, the most common wearable devices at the moment can be difficult to program. One of the critical challenges with wearable technology seems to be usability and user experience. So, this can be difficult for elderly who may lack technical knowledge or not be familiar with this type of devices. Imagine how hard it could be for an elderly person to start interacting with a smartwatch, for this reason, one essential quality of HDM is that it can improve the interaction with types of devices, like on a mobile phone, cloud service, or even on a web page and provide access to the up-to-date data for easy-to-use applications. For example, imagine when Helen goes to the association. She could log in to a single application, and this would create a new HDM instance (HDM Instance Manager) where all Helen's preferences data would start synchronizing. Helen would then grant the system access to the data she feels comfortable sharing. This would allow to perform the data, the HDM instance would die, and all Helen's data would vanish from that system and services it is using.

Finally, the third layer is able to elaborate new sensations from the data provided for the previous layer. In this sense, our aim with HDM is that it can run on different Edge devices. Not all Edge devices are able to percept or process all types of data [16]. Hence, HDM is also allows modifying an instance dynamically and flexibly with processing capabilities while it is running. As depicted in Fig. 2, developers are expected to define new types of sensations with Sensation generators continuously – methods that analyze and combine data from various sources and existing sensations (HDM Programming Interface). In addition, developers define how the data is used by the model instance when it receives the data as well as how the data should be preprocessed or refined

before relaying it further by implementing new *input handler* methods. Finally, developers can implement *Dispatchers* – a specific type of apps or processes – that can access data sources that have not been previously supported.

In the real world, the entities around elderly people may continually change, and the need to interact can be over shortly. To protect the developers from implementing poorly working interactions and false scheduling, we designed HDM to have a quality of ephemeral sensations, which means that the sensation generated and stored by the model become invalid within a relatively short period – time that can be defined by the developer. Next, the sensations are also being removed from the instances to protect the user privacy. In the scenario above, if Helen takes off her smart pyjama or any other wearable, HDM removes sensations that are based on the data provided by that device in order to prevent relaying false or outdated information to the apps.

5 Discussion and Conclusions

The development of applications based on wearable technologies requires certain features such as data collection, synchronization, combining it with data from other sources, and carrying out the necessary processing to make the most out of it. It has been demonstrated that the data provided by intelligent devices on elder's routines and lives are particularly useful for achieving ecosystems that make their daily lives easier. This ranges from automating simple tasks such as adding reminders to take medication, to sharing information with other devices to promote group activities. All the data processing can be done locally on wearable devices, taking advantage of the great computing capacity they may have. One more advantage is that the Internet connection does not have to be permanent. As a trade-off, edge devices' computing capacity cannot be compared to the Cloud servers', so processing takes longer. Also, adaptability is one of the advantages of the proposed model, since new devices can be added to the ecosystem, and data can be easily obtained and associated with discovering new sensations to improve the behavior of wearable technologies applications for elderly people in smart environments.

In addition to this, wearable devices are becoming fundamental elements in people's daily lives, whether it's to perform activities, communicate with others, report data, improve quality of life, or aid in health care. Due to that, new tools are required to simplify the gathering, relating, and processing of this information to perceive the peoples' environment and act to anticipate possible problems, moods, or needs accordingly. Also, it was mentioned that data privacy is an important aspect to take into account and that only the user should have his/her data and decide with whom (s)he shares it. HDM contemplates this aspect and therefore it must be integrated with security protocols. As future work, we are working to define a security mechanism that guarantees the privacy and security of data in HDM to be evaluated.

In this work, a novel model has been presented allowing one to capture the personal information related coming from heterogeneous sources for its later processing and promoting proactive interactions among smart devices and people.

So, we think that such facilities are essential for the wearable devices technologies as well as other related approaches where data related to individuals is processed.

The HDM implementation can be checked at: https://humandatamodel.github.io/.

Acknowledgments. This work was supported by (0499_4IE_PLUS_4_E) funded by the Interreg V-A España-Portugal (POCTEP) 2014-2020 program, by the project RTI2018-094591-B-I00 (MCIU/AEI/FEDER, UE) and FPU17/02251 grant, by project IB18030 funded by the Government of Extremadura. The work of N. Mäkitalo was supported by the Academy of Finland (project 328729). We would especially want to thank Professor Yevgeni Koucheryavy from Tampere University for his contributions and insight.

References

- Hussain, A., Wenbi, R., da Silva, A.L., Nadher, M., Mudhish, M.: Health and emergency-care platform for the elderly and disabled people in the smart city. J. Syst. Softw. 110, 253–263 (2015)
- Berrocal, J., García-Alonso, J., Murillo, J.M., Canal, C.: Rich contextual information for monitoring the elderly in an early stage of cognitive impairment. Pervasive Mob. Comput. 34, 106–125 (2017). https://doi.org/10.1016/j.pmcj.2016.05.001
- 3. Van Hoof, J., Demiris, G., Wouters, E.J.: Handbook of Smart Homes, Health Care and Well-Being. Springer, Cham (2017)
- Berrocal, J., García-Alonso, J., Murillo, J.M.: Facilitating the selection of architectural patterns by means of a marked requirements model. In: European Conference on Software Architecture, pp. 384–391. Springer (2010)
- Solanas, A., Patsakis, C., Conti, M., Vlachos, I.S., Ramos, V., Falcone, F., Postolache, O., Pérez-Martínez, P.A., Di Pietro, R., Perrea, D.N., et al.: Smart health: a context-aware health paradigm within smart cities. IEEE Commun. Mag. 52(8), 74–81 (2014)
- Abowd, G.D.: Beyond weiser: from ubiquitous to collective computing. Computer 1, 17–23 (2016)
- 7. Dastjerdi, A.V., Buyya, R.: Fog computing: helping the Internet of Things realize its potential. Computer 49(8), 112–116 (2016)
- Mäkitalo, N., Ometov, A., Kannisto, J., Andreev, S., Koucheryavy, Y., Mikkonen, T.: Safe, secure executions at the network edge: coordinating cloud, edge, and fog computing. IEEE Softw. 35(1), 30–37 (2018)
- Makitalo, N., et al.: The internet of bodies needs a human data model. IEEE Internet Comput. 24, 28–37 (2020)
- Liu, Y., Liu, X., Ma, Y., Liu, Y., Zheng, Z., Huang, G., Blake, M.B.: Characterizing restful web services usage on smartphones: a tale of native apps and web apps. In: 2015 IEEE International Conference on Web Services, pp. 337–344. IEEE (2015)
- Pantelopoulos, A., Bourbakis, N.G.: A survey on wearable sensor-based systems for health monitoring and prognosis. IEEE Trans. Syst. Man Cybern. Part C (Appl. Rev.) 40(1), 1–12 (2009)
- Kim, J., Campbell, A.S., de Ávila, B.E.F., Wang, J.: Wearable biosensors for healthcare monitoring. Nat. Biotechnol. 37(4), 389–406 (2019)

- 13. Appelboom, G., Camacho, E., Abraham, M.E., Bruce, S.S., Dumont, E.L., Zacharia, B.E., D'Amico, R., Slomian, J., Reginster, J.Y., Bruyère, O., et al.: Smart wearable body sensors for patient self-assessment and monitoring. Arch. Public Health **72**(1), 28 (2014)
- Gulliksen, J., Göransson, B., Boivie, I., Blomkvist, S., Persson, J., Cajander, Å.: Key principles for user-centred systems design. Behav. Inf. Technol. 22(6), 397–409 (2003)
- Flores-Martin, D.: Meeting IoT users' preferences by emerging behavior at runtime. In: International Conference on Service-Oriented Computing, pp. 333–338. Springer (2017)
- Berrocal, J., García-Alonso, J., Fernandez, P., Pérez-Vereda, A., Hernández, J., Canal, C., Murillo, J.M., Cortés, A.R.: Early evaluation of mobile applications' resource consumption and operating costs. IEEE Access 8, 146648–146665 (2020). https://doi.org/10.1109/ACCESS.2020.3015082



Enhanced Living Environments (ELE): A Paradigm Based on Integration of Industry 4.0 and Society 5.0 Contexts with Ambient Assisted Living (AAL)

Edward Wilder Caro Anzola^(⊠) and Miguel Ángel Mendoza Moreno

Facultad de Ingeniería, Universidad Pedagógica y Tecnológica de Colombia, Av. Central del Norte, Tunja 150001, Boyacá, Colombia

{edward.caro,miguel.mendoza}@uptc.edu.co

Abstract. Enhanced Living Environments (ELE) are a kind of paradigm for life, well-being and social inclusion. Improving an environment implies the development of processes that, based on people needs and conditions, make pertinent adjustments, so that, the feeling of comfort and security arises when the interaction takes place. The connotation of *enhanced environment* entails criteria of Ambient Intelligent (AmI) based on new Information and Communication Technologies (ICTs), Internet of Things (IoT) and the security and privacy that ubiquitous systems can give by means of harmonious integration, from their conceptual base to the systems interoperability. ELE paradigm is proposed as an effective resource for the formulation of smart spaces systems, those are the bases of smart cities where attention is centered on the user, citizen or patient in medical cases. Therefore, a review of the main concepts that justifies the use and implementation of ELE in health context is carried out, where the personalization of systems and services to the patients are according with the primary objective of improving living conditions from social integration, autonomy and independence of people limited in their daily functions due to a disability or being in the condition of an elderly person. Finally, the viability for integrating Industry 4.0 and Society 5.0 paradigms has been determined in this research proposal; that allows to make an ELE ecosystem centered on patients and elderly people in extrahospitalary environments, it means, it will promote technological increase actions in favor of the adaptation of individual life conditions.

Keywords: Ambient Assisted Living · Ambient Intelligence · Enhanced Living Environments · Industry 4.0 · Society 5.0

1 Introduction

Among the most outstanding characteristics of technological developments are their potential to generate new solutions to problems in the real world, which are described based on the needs that both, human being and society itself, that show to be inherent in the execution of daily activities in any context. If we have to talk about contexts,

people are dependent on them from the perspective in which all contexts define the *modus operandi* of society based on the personal adaptation to a *social niche*, however, the modern human being objects to be an entity that adapts to the environment, this means that the society transforms the environment, so that it adapts to its needs, thus, improvement and evolution are achieved [1, 2]. Now, the environments are modified in order to improve the spaces in which daily activities are carried out, seeking wellbeing, enhancing the quality of life (QoL) and comfort, which allow the following tasks to be carried out optimally; this aspect defines the perspective of actions centered on the person where physical and mental health are a priority [3]; so, it can be possible, the human beings must be constructors of their environment based on their experience, cognitive and transformative abilities [4].

There are different scenarios that can be had in the development of daily activities, various strategies are proposed that allow making pertinent adaptations of the environments from the cultural, psychological, economic, political, educational and technological visions [5, 6]. Among considerations for the treatment of environments, the concept of Ambient Intelligence (AmI) arises as one of these strategies; AmI is defined as an emerging paradigm that focuses on people, who apply smart tools through the integration of various elements or objects in context-awareness with the environment where they interact, through their adaptation, availability and transparency that are used to the service of people [7]; this perspective creates an interactive functional environment mediated by physical elements and software that allow improving the experience of the different actors in a framework defined as an *intelligent environment* [8]. Therefore, the primary goal of AmI is to provide systems and services that are tailored to collective and individual needs by improving lifestyles [9].

AmI is present in different contexts, including Ambient Assisted Living (AAL) and Enhanced Living Environments (ELE); in the first case, AAL is a way for applying AmI in people with several health problems, essentially in elder people, where strategies and methods are sought to correct these problems, increasing the well-being, independence and autonomy of the patient through multidisciplinary interaction of innovative technologies, systems, products and services [10]. Figure 1 shows that ELE paradigm is reaffirmed as the integrating element of the AmI and AAL concepts with the new technologies based on processing and communication architectures, hardware, software and middleware dedicated to the security and services of assisted people [11].

By the other hand, ELE can be implemented for other people in any condition, since its objective is improving the QoL from the adaptation of intelligent environments. However, its application to AAL implies a redefinition in the concept of life assistance, extending beyond the elderly to people with disabilities, where medical problems impede their normal performance in different aspects such as family and social relationships; ELE represents a step forward towards the concepts of intelligent societies mediated by IoT systems for anyone and IoMT (Internet of Medical Things) for patients [12]. In this document, the prior analysis to the research is carried out, this constitutes the first stage for the proposal of integration between ELE and the Industry 4.0/Society 5.0 paradigms; so, the opportunity of development for conceptual integration axes will be detected for the second stage in this study.

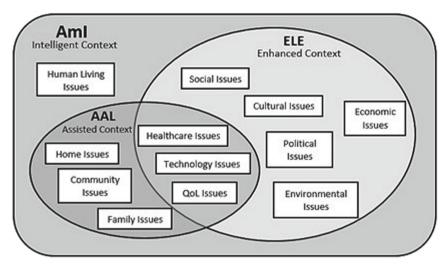


Fig. 1. Relationship among AmI, AAL and ELE contexts.

2 ELE and eHealth Relationship

Nowadays, IoT is considered as a pervasive paradigm covering each moment more functionalities for the human activities and environments; it is a good tool that allows keeping records and controls of the activities that arise around it, this task has been carried out with the accelerated growth of the Information and Communication Technologies (ICT) that has provided benefits in multiple contexts thanks to its ubiquity and transparency, for example, in Electronic Health (eHealth), Mobile Health (mHealth) and AAL [13]. This emerging development brings on the implementation of ELE services based on IoT tools applied to medicine (IoMT) in real-time supervision with cyber-physical environments based on the connectivity of systems, networks, devices and processes [14]. Thus, eHealth and ELE are interrelated through ELE's own domains with eHealth application opportunities; in this relationship, there are a tendency to obtain valuable characteristics from IoT that make it holistic, resilient, configurable, dynamic, customizable, affordable, available, among other attributes [15]. Service personalization is the remarkable aspect of eHealth systems that defines in part the design of an improved environment, related with traditional medicine whose aspect is reactive and in opposite to the proactive framework of eHealth; this becomes to ELE in a kind of personalized medicine service where treatment, patient-doctor communication, diagnosis, risk assessment and resource management are combined with integrated technological systems [16].

The conjunction between eHealth and ELE implies three essential domains: the first is the *determination of the personal characteristics* that make up the identity, the disease or limitation and the risk factors; a second element corresponds to the *execution of the daily activities* that compromise the patient self-care, leisure and work; finally, a domain of *environmental factors* are framed from contexts like services, assistive technology, care and life [17]. In this way, ELE has three interrelated domains that include people's cosmovision, technology reference and committed institutions, while, eHealth proposes

assistance opportunities to the elderly and people with special needs through people adaptivity according to their characteristics, applicability of technologies to the real environment and success decisions of a conscious society; Fig. 2 shows an abstraction for this possible integration between ELE and eHealth to provide an optimal assistance that cover patient needs in two possible scenarios, inside and outside environments of the hospital system which aims to achieve improvements in the QoL and well-being.

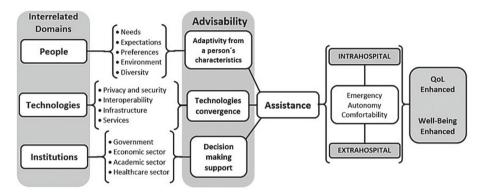


Fig. 2. ELE's interrelated domains and eHealth advisability integration.

2.1 Assisted Living Technology and ELE

The impact of technology in health and society contexts has been relevant from the point of view of services that can be provided; at patient level, eHealth paradigm has allowed that people with dysfunction or limitation of their physical, psychological, cognitive or social abilities to be integrated into the different processes where they were previously excluded, so that, the environment is now influenced by adapting requirements to needs of new users, where patients, medical staff and families are immersed; thus, services and systems converge towards the development of assistance frameworks classified into two groups: intelligent eHealth and eCare technologies, where, for both cases, resources such as tools, devices and support equipment are committed [18].

Assistive technologies correspond to the operational fact of ELE [19, 20], and are evidenced within the field of development of support systems, where the new findings compose the application contexts of new techniques and methodologies categorized by an orientation towards the needs of the users, among which stand out mental functionality, mobility support, sensory functions, orthotics and prosthetics, communication skills, recreation and sports, improvement of home and work environments and daily activities [21]. Although technological developments allow systems to be integrated in a variety of ways that are dependent of defined methodology, there are still limiting factors for the conformation of healthcare support systems, such as, the characteristics of the company that performs the integration, orientation of the problem kind to treat, business and commercial monopolies, support of external agents, unknowingness of real needs of the users and segmentation of markets [22].

An important factor in the implementation of assistive technologies is the user experience, which promotes the use of the user-centered design methodology where ergonomics, functionality, emotionality and quality are determining factors in the design where positive experiences are provided and these allow the acceptance of ELE later; this results in a better acceptance of the systems that make up the intelligent environment [23].

3 General Architecture of ELE Paradigm

ELE paradigm is envisioned as a possible context sensitive architecture where its composition demands multiple elements and systems that are related through visible contexts called *entities* that can be people, objects or physical spaces, they are linked by low-level or raw data and high-level data or context through representations of situations [24]. In ELE there is evidence of a learning condition on the people status from the behavioral, psychosocial and environmental levels, so, this is an interpretation of the activities and interactions of the subject with their environment; an event that defines the type of architecture between centralized context systems or distributed context systems; in the first case, monitoring and control are carried out from a central processing unit that works with different actions for the interconnected elements; in the second case, they are not discriminate processes on a single control element, rather, they integrate multiple elements with intelligent characteristics linked through a complex communications network associated with two types of units, multi-agent systems and service-oriented architectures [25].

These architectures demand that standards and modalities must be defined due to their heterogeneous nature, that determines the use of middleware as the link layer between the constituent elements of the integrated network and the applications that are designed from the knowledge base of devices and processes, until the execution of the different procedures and the appropriate user interfaces [26]. Thereby, it is observed that ELE must adapt elements that allow an adequate composition of the architectures that are proposed and determined by the subject and the environment; these actions are seen in the organization and management like value chains of Industry 4.0. So, ELE adopts this orientation by adjusting several systems and protocols of Industry 4.0 context to smart living environments [27].

3.1 Industry 4.0 in ELE Context

The added value evidenced in Industry 4.0 is applicable to the adaptability of smart environments proposed by ELE by its multidimensional nature that provides opportunities, benefits, flexibility, new services, cost reduction and optimization of value chains from integration of emerging technologies in IoT, Big Data analytics, systems integration, cyber-physical systems, cloud and edge computing, artificial intelligence and simulation of environments [28].

The concept of Industry 4.0 has an impact on what is now called Health 4.0 or Healthcare 4.0, where all its particularities are adopted and integrated into services and technologies that are managed from eHealth as a new ecosystem from ELE [29];

Figure 3 shows this concept as a characterization of new aspects that are derived, especially, of IoT, including the Internet of Body Objects used in telemedicine (WIoT), the Internet of Health Things that combines the action of wearable medical devices with context-awareness systems (IoHT), the Internet of Medical Things that personalizes the interaction between implantable and wearable devices with the cloud and the Internet (IoMT), the Internet of Nano Things that applies the new nanotechnologies for health services (IoNT) and the Internet of Mobile Things in Medicine that related personal area communication services with monitoring of physiological variables through 4G and 5G networks that are characteristics of mobile Health (*m*-IoT) [30].

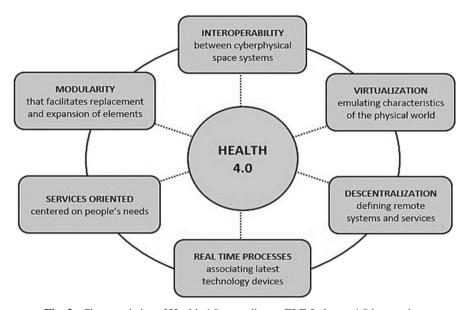


Fig. 3. Characteristics of Health 4.0 according to ELE-Industry 4.0 integration.

3.2 Society 5.0 in ELE Context

Intelligent spaces are always improved environments from the technological and conceptual bases; among the most important concepts for the implementation of organized, inclusive, optimized and comprehensive life contexts proposed by ELE, there are emphasis given to people from the perspective of Society x.0 and its close relationship with the evolution of the Industry x.0, which has generated a positive impact from the experience of the various social nuclei, where four states of current knowledge are differentiated, that differ from the temporal aspects and give rise to the perspectives of action and implementation of this classification: data society, information society, knowledge society, and the new proposal, a wisdom society [31].

Japan has led the implementation of this paradigm from its conception like digital transformation within the globalization framework, technological evolution and value

given to people and environments; for this reason, each one of the societies evolution stages are characterized as an inherent function of the development of industrial eras in which people have adapted to their environments for their subsistence, however, the philosophy of Society 5.0 frames an economic, political and social development that focuses on responsible people as the transforming axis of their environment where the general well-being of each one is sought as an active component of a social *status quo*. This delimits the framework of the so-called *super intelligent societies* (or Super Smart Societies); for this case, ELE, like a paradigm, provides a valid reference frame, considering that the objectives are the same as they are supported by emerging technology, new dynamic processes and social transformation [32]. Figure 4 shows the intrinsic relationship between industry development and social evolution from technology innovation that change the people environment based on human beings needs; actually, knowledge provides continuous data that must be analyzed with the purpose to feedback a new information management, after a learning stage is carry out, the new required information is generated for optimal society performance.

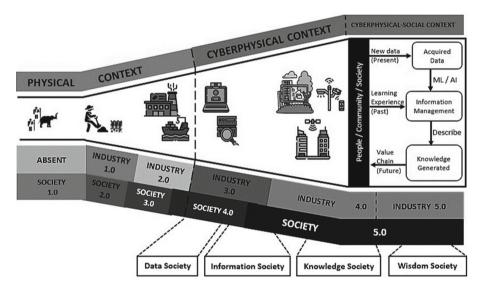


Fig. 4. Relationship among societies evolution from industrial development ages.

Environment transformation is, therefore, a principle that normalizes ELE under the postulate of *human habitat innovation*, which corresponds to the necessary adaptation activities of the personal, social and cultural niche, through convergence frameworks of emerging technologies present in cyber-physical spaces, structural transformation under the formulation of effective policies, and people's QoL from support and assistance services based on new information [33]. Bearing in mind, that information produces knowledge, it must be transformed into action, which becomes a benefit for the community, which allows conditioning the personal social environment to their needs and perspectives [34]; thus, ELE takes the process of environment transformation from the information management by capturing a high volume of data that is managed for the

formation of services using intelligent community connectivity [35]; that leads to an innovated ecosystem that is modeled environmentally and it is promoted from science and technology at a socioeconomic, political and cultural levels that has a positive impact on personal *modus vivendi*, a specific purpose of ELE [36].

4 Industry 4.0 and Society 5.0 Paradigms Inside ELE Context

ELE paradigm has a huge potential for elderly people and patients in their extrahospitalary contexts; the integration of new technologies and methodologies are a challenge for researchers due to its complexity; however, the conjunction of elements can be observed like opportunities, specially, if a framework is created using the interrelated concepts that here are commented. The advances in this work from the authors, have as objective the design of a first composition of actions for three domains, medical research, sociology research and information sciences, that ELE could use like a possible framework. Figure 5 shows as the technology will be the center that focuses on patient requirements, social inclusion and information resources for the main ELE actors (people, medical staff and society); technology convergence brings opportunities through awareness context, ubiquitous environments, successful services, operational tools, data security, among others; ELE takes purposes and goals of Industry 4.0 and Society 5.0 paradigms.

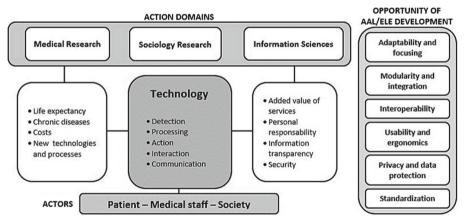


Fig. 5. Action domains and opportunities on ELE, Industry 4.0 (medical) and Society 5.0 (sociology) integration proposal. *Source*: adapted from [11].

The elements of the ELE, Industry 4.0 and Society 5.0 integration proposal will be described below:

- Medical research: using the emergent technologies for enhanced the QoL of patients and elderly people through the application of processes and methodologies that are suitable in different extrahospitalary environments.
- Sociology research: like a way to understanding the people behaviors under situations
 that are adverse with their daily life by means of the comprehension of their community
 interaction and social reality.

Information sciences: through a big data collected from ubiquitous systems that record
a lot of signals of people and environments; likewise, the acquired information will
let create added value services and optimized processes.

Industry 4.0 and Society 5.0 are very important concepts for ELE as integrating cores, for example, in efficient frameworks that will allow to gather new technological concepts of Industry 4.0 with the social reform and innovation formulate by Society 5.0. ELE will be most suitable for extrahospitalary context in smart cities and the next reliable wisdom society, as it will be more inclusive and adapted to the true needs of its users.

5 Conclusions

The relevant aspect of modern society is to maintain an appropriate state of well-being in its members using innovative mechanisms that generate a positive impact on its evolution; it becomes an emerging object of study from the tendency to keep the social system in which a person is part. It should be considered that the human beings are entities of customs that, to a large extent, are shaped by their living environment, that can be unfavorable to them, individual and social development is diminished, generating states that are opposite to the objective of maintain QoL.

This exploratory study brings the interpretation of ELE like a trend that has been strengthening from different aspects that, when is properly integrated, allows the environment for daily activities development in the human being adapts, not only their needs, but their expectations and preferences, aspects that are mediated by new emerging technologies. ELE makes use of these technologies to make changes required by different environments for personal development and community activities, through different fields that potentiate its conception; ELE can intervene satisfactorily in these development fields in a transparent, objective, sensitive and proactive manner, considering ubiquitous systems, ICTs and the philosophies proposed by eHealth, Smart Cities and Society 5.0 have the same characteristics [37, 38].

The field of work, in a near future for ELE, is promising, considering that the diversity of solutions proposed for different aspects of environments improvement, are framed in the accelerated advance of the scientific and technological processes, as well as, the transformation of thinking that is emerging in new governmental, academic and cultural organizations. It is, therefore, that ELE will be a provider of services, systems, devices, trends, methodologies and techniques that will adjust to those needs, as AmI, AAL and the different conceptions of the IoT infrastructure are already doing, thus, this proposed convergence brings an integration framework based on applications and extended services with social inclusion, data security, transparency and reliability.

Society 5.0 intends to generate balances between all the lines of the communities, but without losing sight of the fact that the central axis is the citizen, and in that sense, the requirements in the different developments must arise from he/she and towards he/she must arrive the functionality and enjoyment of the improvement in the different systems that are technologically implemented; in this way is the technological provision of Industry 4.0. From this perspective, the range of opportunities and impacts that can be generated so that health, well-being and adaptation are combined to aim for high levels of happiness in people, their families and communities is undeniable.

As part of future works, the authors will present the investigative process focused on the identification of ELE within the framework of Industry 4.0 and Society 5.0 paradigms. After, the conceptual validation will be done, and finally, the technical validation will be carried out using implementations regarding the detected opportunities, usability criterions and user centered design.

In terms of practical models, several frameworks for applied assistive technologies have been proposed with multiple approaches, for example, in treatment of children autism spectrum disorder using painter exercises [39], methodologies to create healthcare projects [40], or strategies for improvement the medical processes [41], among others. ELE goes beyond applied technology with the transversal integration of new paradigms.

Acknowledgements. Authors give a special acknowledgment to TELEMATICS Research Group for its support. TELEMATICS belongs to Faculty of Engineering at Universidad Pedagógica y Tecnológica de Colombia, Tunja, Colombia.

References

- Low, F.M., Gluckman, P.D., Hanson, M.A.: Niche modification, human cultural evolution and the anthropocene. Trends Ecol. Evol. 34(10), 883–885 (2019). https://doi.org/10.1016/j. tree.2019.07.005
- Yamagishi, T., Hashimoto, H.: Social niche construction. Curr. Opin. Psychol. 8, 119–124 (2016). https://doi.org/10.1016/j.copsyc.2015.10.003
- Spano, G., Giannico, V., Elia, M., Bosco, A., Lafortezza, R., Sanesi, G.: Human healthenvironment interaction science: an emerging research paradigm. Sci. Total Environ. 704, 135358 (2020)
- Karakas, T., Yildiz, D.: Exploring the influence of the built environment on human experience through a neuroscience approach: a systematic review. Front Archit. Res. 9(1), 236–247 (2020). https://doi.org/10.1016/j.foar.2019.10.005
- Richerson, P.J., Boyd, R.: The human life history is adapted to exploit the adaptive advantages of culture. Philos. Trans. Roy. Soc. B Biol. Sci. 375(1803), 20190498 (2020). https://doi.org/ 10.1098/rstb.2019.049
- Kopnina, H.: Human/environment dichotomy. Int. Encyclopedia Anthropol. (2019). https://doi.org/10.1002/9781118924396.wbiea2397
- Bravo, J., Cook, D., Riva, G.: Ambient intelligence for health environments. J. Biomed. Inform. 64, 207–210 (2016). https://doi.org/10.1016/j.jbi.2016.10.009
- Augusto, J.C., Callaghan, V., Cook, D., Kameas, A., Satoh, I.: Intelligent environments: a manifesto. Hum. Centric Comput. Inf. Sci. 3(1), 1–18 (2013). https://doi.org/10.1186/2192-1962-3-12
- 9. Coutaz, J., Crowley, J.L (2013). https://doi.org/10.1002/9781118580974.ch1
- 10. Queirós, A., Rocha, N.P.D. (2018). https://doi.org/10.3390/informatics4030019
- Dobre, C., Mavromoustakis, C.X., Garcia, N.M., Mastorakis, G., Goleva, R.I. (2017). https://doi.org/10.1016/B978-0-12-805195-5.00001-6
- Dobre, C., Ganchev, I., Garcia, N.M., Goleva, R., Valderrama, C.A. (2017). https://doi.org/ 10.1007/978-3-030-10752-9
- Rahmani, A.M., Gia, T.N., Negash, B., Anzanpour, A., Azimi, I., Jiang, M., Liljeberg, P.: Exploiting smart e-Health gateways at the edge of healthcare Internet-of-Things: a fog computing approach. Future Gener. Comput. Syst. 78(2), 641–658 (2018). https://doi.org/10.1016/j.future.2017.02.014

- Marques, G., Miranda, N., Bhoi, A.K., Garcia-Zapirain, B., Hamrioui, S., de la Torre Díez, I.: Internet of things and enhanced living environments: measuring and mapping air quality using cyber-physical systems and mobile computing technologies. Sensors 20(3), 720 (2020). https://doi.org/10.3390/s20030720
- Firouzi, F., Farahani, B., Ibrahim, M., Chakrabarty, K.: Keynote paper: from EDA to IoT eHealth: promises, challenges, and solutions. IEEE Trans. Comput. Aided Des. Integr. Circ. Syst. 37(12), 2965–2978 (2018). https://doi.org/10.1109/tcad.2018.2801227
- 16. Sebri, V., Savioni, L. (2020). https://doi.org/10.1007/978-3-030-27994-3_4
- 17. Willems, C.G., Hamers, E.P. (2017). https://doi.org/10.1201/9781315368818
- Merilampi, S., Sirkka, A., Tupala, R., Jaakkola-Hesso, S. (2017). https://doi.org/10.1201/978 1315368818
- Zinner, T., Wamser, F., Leopold, H., Dobre, C., Mavromoustakis, C.X., Garcia, N.M. (2017). https://doi.org/10.1016/B978-0-12-805195-5.00001-6
- Gambi, E., Montanini, L., Raffaeli, L., Spinsante, S., Lambrinos, L.: Interoperability in IoT infrastructures for enhanced living environments. In: IEEE International Black Sea Conference on Communications and Networking (BlackSeaCom), pp. 1–5 (2016)
- 21. Leo, M., Medioni, G., Trivedi, M., Kanade, T., Farinella, G.M.: Computer vision for assistive technologies. Comput. Vis. Image Underst. **154**, 1–5 (2017). https://doi.org/10.1016/j.cviu. 2016.09.001
- Plos, O., Buisine, S., Aoussat, A., Mantelet, F., Dumas, C.: A universalist strategy for the design of assistive technology. Int. J. Ind. Ergon. 42(6), 533–541 (2012). https://doi.org/10.1016/j.ergon.2012.09.003
- Mallin, S.S.V., de Carvalho, H.G.: Assistive technology and user-centered design: emotion as element for innovation. Procedia Manuf. 3, 5570–5578 (2015). https://doi.org/10.1016/j. promfg.2015.07.738
- van Engelenburg, S., Janssen, M., Klievink, B.: Designing context-aware systems: a method for understanding and analysing context in practice. J. Log. Algebr. Methods Program. 103, 79–104 (2019). https://doi.org/10.1016/j.jlamp.2018.11.003
- Mshali, H., Lemlouma, T., Moloney, M., Magoni, D.: A survey on health monitoring systems for health smart homes. Int. J. Ind. Ergon. 66, 26–56 (2018). https://doi.org/10.1016/j.ergon. 2018.02.002
- Vasilateanu, A.: Context-aware IoT middleware for home care-R2V adaptive. In: 3rd International Conference on Smart and Sustainable Technologies (SpliTech), p. 9789532900835 (2018)
- Batista, N.C., Melício, R., Mendes, V.M.F.: Services enabler architecture for smart grid and smart living services providers under Industry 4.0 (2017). https://doi.org/10.1016/j.enbuild. 2017.02.039
- 28. Bigliardi, B., Bottani, E., Casella, G.: Enabling technologies, application areas and impact of Industry 4.0: a bibliographic analysis. Procedia Manuf. 42, 322–326 (2020)
- 29. Thuemmler, C., Bai, C. (2017). https://doi.org/10.1007/978-3-319-47617-9
- 30. Aceto, G., Persico, V., Pescapé, A.: Industry 4.0 and health: internet of things, big data, and cloud computing for Healthcare 4.0. J. Ind. Inf. Integr. 18, 100129 (2020)
- 31. Zeleny, M.: From knowledge to wisdom: on being informed and knowledgeable, becoming wise and ethical. Int. J. Inf. Technol. Decis. Making **05**(04), 751–762 (2006)
- 32. Harayama, Y.: Society 5.0: aiming for a new human-centered society. Japan's science and technology policies for addressing global social challenges. Hitachi Rev. **66**(6), 558–559 (2018)
- 33. Matsuoka, H., Hirai, C. (2020). https://doi.org/10.1007/978-981-15-2989-4_2
- Scott, R., Saunders, C., Palacios, M., Nguyen, D., Ali, S. (2012). https://doi.org/10.1007/978-1-4614-3495-5

- 35. Lee, S.: Cities are getting smarter than ever before. smart societies, infrastructure, technologies and applications. In: First International Conference, SCITA 2017, Jeddah, pp. 9–11 (2017)
- 36. Fukuda, K.: Science, technology and innovation ecosystem transformation toward Society 5.0. Int. J. Prod. Econ. **220**, 107460 (2020)
- 37. Enler, E., Pentek, I., Adamko, A.: Healthcare framework for smarter cities with biosensory data. In: 11th IEEE International Conference on Cognitive Infocommunications (CogInfoCom), pp. 337–342 (2020)
- 38. Azorin-Lopez, J., Fuster-Guillo, A., Saval-Calvo, M., Bradley, D.: Home technologies, smart systems and eHealth. In: Mechatronic Futures, pp. 179–200 (2016)
- Pazzagli, C., Fatuzzo, G., Donnari, S., Canonico, V., Balboni, G., Mazzeschi, C.: Assistive technologies for children with. autism spectrum disorder. In: Assistive Technology Assessment Handbook, pp. 978–979 (2018)
- Chanchaichujit, J., Tan, A., Meng, F., Eaimkhong, S. (2019). https://doi.org/10.1007/978-981-13-8114-0
- Lee, E.K., Atallah, H.Y., Wright, M.D., Thomas, IV.C., Post, E.T., Wu, D.T., Haley Jr., L.L.: Systems analytics: modeling and optimizing clinic workflow and patient care. In: Healthcare Analytics: From Data to Knowledge to Healthcare Improvement, pp. 263–299 (2016). https://doi.org/10.1002/9781118919408.ch9



Design of an App for the Awareness of Active **Ageing Linked to Cultural Heritage**

Juan Francisco Ortega Morán¹(⊠), José Luis Moyano García-Cuevas¹, Francisco Manuel Esteban Gómez¹, Carolina Vila-Cha², Nuno Serra², Debora Zamillo³, Aurelia Curaj⁴, Francisco M. Sánchez Margallo¹, and J. Blas Pagador¹

Centro de Cirugía de Mínima Invasión Jesús Usón, Cáceres, Spain jfortega@ccmijesususon.com

² Instituto Politécnico da Guarda, Guarda, Portugal

Abstract. The promotion of cultural heritage is an area in which older people can be actively involved, as their experiences and memories are an active and relevant source of information. However, older people are not fully aware of this. Therefore, it is important to promote a campaign of awareness towards them in this aspect, since this would also contribute to favor an active ageing, enhancing certain cognitive capacities. New technologies are an increasingly useful mean for this active ageing, with mobile phones, tablets and computers being used more and more commonly among the older population. The development of mobile applications for use with these devices is on the increase, solving the limitations that the elderly population would have towards the use of these new technologies. The aim of this project is to design an app for the dissemination among the elderly of the awareness of active ageing linked to cultural heritage. Taking into account the requirements associated with the limitations of the elderly for its correct use, a very simple app for Android platform has been designed for Smartphone devices through which they can access content corresponding to different cultural areas, mainly composed of videos in which elderly people promote cultural heritage. This app, which has an interface very simple with few buttons and easy menus, supposes an important means to promote active ageing using cultural heritage, involving them more and more in the use of new technologies.

Keywords: Active ageing · App · Awareness · Cultural heritage

Introduction

Mobile applications have become an essential tool in our daily lives. These applications allow the user to access and manage any type of information quickly, directly and practically from anywhere. It is for this reason that together with the mobile device they form an essential union in different sectors [1].

³ Centro Sportivo Educativo Nazionale, Rome, Italy ⁴ Geron Foundation, Bucharest, Romania

[©] The Author(s), under exclusive license to Springer Nature Switzerland AG 2021 J. García-Alonso and C. Fonseca (Eds.): IWoG 2020, LNBE, pp. 133–138, 2021.

The number of apps with application in the field of active aging are increasingly been used [2]. There are multiple applications for cognitive stimulation of the elderly, fitness and even many of them for the access to social networks to share their experiences. The AGEment project [3] aims to raise awareness among the population, especially adults and elderly people, towards the concept of active ageing, linking it to cultural heritage. The objective of this work is to design an app for the dissemination of the awareness raising material created in the project.

2 Methods

2.1 Platform

The first question when implementing an app is what the target platform is. The two main platforms are Android and IOS. For this development, the target platform chosen for Smartphone has been Android. The main reason for choosing Android has been the number of users of this platform, superior not only in Europe but also in most of the rest of the world (Fig. 1) [4].



Fig. 1. Distribution of prevalence between Android and IOs operative system worldwide

In addition, regarding the number of downloads of applications, the google market is far higher, as reflected by the data (Fig. 2) [5]. So, we think it can have a greater impact.

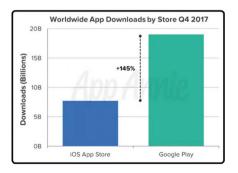


Fig. 2. Number of downloads: IOs vs. Android

2.2 Requirements

Given that the main target audience of this app is the elderly, its design aims to minimize the options for interaction without decreasing the functionality of the app. To achieve this in the design, the following requirements have been taken into account:

- Minimize the number of buttons with which to interact
- Maximize the size of all interaction systems
- Prioritize images and video over text
- No drop-down menus
- All possible links are on screen and not hidden

The development of this type of apps requires the use of a participatory design process with the different end users and stakeholders involved during the problem definition phase [2]. In the AGEment project, some partners work directly with elder people and stakeholders related to health care providers, so they have involved them in the selection process of the above-mentioned design requirements.

According to the objectives of the project and the work carried out to define the generation of content for awareness-raising, these have been organized as follows:

- All contents have been organized in European cultural heritage areas.
- The contents have been multimedia material, mainly videos in which the adults themselves are the protagonists of their experiences and knowledge related to concepts of active aging.
- The contents have been labelled to facilitate their consultation.

3 Results

Based on the identified requirements, the app has been designed for Smartphone devices. Figure 3 shows the app starting screen.



Fig. 3. Starting screen of the app

As can be seen, the interface is very simple and there are no submenus. At the top, in addition to displaying the project logo, it also incorporates a search bar so that users can search the video directly. Then, and according to the contents, the categories corresponding to the cultural areas of the case studies appear. Each category element consists of a representative image and the descriptive title of the category.

When a specific category is accessed, the user will be able to view a list of all the resources in the category (Fig. 4). As in the previous screen, each element shows an image and the title of the video. The user will be able to click on both the frame and the title, being the interaction easier for older people in this way.

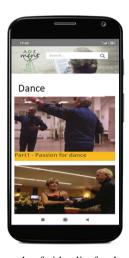


Fig. 4. Example of video list for dance category

Clicking on a specific video, a new window with the video to reproduce and a broader description of the content of the video and related areas of active aging and cultural heritage will be shown to the user (Fig. 5).

When the user wants to play back the video, this will be displayed in full screen. This video will incorporate the playback controls (Fig. 6).



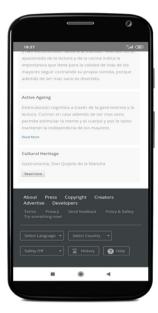


Fig. 5. Screen show the selected video and its description in detail



Fig. 6. Example of full screen video

4 Conclusions

The resulting app is the first one aimed at raise awareness about the importance of active ageing using the cultural heritage for older adults, as well as to incorporate the physical, cognitive and social activities during the daily life contests as a part of ageing well process. Therefore, this result combines current user-centered technologies to provide an innovative tool that allow self-training and delete the existing barriers between the

ICT and the elderly. This developed app will facilitate a progressive learning on ICT skills and will promote digital competences in Adults.

In order to increase the accessibility, acceptance and to facilitate the training communication, the app has been translated from English into the national languages of the consortium partners (Spanish, Italian, Portuguese and Romanian).

This app could serve as basis for include material and content to training another aspect of the active ageing, such as nutrition or security. For this, new practical cases and new videos would have to be created and incorporated in the app.

As future work, a validation of the app has to be performed to evaluate the user-friendliness and the appropriateness of the awareness content.

Due to the barriers of using ICT by very elder people, the app should also be available not only for mobile devices (tablets and smartphones), but also for SmartTV, as older adults can use the technologies with which they are more familiarized using just a remote control.

References

- Sharma, Y., Dak, M.B.K., Acharya, M.N.: Emerging trends in mobile apps market and their potential impact on mobile users engagement in the global economy. Annu. Res. J. SCMS 5, 61–81 (2017)
- Helbostad, J.L., Vereijken, B., Becker, C., Todd, C., Taraldsen, K., Pijnappels, M., Aminian, K., Mellone, S.: Mobile health applications to promote active and healthy ageing. Sensors 17(3), 622 (2017)
- 3. AGEment project. https://agement-project.eu/. Accessed 05 Oct 2020
- 4. https://deviceatlas.com/blog/android-v-ios-market-share. Accessed 05 Oct 2020
- https://elandroidelibre.elespanol.com/2018/01/descargas-google-play-app-store.html. Accessed 05 Oct 2020



TechCare - Training on the Adaptability of Assisted Living Technologies in Home and Community Care

Ruth Dankbar¹(⊠), Georgios Koumanakos², and Eulàlia Hernández Encuentra³

- ¹ Wohlfahrtswerk für Baden-Württemberg, Stuttgart, Germany Ruth.dankbar@wohlfahrtswerk.de
- ² "Frontida Zois" Home Care for Older People, Patras, Greece gkoumanakos@frontidazois.gr
- ³ Psychology and Education Studies, Universitat Oberta de Catalunya, Barcelona, Spain

Abstract. On the one hand we are an ageing society due to the demographic change and on the other hand Assisted Living Technology (ALT) progress rapidly to meet this demand. So that it is expected in the following years to become an abrupt part of the long term care (LTC) services and the care of older people. Under this perspective the digital literacy of the target group (formal/informal caregivers, health care and personal care workers in LTC) is more than essential in the newly shaping, technologically driven, care giving environment. The scope of the three year Erasmus+ project TechCare was to further progress the digital literacy-related knowledge of the direct target group. The digital literacy should go beyond the simple knowledge of the function of ALT's, to the critical adaptation and evaluation of ALT's into the long term care environment according to the specific needs of each beneficiary. In other words: The main objective of the TechCare project was to promote an ethically sound and practically viable adaptation of assisted living technologies in long term care. The project's contribution to this objective was to train carers as evaluators and primary level counsellors upon the ethical and practical challenges that determine the acceptability of assisted living technologies (ALTs) into home and community care.

1 Introduction

In the last decades, under the mounting pressure of demographic ageing, there has been a veritable proliferation of Assisted Living Technologies (ALTs) designed to help older people remain autonomous and have a good quality of life [1]. The concept of Assistive Technology and ICT based solutions can be broadly defined as systems and resources that take a holistic approach towards tracking, monitoring and fostering the overall health, security, safety and quality of life of its users. It can include systems, software, products, devices, practices as well as a combination of any two or more of these to address the needs of its users who have some form of limitations or disabilities [2].

Older people have a huge array of needs and requirements that they face with increasing age. The variation of these requirements relate to age, gender, background, experience, skills, knowledge and so on. Apart from the impact these varying needs and

challenges may have on autonomy and independence, they also limit the abilities of older adults to perform Activities of Daily Living (ADLs) indepently [3]. Given this profound shift in the age distribution of the population and the prognosis for the future, it is inevitable that in Europe the ratio of older people in need of care to active workers will increase [4]. This phenomenon causes problems and challenges for the society since there will not be enough health care workers to support the older [5]. Therefore, technology-based services and Assisted Living Technologies which aim at supporting older people in performing their daily routine tasks and in sustaining their independent living and quality of life in a supported environment are starting to be more important and are therefore on the rise [5, 6]. On the same direction, EU is focusing on the prioritization of home care, and into this domain assisted living technologies can play a substantial part.

Nevertheless seniors, their relatives and caregivers are often still uncertain and skeptical about the various new technologies in older people care. Acceptability of new technologies is a very complex issue entailing several crucial factors that have impact on the final decision on behalf of the patients and their caregivers. The complexity is mainly due to the fact that while new technologies aim to maximize the autonomy, general wellbeing and self-determination of the patients and in parallel to soften the overload the caregivers experience, they may produce some negative effects to other equally important aspects around the personality and the personal requirements of the patients. There is a delicate balance in the form of a trade-off between what technology offers and what it takes that should be considered, under the specific characteristics that constitute a patient's personal and social environment. Subsequently, there is an obvious need, in European societies, the rapid advance of the assisted living technologies to be followed by a corresponding knowledge and patient-centered critical evaluation of the services and applications offered.

Towards the European wide goal of integrated care, patients, caregivers and health-care professionals should be placed at the center of healthcare innovation and policy reforms. This implies supporting people to lead healthy lives and in being engaged in the management of their conditions and risk factors, in adhering to treatments and in having a voice in care decisions [7].

First of all, we have to start with raising awareness on the role and impact of assisted living technologies in older people's care and on having an understanding of what their function and services are.

The lack of awareness of the potential added-value and trust towards ICT-based support solutions requires strategies to raise awareness among all stakeholders—including policy makers, health care professionals, informal caregivers, and care recipients—about support opportunities offered by ICT [8] and ALT's.

At first, care recipients and caregivers should understand the impact new technologies may have in relation to their wellbeing, way of living and ethical integrity. This first approach and critical stance towards assisted living technologies, as a new necessary part in health care and especially in care of older people, is the objective of the TechCare project (http://techcareproject.eu/blog/). The scope of the project is to contribute towards the wider implementation of digital solutions serving towards the so-called "digital transformation" as an essential key to the success of implementation of innovation in health-care systems, at micro-level [9]. In order to obtain that, TechCare focuses on the

ability of formal and informal caregivers to act as practical evaluators and primary level counselors upon the ethical challenges posed by ALT's that determine the acceptability of ALT's into home and community care. Respectively, the TechCare e-learning platform was developed to deal the above issues through the following six modules:

- 1. How can I identify the needs with the older person?
- 2. Search and find available information about ALT.
- 3. What are the ethical issues that emerge from the use and presence of ALTs?
- 4. What is the best solution to meet the needs of a specific older person?
- 5. How and who should introduce an ALT solution?
- 6. The ALT solution that I chose, was it useful and worthy?

The platform (https://techcare.httc.de/course/) provides caregivers with specialist knowledge in order to assess and weigh up ethical, social and legal aspects of new technologies. The course is offered through "blended learning", a combination of face-to-face offers and distant learning but it can also be used completely online.

The course has been developed based on 1. a literature review offering a taxonomy of ICT for home and community care, 2. a list of concerns of patients and caregivers in relation to ALTs as they emerge from specialized social science literature, and 3. Semi-structured interviews conducted by the authors in three different European countries: Germany, Greece, and Spain. The interviews were conducted using an adapted version of the Unified Theory of Acceptance and Use of Technology is (UTAUT2) [10, 11].

2 Methodology

The main innovation of the TechCare training is the focus on the ethical and practical validation of assisted living technologies for home and community care of elderly people that directly affect the quality of life of both the beneficiaries and their formal and informal caregivers, as it is:

- a) The practical parameters that determine the patient's acceptability of ALT's.
- b) The role of the caregiver in this new environment and the smooth cooperation between the caregiver and the ALT's.
- The impact assisted living technologies have on the ethical and social sphere of the beneficiaries, namely - Privacy - Autonomy - Obtrusiveness - Passivity - reliance on automation - Reduction of social interaction.

The second innovation is the development of a flexible pedagogical framework that is needed to underpin e-learning environments in order to ensure that they address effectively the individual learning approaches of the diverse population of formal and informal care giver and social worker in partner countries.

Two consecutive pilot studies were conducted to evaluate the feasibility, usability and usefulness of the e-learning platform as well as to assess the achievement of objectives. These objectives were translated into the following research questions:

1. How many participants enroll and finish the TechCare training? (Adherence)

- 2. Are the modules as well as the e-learning platform feasible? (Feasibility)
- 3. Are the modules as well as the e-learning platform accepted? (Acceptance)
- 4. Is the e-learning platform usable? (Usability)

To answer these questions, the following methodology was chosen and agreed upon by all partners in the Final Methodological Plan. The Methodological Plan contained specific instructions, goals, and deadlines for the pilots. (please, see the website of the project).

Two consecutive pilot studies were conducted in Belgium, Germany, Greece and Spain. Both pilots focused on the modules (content), the TechCare e-learning platform as well as the overall concept (content mediated via e-learning platform). The feedback from the participants in the first pilot was used to adapt the content, the e-learning platform as well as the procedure for the second pilot. Each pilot ran for six weeks. In both pilots, quantitative measures were used through questionnaires. Roughly, the procedure was as follows: 1) Training for the trainers; 2) Recruitment of participants; 3) Introduction for learners; 4) Implementation of the e-learning platform and content for six weeks; 5) Evaluation.

3 Recruitment

As each partner organizations had diverse preconditions (different care systems per country, existing networks, possibilities to reach the target group, focus on formal versus informal carers, etc.), each partner organization was in charge for the recruitment process by itself. Different approaches were chosen. A short overview of the strategies is provided below. Next to the successful recruitment strategies, also problems will be mentioned as the reach of the target group became very difficult.

Belgium: The Belgium partner belongs to the Interdisciplinary Research Group on Law Science Technology & Society at the University and faced some problems to recruit learners from the social care domain which was the original target group of the project. The partner contacted a day care center for people with dementia to involve the care givers but due to lack of time they could not participate. Then he contacted the faculty of health and could involve some experts.

Greece: For the Greek partner there was no particular problem in recruiting the participants. Frontida Zois has a large deposit of collaborating caregivers so addressed to them to participate into the pilots.

Germany: As the German partner is an organization providing all kinds of services they have direct access to formal caregivers. An education center providing VET also is part of the organization. The partners recruited one nursing class (health care professionals in elderly care) per pilot to reach formal carers in training. In order to include even more learners the partner involved Bachelor students from two different Universities studying nursing science, nursing management or social work.

Spain: The Spanish partner organization sent information about the project and an invitation to follow the training to several associations (gerontology and health social work societies, and several health social work student forums). Mainly social workers and informal carers were interested and connected to the platform. Unfortunately not all

completed the course even though they were given all the time they needed to complete it. Some entered the platform and downloaded the material, without doing any activity.

4 Procedures (Training and Implementation)

140 Formal and informal caregivers and social workers from Belgium, Germany, Greece and Spain took part in two consecutive pilot studies. Participants were recruited per country, following different and individual recruitment strategies according to the preconditions of each partner organization. At first two trainers from each partner country attended the common three-days training activity in Greece acquiring information in the TechCare learning methodology and training framework in order to deliver and supervise the pilot programs.

The first pilot study was conducted between January and the middle of March 2020. The second pilot was supposed to start in the Middle of April and end in May 2020. The second pilot faced unsurpassed problems due to the COVID-19 pandemic. In the first pilot all partners except the Spanish used the blended learning methodology. This means the learning material was delivered through a combination of face-to-face and self-directed learning in order to ensure that the learning outcomes depend heavily on learning interaction and sufficient face to- face sessions. As the Spanish partner is a University delivering all courses fully online they used their proofed methods to deliver the TechCare training. After the first pilot the evaluation questionnaires were filled out by the participants. The data were collected by the partners/study coordinators in each country and summarized. Then some changes to the TechCare e-learning platform as well as the training content where made according to the received feedback. Due to the COVID-19 pandemic all partners had to change to distant learning in the second pilot phase.

5 Results

As the objective was to test the feasibility, acceptance, adherence, usability of the training material and the e-learning platform the TechCare training course is evaluated positive in its biggest parts. The e-learning platform is usable and user friendly, the information provided are comprehensible and appropriate for the target group. The platform fully covered the expectations and demands of the learners. The division of the training content into learning units accompanied by specific interactive educational videos, that provided visualization of the training content, assisted learners to comprehend better the educational points, and to be able to produce in the same way their own cases.

Many participants were not familiar with the training content and its narration of new approaches in care combined with the use of new technological applications. This resulted into a restrictive interaction of the participants with the training content. Several contacts between the trainers and the learners were made to help learners match their experiences with the training examples and be able to extract their own conclusions.

For many of the learners the educational content was their first introduction to the function and requirements of the Assisted Living Technologies. For this reason, the training content itself, had to confront the same problems it was developed for, as it is

hesitation towards the unknown, lack of previous familiarization with the issue, fear for the impact that technologies may have on the caregiving tasks. Consequently, the piloting of the training content was the study of the parameters that impact ALT acceptance and at the same time their real time experience. All these factors it seems that in general resulted to a problem of interest in the course. In this sense, during the needs analysis, the caregivers interviewed already seemed to be more interested in the existing ALT catalogue and how to use it in their daily practice, rather than in the ethical issues involved. This is something they see as less useful and inapplicable, especially if, and this is particularly important, neither the care receivers nor their families requested the use of ALTs, let alone were worried about the ethical issues implied in it. But here a question arises: Should we act proactively for when the ALT's will become an irreplaceable reality into home and community care? Should we start to consider this development already?

6 Conclusion

Assisted living technologies are the new reality in older people care and in long term care. Providing to caregivers the opportunity to get to know with these technologies and to learn how to evaluate them in a primary level is very important for improving the performance of their tasks and for lessening their workload without compromising the safety and the quality of life of the beneficiary.

The conclusion deriving from the TechCare project's pilots is that the caregivers regard yet as distant or - when the time comes – as complementary the incorporation of assisted living technologies into home and community care. Apparently, this estimation relates to their limited experience on the field, not to mention their probable self-fulfilling perception.

Another valuable conclusion that came out from TechCare project is that the introduction of formal and informal caregivers into assisted living technologies and ICT should focus at first into their digital health literacy. Even though the ability to search and do the right selection of new technologies was in details analyzed in TechCare, the digital literacy in terms of getting to know what the purpose of the equipment is and how it works should be a training priority.

That is why the consortium of TechCare already works on the components of such a digital health literacy training that will come up hopefully as TechCare 2.

Nevertheless, one of the major issues nowadays is the integration of care, meaning the connection and collaboration of the different care levels and different health provision stakeholders. Assisted living technologies is an essential part of it, as they can increase the efficiency of the health and social care systems and respond to a series of pending problems related to the lack of caregiving workforce and the avoidance of hospitalization. TechCare by training caregivers to act as agents for the successful and acceptable implementation of assisted living technologies into home and community care, seeks above all to ensure the empowerment of the patients and of their caregivers.

Above all, digital innovations and assisted living technologies, should meet the needs and expectations of health-care professionals, patients, and carers, respecting the importance of human contact, not replacing it but complementing it, notably in terms of quality and personalization [12].

For the participating organizations, regarding the care provision organizations, it was presented the opportunity to update the knowledge deposit of their personnel aiming to incorporate new services into the ones already provided.

For the Academic Institutions, TechCare presented an excellent opportunity for the involved experts to search the impact of new technologies in elderly care environments and to prepare the ground for further research and publications on the field.

Furthermore, it is essential to develop a communication channel between the assisted living manufacturers and the care providers, and TechCare project can empower the critical abilities of the care providers towards better and more individualized devices [13].

References

- Schultz, T., et al.: Technische Unterstützung für Menschen mit Demenz Ein Überblick (2014). Available via Researchgate. https://www.researchgate.net/profile/Nora_Weinberger/ publication/271833785_Chapter_1/links/54d3368b0cf250179181aef8.pdf. Accessed 26 Nov 2020
- 2. Kon, B., Lam, A., Chan, J.: Evolution of smart homes for the elderly. In: Proceedings of the 2017 International World Wide Web Conference Committee (IW3C2), Perth, Australia, pp. 1095–1101 (2017)
- 3. Thakur, N., Han, Ch.: A review of assistive technologies for activities of daily living of elderly. In: Eckstein, S.M. (ed.) Elderly Care: Current Issues and Challenges, pp. 61–84. Nova Publishers, Inc., New York (2020)
- Spasova, S., Baeten, R., Coster, S., Ghailani, D., Peña-Casas, R., Vanhercke, B.: Challenges in long-term care in Europe. A study of national policies, European Social Policy Network (ESPN). European Commission, Brussels (2018)
- 5. Weegh, H., Kampel, M.: Acceptance criteria of ambient assistant living technologies. Stud. Health Technol. Inform. **217**, 857–864 (2015)
- Christophorou, C., Kleanthous, S., Georgiadis, D., et al.: ICT services for active ageing and independent living: identification and assessment. Health Technol. Lett. 3(3), 159–164 (2016)
- 7. Second European Summit on Innovation for Active and Healthy Ageing Blueprint Digital Transformation of Health and Care for the Ageing Society, p. 4, 5–8 December 2016
- 8. Hassan, A.Y.I.: Challenges and recommendations for the deployment of information and communication technology solutions for informal caregivers: scoping review. JMIR Aging **3**(2), (2020)
- 9. Kardas, P.: Europe opens a new era in digital revolution: the blueprint on digital transformation of health and care for aging society has been launched. Digit. Med. 3, 6–10 (2017)
- Venkatesh, V., Thong, J., Xu, X.: Consumer acceptance and use of information technology: extending the unified theory of acceptance and use of technology. MIS Q. 36(1), 157–178 (2012)
- Hernández Encuentra, E., et al.: Perceptions and needs with regards to technologies for professional practice. A prospective qualitative study among caregivers in Spain. In: García-Alonso, J., Fonseca, C. (eds.) 1st International Workshop on Gerontechnology, IWoG 2018, vol. 1016, pp. 48–61. Springer (2019). ISBN 978-3-030-16027-2
- Chapman, S., Miller, J., Spetz, J.: The Impact of Emerging Technologies on Long-Term Care and the Health Workforce. UCSF Health Workforce Research Center on Long-Term Care, San Francisco, CA (2019)
- 13. TechCare Consortium: Pilot Summary Report. TechCare Erasmus+ project, Stuttgart (2020)

Solutions for Active Aging, Social Integration and Self-care



Promotion of Functional Independence in the Self-care Deficit of the Elderly Person with Orthopedic Disease and Technology

Anabela Silva¹, Susana Silva¹, César Fonseca², José Garcia-Alonso³, Manuel Lopes², Inês Cardoso², and Lara Guedes de Pinho²,

 Portalegre School of Health, Portalegre, Portugal
 University of Évora, Comprehensive Health Research Center, POCTEP 0499_4IE_PLUS_4_E, Évora, Portugal
 University of Extremadura, POCTEP 0499_4IE_PLUS_4_E, Cáceres, Spain

Abstract. Functional disability can arise at any time in the life cycle of the elderly person, impairing autonomy and independence in their daily life activities. Making early intervention by the Rehabilitation Nursing Specialist (RNS) essential to maximize independence in self-care and improve quality of life through physical and emotional recovery, with verification of health gains. Objective: Acquire RNS skills through an intervention program for people with orthopedic disease with self-care deficit and demonstrate health gains. Methodology: Training of functional activities in elderly people with orthopedic disease, with intervention based on the Yin Case Studies (2018), Orem's Self-Care Nursing Deficit Theory (SNDT), Lopes Mid-Range Theory (2006), through the ENCS instruments and Barthel Index. Results: Health gains in functionality with decrease in self-care deficit. Conclusion: Acquisition of RNS skills by providing specialized care to the person with orthopedic disease, improving the capacity of functional and self-care activities, promoting autonomy and quality of life.

Keywords: Person · Nurse specialist in rehabilitation nursing · Self-care

1 Introduction

Health is defined as a condition we face at the moment, from which we do not suffer from pathologies, deficits, inaptitudes or needs [1], but in a sudden and unforeseen way, the state of acute illness appears, generally transitory, which interrupts sometimes severely the normal way of life, and there is no time to adapt to new conditions [2].

The orthopedic service welcomes people of different ages, victims of accidents with bone fractures and traumatic injuries, not only affecting the bone structure, but also the structures surrounding it, causing injury to the surrounding soft tissues, hemorrhages, joint effusions, hemarthrosis, dislocations and muscle ruptures [3], causing immobility, pain, functional limitation and anxiety.

Autonomy in daily life activities is vital, regardless of a person's age [4] where early recovery is consistent with the prevention of hospital infections, joint stiffness, decreased

muscle strength, promoting a return to family, social and professional environments, and active reintegration into society. This makes early RNS intervention, in this area, important for the reduction of dependency, length of stay, and complications, evidencing gains in health and quality of life [5].

This work aims at the acquisition of RNS skills, through an intervention program for people with orthopedic problems of a traumatic nature, for whom it is necessary to create appropriate strategies for training self-care [6] and functionality [7] to return to active life.

RNS being responsible for generating, executing and supervising specific patient rehabilitation plans, based on possible and current problems of the people, based on Orem's theory of self-care, in the sense of developing capacities of adaptation in the processes of evolution between health and disease promoting self-control and self-care in the person [8].

SNDT consists in helping the person, until he/she is able to help himself/herself, giving him/her the necessary skills and knowledge to be able to take care of him/herself, being the self-care, a set of activities that promote the progress and maturity of the person in a certain period of time, with the objective of maintaining and preserving life [9].

RNS provides care to minimize the effects of the self-care deficit [7], but it is important to emphasize that the relationship nurse-doctor, through trust, proximity and availability [10], is an important step towards the success of this same intervention.

2 Methodology

Three case studies were carried out, through the approach to the method of [11] based on sources of evidence, direct observation, interview, based on documents, allowing to maintain in a holistic way the particularities of the real events, in the life cycle of each individual [11]. Based on the middle range theory [12], based on a therapeutic relational intervention between nurse-patients, supported by diagnostic evaluation and therapeutic intervention, based on strategies such as interviewing the sick person, the family and data collection[12].

The main tool used for data collection was the Elderly Nursing Core Set [13], based on the International Classification of Functionality (ICF) which evaluates the disability of the person or population according to the health context [14, 15], using a unique, standardized language, describing health and the conditions associated with it, through a conceptual arrangement of information extensible to personal health care, in which the needs of nursing care are defined [16].

The selection criteria in the person with orthopedic disease were highlighted, focusing on traumatic orthopedic situations, including 3 people (A1, A2, A3) admitted to the orthopedic service, of working age and integrated into professional life, manifesting changes in mobility caused by traumatic injuries, subject to surgical intervention. This is identified by letters and numbers to hide their identity, protecting their intimacy and confidentiality [17].

This being an intentional and rational selection sampling, because the members of the population are chosen due to the relationship between them and the purposes of the study [18], not probabilistic, and representative by the various variables [19]. The characteristics of the participants of this study are presented in Table 1.

| Case study | A1 | A2 | A3 |
|-------------------|---------------------------|-------------------|----------------------|
| Age | 68 | 60 | 58 |
| Gender | Male | Female | Female |
| Nationality | Portuguese | Portuguese | Portuguese |
| Marital status | Married | Married | Married |
| Family attaché | Wife and child | Husband and son | Husband and two sons |
| Level of eduation | 9th year of school | Teaching degree | Teaching degree |
| Profession | Building and construction | 1st cycle teacher | 2nd cycle teacher |

Table 1. Sociodemographic characterization of study participants.

The mean age of study participants is 48.60 years with a standard deviation of 8.21 years of age. It is verified that 66.66% of the population is female and with higher academic level, and in general in professional working age.

Strategies were developed that initiated the Diagnostic Assessment Process through the medium range methodology [12], with consultation of the clinical process in a computer system, approaching the person through interview and observation, evaluating knowledge, disabilities, motivations, potentialities and objectives following the therapeutic intervention for recovery and rehabilitation. The first moment of evaluation related to the diagnostic evaluation occurred in the first uprising after the surgical intervention, the second moment is materialized on the day of discharge, after the therapeutic intervention of RNS.

3 Plan of Intervention

A rehabilitation program, helps adaptation to a new condition and improvement of the quality of life [20], which reinforces these cares, as an area specialized in maintenance, promoting comfort and quality throughout the life cycle, preventing complications, disabilities caused by illness or accident, based on decision making for the design of intervention plans in various areas including motor training and self-care [21]. This plan was adapted to functional limitations and comorbidities [22], according to people's needs, as well as personal preferences, environment and resources, and is described in Table 2.

 Table 2. Motor functional rehabilitation intervention plan.

| Indicators of results | Objectives | Interventions | Expected results |
|------------------------|---|---|---|
| Knowledge about people | - To know the expectations of the person, taking into account their personal goals and health project [8] - Assess functional capacity to obtain necessary information and be able to plan interventions [23] | - Provide a calm and welcoming environment [24] - To evaluate the person through subjective and objective examination [25] and to collect pertinent information [8] in observation and interview - To use scales and measurement instruments8, such as the ENCS [26], Barthel Index [27], to verify physical and motor capacity [28] - Prepare registration documents, field notes [12] and Clinical record - Implementation and evaluation of an intervention plan with the use of evaluation instruments according to the diagnoses identified [30] | - Selection of a program adapted to the needs of each person [28, 29] - The person must feel, encouraged and accompanied [30], from the beginning to the end of the program |
| Training for self-care | - To enable the functioning of the self-care, helping the family in the management of the disease, allowing to enhance the autonomy and well-being [7] | - Assess potential for rebuilding autonomy: - Encourage self-care [30]; - Promote awareness and autonomy to perform tasks that allow independence at home [28] - Enhance respiratory control through the dissociation of breathing times and diaphragmatic breathing, relaxation techniques and rest positions [32] | - Improvement in quality of life [22, 29, 31, 33, 34] |

(continued)

 Table 2. (continued)

| Indicators of results | Objectives | Interventions | Expected results |
|--|---|--|---|
| Increased physical capacity in muscle and joint movement | - Prevent muscle contractures, activate circulation, vascular dynamics; avoid pain, joint injuries, maintaining tone, strength and function [23] - To enable the increase of strength, muscle tone, maintaining an adequate level of muscle strength for safe walking, transference, up and down stairs safely [36] | - To perform early mobilizations in all joint segments still in bed, isometric and isotonic exercises with passive and active mobilizations assisted in the operated limb and active exercises with the contralateral limb [35, 37] - Isometrics applied to the abdominal muscles, buttocks and quadriceps, extension of the popliteal region against the mattress surface, and use of a reduced volume roller, for 4 s, 2 series of 10 repetitions [38] - Isotonic with free active exercises, assisted, resisted from unaffected limbs; assisted non-resisted active in the operated limb (without load) according to the tolerance, at the level of the hip joint perform flexion, extension, abduction, knee extension and flexion, tibiotarsis, flexion and extension, 2 series of 10 repetitions [38] - Therapeutic activities: rolling; bridge and elbow loading [39] | -To prevent the reduction of joint amplitude and complications associated with inactivity and prolonged bed rest [40] |
| Functional state improvement in body balance | - Increase volume and muscle strength, physical resistance, improve body balance [41] | - Train balance [41] assess blood pressure and heart rate to maintain clinical safety [42], put on elastic stockings - To assist in the promotion of static and dynamic balance sitting in bed [39] and to encourage orthostatic balance training, dynamic, static with support from the walker, twice a day, in the raising and return to bed [43] | - Body awareness, correct posture, maintenance of balance [44], preventing and correcting postural defects [45] |

(continued)

 Table 2. (continued)

| Indicators of results | Objectives | Interventions | Expected results |
|--|---|--|--|
| Functional state improvement in transfers | - Training for safe transfer techniques and gait training [46] | Assist in the transfer to an armchair, with no load on the affected member: - Maintain a safe environment, with an armchair next to the bed, with the wheels locked - Person sitting on the bed, with feet resting on the ground; closed and adherent shoes - Instruct to transfer with device (walker), to chair - Use the same technique to transfer to the bed [46] | - Training to walk [47] |
| Functional state improvement in gait with gait aid | - To be able to walk with a walking aid, to promote locomotion autonomy [47] | - Encourage, assist, train to walk with walking aid, selected according to needs45: - Walking for greater stability [46] (Cases A2 and A3); - Maintain body alignment; - Moving forward with walker, moving forward with the affected lower limb (no load), and then with the healthy lower limb, walking a distance of 6 m (do not exceed the base of the walker while walking); - Advance with the 2 axillary support crutches (Case A1), transferring to them the weight of the body, with a 3 point walk, walk 10 m; - Descend and ascend scales; - Climbing stairs (2 repetitions), advance first with the unaffected limb, followed by the crutches and finally the affected limb; - Going down stairs (2 repetitions), moving forward with the axillary crutches, then with the affected limb and then the unaffected limb [46] | - Reduce the load on intervened structures, improve the balance and reduce pain [46] - Improvement in physical resistance and functional capacity [48] |

(continued)

| Indicators of results | Objectives | Interventions | Expected results |
|-----------------------|---|--|--|
| Evaluation | - Quantify [25], and monitor health gains, produce sensitive indicators aiming at continuous quality improvement in health [21] | - Evaluate results at the beginning and end of the program [25], identify physiological adaptations [28] | - Confer significant gains in health [49], mobility and self-confidence [41], self-care and self-management [7] |

 Table 2. (continued)

Considering also the safety, pain, tiredness, intensity and rhythm of the exercises, it is necessary to plan periods of rest with the person, in order to be able to perform the activities when the person presents more energy [23], and thus obtain gains and progress in the exercises. Once the intervention plan has been defined, the analysis of the gains in terms of functionality and self-care, as a result of RN care, is highlighted.

4 Results and Discussion

The moment of individual presentation of each case study [11] has arrived, it is not only based on the description, it forms hypotheses based on the data obtained [18], derived from the facts observed during the data collection, are analyzed and presented, allowing the logical connection with the object under study and the proposed problem [18]. The evaluation of the gains obtained after the RNS intervention are described in Table 3.

All cases, in general, obtained visible gains. In the analysis of the data, it can be seen that the case study A1 distinguished itself in the global score of the functional with 14.00% of gains, compared to A2 and A3, obtaining in the globality 9.00% of score after intervention. But it was at the level of the self-care parameter that the gains were more evident, reaching in general 19%. The learning and memory functions presented the most significant value in case A1, with 8.00%, noting that A3 shows no deficit in this parameter.

There are still no problems in terms of communication and relationship with caregivers.

Regarding the Barthel Index, gains of 31.6 score were achieved after intervention, where all cases evolved from a severe to moderate dependence.

Functional gains were also observed regarding the ability to walk with a walking aid with the objective of autonomy in locomotion [47]. In the A1 study, tolerance in a 30 m walk with axillary crutches, as well as up and down stairs [46] in 2 series and 4 repetitions, the A2 case presented an evolution from walker to ergonomic crutches tolerating the distance of 10 m, while the A3 person was able to walk 10 m and transfer to a chair. Briefly, at the level of training for AVD [50], we verified gains in transfers

| Cases | Evaluation | Global functionality score | Self-care | Learning and memory functions | Communication | Relationship with friends and caretakers | Barthel index |
|--------|----------------|----------------------------------|-----------|-------------------------------|---------------|---|------------------|
| A1 | Initial | 21.00% | 44.00% | 8.00% | 0.00% | 0.00% | 30 |
| | Final | 7.00% | 17.00% | 0.00% | 0.00% | 0.00% | 70 |
| | Gains | 14.00% | 27.00% | 8.00% | 0.00% | 0.00% | 40 |
| A2 | Initial | 15.00% | 35.00% | 4.00% | 0.00% | 0.00% | 50 |
| | Final | 7.00% | 17.00% | 0.00% | 0.00% | 0.00% | 75 |
| | Gains | 8.00% | 18.00% | 4.00% | 0.00% | 0.00% | 25 |
| A3 | Initial | 12.00% | 31.00% | 0.00% | 0.00% | 0.00% | 40 |
| | Final | 7.00% | 19.00% | 0.00% | 0.00% | 0.00% | 70 |
| | Gains | 5.00% | 12.00% | 0.00% | 0.00% | 0.00% | 30 |
| Averag | ge Gain ore | 9.00% | 19.00% | 6.00% | 0.00% | 0.00% | 31.6 |

Table 3. Evaluation of gains according to the ENCS scale

and mobility in studies A1, A2, A3, going up and down stairs and eating in person A1, as well as bathing also in A1 and A2 and use of toilet in studies A1, A2, A3. It should also be noted the early discharge in these people, as a result of the RNS intervention, which after this enabled them to adapt at home.

5 Conclusion

According to the results verified in this work, the importance of the Rehabilitation Nursing in an orthopedic service is affirmed, besides the visible gains in the use of the ENCS, the number of days of hospitalization was reduced, after the application of the intervention plan. In these case studies, the advantages of early lifting and mobilization after surgery were verified, being fundamental to restore a set of organic changes incited by inactivity in the bed [46].

The importance of applying a methodical and organized register, with the purpose of providing health professionals with a tool for collecting information that can measure the gains in functionality, is demonstrated [51].

Being the responsibility of the RNS, to evaluate the impact of the change in functional capacity on the quality of life and comfort of the person in all phases of the life cycle, with emphasis on functionality and independence in various contexts It is essential, to enable the person with disability or with limitation of their activity and/or restriction of participation for reinsertion and exercise of citizenship [8], the early recovery of the person of working age, becomes important to be able to return to society and social life, avoiding complications such as depression, anxiety and disabilities, being these people in most cases the source of family income.

It is verified that the sensible gains as a result of the RN care, demonstrate improvement in the quality standards and excellence of care in the various contexts of practice, recognizing this specialty as a reference for prevention and recovery of the person [21]. Being profitable in the future new studies in this field to demonstrate the importance of RNS, in other contexts of practice and in its ability to recover and/or adapt the different areas of functionality in the person with disabilities.

Faced with this context, it was possible to acquire RNS skills by planning interventions, based on functionality, promoting education, setting goals and commitment, walking the path of rehabilitation alongside the person, providing them with capabilities and tools to maximize their functionality.

References

- Honoré, B.: A saúde em projecto. Lusociência-Edições técnicas e científicas, Lda, Loures (2002)
- Roper, N., Logan, W., Thierney, A.: Modelo de Enfermagem (3rd Edição). McGraw-Hill, Alfragide, Portugal (1995)
- 3. Cunha, E.L.: Enfermagem em Ortopedia. Lidel, Edições (2008)
- Nascimento, V., Fonseca, C., Ferreira, R., Lopes, M., Moguel, E.: Structured Proposal for Rehabilitation Nursing (RN) Care Intervention: Sensitive Gains to RN Care for the Person with Self-care Deficit and in the Surgical Process. In: García-Alonso, J., Fonseca, C. (eds.) Gerontechnology. IWoG 2019. Communications in Computer and Information Science, vol. 1185. Springer, Cham. https://doi.org/10.1007/978-3-030-41494-8_27
- Soares, M., Ribeiro, S., Fonseca, C., e Santos, V.: Ganhos sensíveis dos cuidados de Enfermagem de Reabilitação nas Pessoas Idosas com alteração da mobilidade. J. Aging Innov. 7(2), 159–176 (2018)
- 6. Braga, A., Silva, E.: Peplau X Orem: interação e autocuidado como estratégia da assistência de enfermagem. Rev. Univ. **08** (1), 08–11 (2017). http://editora.universidadedevassouras.edu. br/index.php/RPU/article/view/690
- 7. Gautério, D.P., et al.: Risk factors for new accidental falls in elderly patients at traumatology ambula-tory center. Invest. Educ. Enfermeria 33(1), 35–43 (2015)
- Regulamento nº 392/2019 de 3 de maio.: Regulamento das competências específicas do enfermeiro especialista em Enfermagem de Reabilitação. Diário da República, 2ª série, n.º 85, 13565–13568 (2019). https://dre.pt/web/guest/pesquisa/-/search/122216893/details/ normal?l=1
- 9. Tomey, A., Alligood, M.: Teóricas de Enfermagem e sua Obra: Modelos e Teorias de Enfermagem (5ª edição). Lusociência, Loures, Portugal (2004)
- Lopes, M.: Os clientes e os enfermeiros: construção de uma relação. Revista da escola de enfermagem da Universidade de São Paulo 39(2), 220–228 (2005). http://www.ee.usp.br/ree usp/upload/pdf/33.pdf
- 11. Yin, R.: Case Study Research and Applications: Design and Methods, 6th edn. Sage Publications, Inc, Los Angels, United States of America (2018)
- Lopes, M.: A relação Enfermeiro-Doente como intervenção terapêutica. Formasau, Coimbra, Portugal (2006)
- Moguel, E., et al.: Enriched elderly virtual profiles by means of a multidimensional integrated assessment platform. Proc. Comput. Sci. (2018). https://doi.org/10.1016/j.procs.2018.10.009
- 14. Reis, F., Pereira, C., Escoval, A., Reis, F.: Contributo para a classificação da funcionalidade dos utentes da Rede Nacional de Cuidados Continuados Integrados segundo a Classificação Internacional de Funcionalidade. Revista Portuguesa de Saúde Pública, 33 (1), 84–97 (2015). https://doi.org/10.1016/j.rpsp.2014.02.004

- 15. Goes, M., Lopes, M.J., Oliveira, H., Fonseca, C., Marôco, J.: A nursing care intervention model for elderly people to ascertain general profiles of functionality and self care needs. Sci. Rep. **10**(1), 1–11 (2020)
- 16. Organização Mundial da Saúde: CIF: Classificação Internacional da Funcionalidade, Incapacidade e Saúde. Lisboa, Portugal: Direção Geral de Saúde (2004). https://www.dgs.pt/estatisticas-de-saude/documentos-para-download/classificacao-internacional-de-funcional idade-incapacidade-e-saude-cif.aspx
- 17. Nunes, L.: Considerações éticas a atender nos trabalhos de investigação académica de enfermagem. Departamento de Enfermagem ESSIIPS, Setúbal, Portugal (2013)
- 18. Freixo, M.J.V.: Metodologia Científica: Fundamentos Métodos e Técnicas, 4th edn. Instituto Piaget, Lisboa, Portugal (2012)
- Fortin, M.: Fundamentos e etapas de processo de investigação. Lusodidata, Loures, Lisboa (2009)
- Ettinger, L., Soares, M., Vaez, A., Araújo, D., Pinheiro, F., Sousa, D.: Qualidade de vida das vítimas de trauma raquimedular atendidas em centros de reabilitação de aracaju. Interfaces Científicas. Saúde e Ambiente 5(2), 53–62 (2017). https://doi.org/10.17564/2316-3798.201 7v5n2p53-62
- 21. Ordem dos Enfermeiros.: Assembleia do colégio da especialidade de Enfermagem de Reabilitação: Padrões de Qualidade Especializados em Enfermagem de Reabilitação. Colégio da Especialidade de Enfermagem de Reabilitação. Lisboa, Portugal: Colégio da Especialidade de Enfermagem de Reabilitação (2018). https://www.ordemenfermeiros.pt/media/8141/ponto-4_regulamento-dos-padr%C3%B5es-qualidade-ceer.pdf
- Luk, E., Hutchinson, A., Tacey, M., Irving, L., Khan, F.: COPD: health care utilisation patterns with different disease management interventions. Lung 195(4), 455–461 (2017). https://doi.org/10.1007/s00408-017-0010-9
- Hoeman, S.: Enfermagem de Reabilitação: Prevenção, Intervenção e Resultados Esperados,
 4ª edn. Lusodidacta, Loures, Portugal (2011)
- Cordeiro, M., Menoita, E.: Manual de boas práticas na reabilitação respiratória, 1ª edição. Lusociencia, Loures, Portugal (2012)
- 25. Marques, A., Figueiredo, D., Jácome, C., Cruz, J.: Doença Pulmonar Obstrutiva Crónica (DPOC). E agora?: Orientações para um programa de reabilitação respiratória, 1ª edição. Lusodidata, Loures, Portugal (2016)
- Lopes, M., Fonseca, C.: Elderly core set: short form-manual & instrumento. Universidade de Évora, Évora, Portugal (2018)
- Mahoney, F., Barthel, D.W.: Functional evaluation: the barthel index: a simple index of independence useful in scoring improvement in the rehabilitation of the chronically ill. Maryland State Med. J. 14, 56–61 (1965). https://www.semanticscholar.org/paper/Functional-evaluation%3A-The-Barthel-Index%3A-A-simple-Mahoney-Barthel/c71fe40c867d7e7046e2b655cf70e12eedaac8b3
- Accioly, M., Patrizzi, L., Pinheiro, P., Bertoncello, D., Walsh, I.: Exercícios físicos, mobilidade funcional, equilíbrio, capacidade funcional e quedas em idosos. ConScientiae Saúde 15(3), 378–384 (2016). https://doi.org/10.5585/conssaude.v15n3.6338
- 29. Lee, E., Kim, M.: Meta-analysis of the effect of a pulmonary rehabilitation program on respiratory muscle strength in patients with chronic obstructive pulmonary disease. Asian Nurs. Res. **13**, 1–10 (2019). https://doi.org/10.1016/j.anr.2018.11.005
- Vieira, J.V., Fonseca, C.: Rehabilitation nursing in the elderly with mobility deficit due to fracture of the femur. In: Gerontechnology: Second International Workshop, IWoG 2019, Cáceres, Revised Selected Papers, vol. 1185, p. 292. Springer Nature (2020)

- 31. Khoshkesht, S., Zakerimoghadam, M., Ghiyasvandian, S., Kazemnejad, A., Hashemian, M.: The effect of home-based pulmonary rehabilitation on self-efficacy in chronic obstructive pulmonary disease patients. J. Pak. Med. Assoc. **10**(65), 1041–1046 (2015). http://search.ebscohost.com/login.aspx?direct=true&db=mdc&AN=26440829&lang=pt-pt&site=ehost-live
- 32. Cerqueira, A., Grilo, E.: Prevenção das consequências da imobilidade na pessoa em situação crítica. Revista Portuguesa de Enfermagem de Reabilitação, pp. 78–89 (2019). https://doi.org/10.33194/rper.2019.v2.n1.10.4574
- 33. McCarthy, B., Casey, D., Devane, D., Murphy, K., Murphy, E., Lacasse, Y.: Pulmonary rehabilitation for chronic obstructive pulmonar disease (Review). Cochrane Database of Systematic Reviews. Wiley (2015). https://doi.org/10.1002/14651858.cd003793.pub3
- Neves, L., Reis, M., Gonçalves, T.: Home or community-based pulmonary rehabilitation for individuals with chronic obstructive pulmonary disease: a systematic review and metaanalysis. Caderno de Saúde Pública, Rio de Janeiro 32(6), 1–25 (2016). https://doi.org/10. 1590/0102-311x00085915
- 35. Xu, J., He, S., Han, Y., Pan J., Cao, L.: Effects of modified pulmonary rehabilitation on patients with moderate to severe chronic obstructive pulmonary disease: a randomized controlled trail. Int. J. Nurs. Sci. 4, 219–224 (2017). https://doi.org/10.1016/j.ijnss.2017.06.011
- 36. Preto, L., Gomes, J., Novo, A., Mendes, M., Granero-Molina, J.: Efeitos de um Programa de Enfermagem de Reabilitação na Aptidão Funcional de Idosos Institucionalizados. Revista de Enfermagem Referência, **4**(8), 55–63 (2016). https://doi.org/10.12707/riv15019
- 37. Santos, M.: Prótese total da anca: efetividade e um programa de reabilitação. (Tese de Mestrado em Enfermagem). Escola Superior de Saúde de Viseu. Viseu, Portugal (2019). http://repositorio.ipv.pt/handle/10400.19/5455
- 38. Sousa, L., Carvalho, M.L.: Pessoa com osteoartrose na anca e joelho em contexto de internamento e ortopedia. In: Marques-Vieira e Sousa, 1ª edição, Cuidados de Enfermagem de Reabilitação à Pessoa ao longo da vida, pp. 405–420. Lusodidacta, Loures, Portugal (2016)
- 39. Menoita, E., Sousa, L., Pão-Alvo, I., Vieira, M.: Reabilitar a pessoa idosa com AVC: Contributos para um envelhecer resiliente. Lusociencia, Loures, Portugal (2012)
- Vieira, J., Ferreira, R.: Mobilização precoce da pessoa submetida a ventilação mecânica invasiva. Revista Ibero-Americana De Saúde E Envelhecimento 4(2), 1388–1399 (2018). https://doi.org/10.24902/r.riase.2018.4(2).1388
- 41. Porto Gautério, D., Zortea, B., Costa Santos, S.S., da Silva Tarouco, B., Lopes, M.J., João Fonseca, C.: Risk Factors for new accidental falls in elderly patients at traumatology ambulatory center. Investigación y educación en enfermería **33**(1), 35–43 (2015)
- 42. Correia, C., Barbosa, L., Rebelo, L., Alves, M., Pinho, N., Magalhães, B.: O treino propriocetivo e de equilíbrio postural no idoso para a prevenção de quedas: scoping review. Revista Portuguesa de Enfermagem de Reabilitação, 66–77 (2019). https://doi.org/10.33194/rper.2019.v2.n1.09.4573
- 43. Delgado, B., Lopes, I., Mendes, E., Leonel Preto, L., Gomes, B., Novo, A.: Modulação cardíaca pelo exercício físico na pessoa com insuficiência cardíaca descompensada relato de caso. Revista Portuguesa de Enfermagem de Reabilitação, 64–73 (2019). https://doi.org/10.33194/rper.2019.v2.n2.02.4583
- 44. Rosa, M.: Capacitação da pessoa com alteração da mobilidade, para a autonomia no autocuidado em transferir-se. (Tese de Mestrado em Enfermagem). Escola Superior de Saúde de Évora. Évora, Portugal (2018). http://dspace.uevora.pt/rdpc/handle/10174/23435
- 45. Vieira, C., Sousa, L., Braga, R.: Reabilitar a pessoa com Acidente Vascular Cerebral. In: Marques-Vieira e Sousa, 1ª edição, Cuidados de Enfermagem de Reabilitação à Pessoa ao longo da vida, pp. 465–474. Lusodidacta, Loures, Lisboa (2016)
- Branco, P., Barata, S., Barbosa, J., Cantista, M., Lima, A., Maia, J.: Temas de Reabilitação
 Reabilitação Respiratórias. Porto, Portugal: Medesign (2012). http://repositorio.chlc.min-saude.pt/handle/10400.17/765

- 47. Ordem dos Enfermeiros: Guia orientador de boas práticas: Cuidados à pessoa com alterações de mobilidade, posicionamentos, transferências e treino de deambulação. Série 1, nº 7. Edição: Ordem dos Enfermeiros (2013). https://www.ordemenfermeiros.pt/arquivo/publicacoes/Doc uments/GOBP Mobilidade VF site.pdf
- 48. Vieira, C., Caldas, A.: A relevância do Andar: Reabilitar a pessoa com andar comprometido. In: Vieira e Sousa, 1ª edição, Cuidados de enfermagem de reabilitação à pessoa ao longo da vida, pp. 547–557. Lusodidacta, Loures, Portugal (2016)
- 49. Cochrane, B., Foster, J., Boyd, R., Atlantis, E.: Implementation challenges in delivering teambased care ('TEAMcare') for patients with chronic obstructive pulmonary disease in a public hospital setting: a mixed methods approach. BMC Health Serv. Res. 16, 2–11 (2016). https://doi.org/10.1186/s12913-016-1592-2
- Murphy, L., Harrington, P., Taylor, S., Teljeur C., Smith, S., Pinnock, H., Ryan, M.: Clinical-effectiveness of self-management interventions in chronic obstructive pulmonary disease: an overview of reviews. SAGE Publ. 14(3), 276–288 (2017). https://doi.org/10.1177/147997231 6687208
- 51. Billinger, S., et al.: American heart association stroke council, council on cardiovascular and stroke nursing, council on lifestyle and cardiometabolic health, council on epidemiology and prevention e council on clinical cardiology. Phys. Act. Exerc. Recommendations for Stroke Surv.: a Statement Healthcare Prof. Am. Heart Assoc./Am. Stroke Assoc. Stroke 45(8), 2532–2553 (2014). https://doi.org/10.1161/str.00000000000000022



Rehabilitation Nursing Technology Intervention Gains Based on the Model of Self-care, in the Elderly Person with a Proximal Femoral Fracture

Ana Brandão¹, Elisabete Lopes¹, Liliana Barbas¹(⋈), César Fonseca², José Garcia-Alonso³, Lara Guedes de Pinho², and Manuel Lopes²

¹ Santarém District Hospital, Santarém, Portugal Comprehensive Health Research Center, POCTEP 0499 4IE PLUS 4 E. University of Évora, Évora, Portugal ³ POCTEP 0499 4IE PLUS_4_E, University of Extremadura, Cáceres, Spain

Abstract. Objective: Identify the Rehabilitation Nursing intervention gains based on the model of self-care in people with a Proximal Femur Fracture. **Methodology:** Descriptive and exploratory study, using Robert Yin's qualitative case study methodology. The Elderly Nursing Core Set (ENCS) was used as a data collection and diagnostic tool; and Fonseca's Self Care Model (2013) was used as an orientation for intervention. **Results:** There was an increase in the gains in the general functionality of patients after the intervention of the Rehabilitation Nurse. Conclusions: The evaluation of the functionality through the ENCS and the systematization of the care through the Self-Care Model allowed the development of an intervention plan, which by taking into account different dimensions, ensured the obtaining of sensible gains of the care of Rehabilitation Nursing. Professional practice implications: Since the patients needed to continue the rehabilitation program at home, teachings were made to the informal caregiver in order to empower him/her.

Keywords: Nursing · Rehabilitation · Self-care · Proximal femur fracture · Informal caregiver

Introduction

Proximal femur fracture is one of the most frequent health problems in the elderly, given the risk factors that this age group presents. It is also one of the major causes of dependence. Patients with proximal femur fracture have an estimated mortality rate between 20–30% in the year following the fracture event and only 15% of these patients recover their previous functional capacity, and it is estimated that about 40% remain with a type of severe disability [1, 2].

When the person is in a situation of dependence and does not have the capacity to take care of himself/herself, the need arises for another person to take care of him/herself,

with the nurse and the family playing a fundamental role in this. Self-care is a human regulatory function that people deliberately perform for themselves or that someone else performs for them, in order to preserve life, health, development and well-being, according to the Orem's Self Care Theory [3].

The Fonseca Self Care Model [4], which serves as the basis for the intervention plan of this study, has as essential components the Orem's Self Care Theory; and the continuum of functionality proposed by CIF, which is composed by the description of the functional level, through which it is possible to determine the self-care deficit, and the need for nursing care.

The patient and the caregiver, due to the new situation of dependency, go through a process of transition that generates changes in family dynamics, particularly with regard to changes in social life, paper dysfunction, and financial burden [5].

The Rehabilitation Nursing Specialist, due to his/her specific skills, plays a primordial role in the recovery and re-adaptation of the patient with proximal femur fracture, as well as his/her caregiver, in order to minimize complications and maximize his/her potential of autonomy reconstruction, obtaining sensitive results from nursing care.

Outcomes sensitive to nursing care can be defined as all those that are relevant, based on the domain and nursing intervention, and for which there is empirical evidence that relates nursing interventions to outcomes [6].

2 Materials and Methods

2.1 Methodology

This study was developed in an Orthopedic Department from May 20 to June 28, 2019. It aims to identify the gains of the Rehabilitation Nursing intervention based on the Model of Self-Care in People with Proximal Femoral Fracture.

This is a descriptive and exploratory study, having chosen Robert Yin's qualitative case study methodology (Fig. 1), in which a detailed and complete examination of a phenomenon linked to a social entity is made, which in the case were three individuals [7].

As for the theoretical references for the practice of care, Lopes' medium range theory and Fonseca's Self Care Model, based on Orem's Self Care Deficit Theory were chosen [3, 4, 8].

In the data collection process, direct observation of the relationship between the patient and his/her family and their actions, interview and interaction with them, physical evaluation, complementary diagnostic tests and records of the clinical process of the patient were used as sources of evidence; following up on the first phase of the Yin methodology [7].

Since the functionality of the patient is one of the objectives of the Rehabilitation Nurse intervention, the ENCS [4, 9], based on the self-care model and the CIF, developed by WHO, was used as a diagnostic tool. It was chosen for this study because it contains sensitive indicators of rehabilitation nursing care, because it evaluates the functionality of the patient, the needs of nursing care in various contexts and also evaluates the effective gains resulting from nursing intervention.

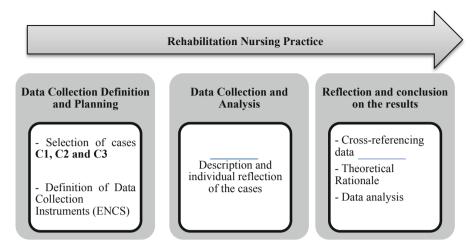


Fig. 1. Multiple case study methodology, adapted from Yin (2003: 73) [7].

For this study three patients were selected in an Orthopedic department. An accidental or convenience sample was chosen, in which easily accessible individuals were selected who met precise inclusion criteria [10]. Thus, the following criteria were taken into account: patients with proximal femur fracture, over 65 years of age, with self-care deficit, and with a need for continuity of care after discharge from hospital, having an informal caregiver.

3 Results and Discussions and Conclusions

3.1 Discussion of Results

Following the Yin methodology [7], the different cases (C1, C2 and C3) will be presented, for which a brief description will be made.

A brief sociodemographic analysis of the population in question shows that the majority of the population is female, with an average age of 78.3 years, of Portuguese nationality, married, retired and with a low level of schooling (Table 1).

It is common for all to have suffered a fall with diagnosis of inter-trochanteric femur fracture after going to the emergency service. They were admitted to the Orthopedic Department, where they were at rest for about six days in the case of C1 and C2 with skin traction. As for the surgical intervention, it was also common to all the fact that it was a digging.

Prior to the fracture, C1 was independent in the ADL's, while C2 was already partially dependent, as well as C3, who used a Canadian as a walking aid.

In the first lift after the surgery, in all cases there was indication to make partial load on the operated limb and to put elastic stockings on. It was found that in all cases there was a decrease in muscle strength (especially in the operated limb), a decrease in static and dynamic balance in the standing position, and moderate dependence on transference, as well as inability to walk.

| Case studies | C1 | C2 | C3 |
|-----------------|--|--|--|
| Age | 76 years | 79 years | 80 years |
| Gender | Female | Female | Male |
| Nationality | Portuguese | Portuguese | Portuguese |
| Estado civil | Married | Married | Married |
| Family attaché | Husband, son-in-law and two granddaughters (>18 years) | Husband | Wife, Son, Daughter-in-law and granddaughter |
| Education level | 4th grade | Did not complete the 4th grade (can read and write). | 4th grade |
| Profession | Rural worker (Retired) | Maid (Retired) | Baker (Retired) |

Table 1. Sociodemographic characterization of participants.

For data analysis and diagnostic evaluation, the ENCS (Table 2) [4, 9] was applied, and the focuses of nursing with need for intervention were identified (General Functionality, Self-Care, Learning and Mental Functions, Communication, Pain, Relationship with Friends and Caregivers, Transference, Walking with Walking Assistant, Muscular Movement, and Balance). It was chosen to make the diagnostic evaluation in the 1st lift after the surgical intervention and the evaluation after the intervention, at the time of discharge, in order to evaluate the patient's evolution in the postoperative and the gains of the Rehabilitation Nurse's intervention plan (Table 3).

When applying the ENCS, it was possible to perceive that, initially, all the evaluated patients presented it as a Serious Problem (50–95%). Regarding the general functionality, it was found that only for C1 was a Serious Problem (62%), while for C2 (45%) and C3 (37%) it was a moderate problem.

Once the different dimensions of the ENCS that contribute to the general functionality were analyzed it was concluded that the main problems for C1 and C2 were Learning and Mental Functions (62.5% and 47.67%) and Communication (56.25% and 31.25%), since these patients were a few days with disorientation of time space and changes in memory and attention, not being able to collaborate in the care.

For C2, however, the relationship with friends and caregivers stands out, which despite being a slight problem (18.75%), will have an influence on his/her recovery, since one of the significant caregivers is not present.

As for C3, it was verified that at the time of the high it maintained the general functionality as a moderate problem (30%), with only slight gains in self-care (16.67%). In this case, the patient always remained oriented, but with the intervention of the rehabilitation nurse, it was found that the main obstacles to their collaboration were pain and anxiety.

Pain is the main problem of the patient after surgical intervention, and interventions at the physical, pharmacological and psychological level are fundamental to promote his comfort and well-being [12]. In cases C1 and C2 it was possible to verify that a significant

19%

| ENCS instrument | | | |
|-----------------|---|---|-----|
| Case study | Diagnostic assessment | Final assessment | |
| C1 | General Functionality - 62% Self-care - 72.92% Learning and Mental Functions - 62.5% Communicate - 56,25% | General Functionality - 36% Self-care - 47,92% Learning and Mental Functions - 33.33% Communicate - 31,25% | 26% |
| | Relationship with Friends and Caregivers - 12.5% | Relationship with Friends and Caregivers - 12.5% | |
| C2 | General Functionality – 45% Self-care - 62.5% Learning and Mental Functions - 41.67% Communicate - 31,25% Relationship with Friends and Caregivers - 18.75% | General Functionality – 22% Self-care - 45.83% Learning and Mental Functions - 8.33% Communicate - 6,25% Relationship with Friends and Caregivers - 18.75% | 23% |
| C3 | General Functionality - 37% Self-care - 68,75% Learning and Mental Functions - 16.67% Communicate - 18,75% Relationship with Friends and Caregivers - 6,25% | General Functionality - 30% Self-care - 52,08% Learning and Mental Functions - 16.67% Communicate - 18,75% Relationship with Friends and Caregivers - 6,25% | 7% |

Table 2. Sensitive gains of Rehabilitation Nursing care, after application of structured intervention plan and diagnostic and final evaluation with the ENCS instrument.

improvement occurred, changing from a serious to a moderate problem, which allowed a greater participation of the patients in the rehabilitation program.

29%

In general, sensible gains were obtained in Rehabilitation Nursing care, and according to the Self-Care Model [4], therapeutic self-care deficits went from severe to moderate.

3.2 Implications in Professional Practice

48%

Global average

functionality

The self-care behavior, as well as the functional and knowledge capacity, were compromised in the different cases under study. Therefore, as Orem [3] recommends, the educational support system, besides being implemented with patients, was also applied to caregivers. For it becomes necessary to train the families/caregivers in a systematic way in order to minimize the stress experienced by them and for them to acquire security to carry out the care at home [13].

Table 3. Rehabilitation nurse intervention plan.

| Interventions | Objective |
|--|--|
| Respiratory Functional Re-education - Awareness of Breathing - Abdominal-diaphragmatic exercises - Costal re-education exercises Motor Functional Re-education | - Improve alveolar ventilation and prevent postoperative complications [11] - Prevent immobility complications, reduce edema, improve contractility and strength of compromised muscles [11] - Promote general patient functionality through early |
| - Isometric exercises (abdominal muscles, buttocks and quadriceps) - Free, Assisted and Resisted active mobilizations of the lower limb and upper limbs; - Free and assisted active mobilizations of the tibiotarsal joint and fingers of the Lower Limb with fracture, according to the patient's tolerance (and the other limb segments after surgery) - Exercises for bridge and bearings Promotion of Patient Functionality - Promote control of pain; - 1st Up (2nd day Post-Operative); - Promote Self-Care; - Teachings and training related to Positioning in bed, Balance, Transfer, Walking with gait aid and Prevention of falls; - Promoting Patient Awareness; - Encouraging their involvement in care and decision making; - Give positive reinforcement in Progress Preparing for Caregiver High and Qualification Informal - To know the patient's background, home conditions and family/friends or caregivers support; - Involve the informal caregiver in the care process; - Teach and train the caregiver about: Prevention of Falls, Transfers; Walking with walking aid; Self-care; and Use of support products (e.g. Toilet Bowl Lighter, Bathroom Board); | mobilization, comfort measures, pain relief and effective communication [12] - Garantir a continuidade dos cuidados na comunidade, quer pela família/cuidador ou instituições de saúde ou sociais [2] |

3.3 Conclusion

The rehabilitation process should be initiated as early as possible, and should include the patient in the decision making and empower the informal caregiver to respond to the continuity of care in the home and to develop coping strategies that facilitate the management of their care.

The inclusion of both motor and respiratory functional re-education teachings from the preoperative period improves muscle strength, joint amplitude, balance, gait, functional capacity in general and quality of life and, on the other hand, contributes to reducing pain, the incidence of pressure ulcers, hospital stay, re-hospitalization rate, institutionalization and mortality [11].

With this study it was possible to reaffirm the importance that the evaluation of the functional capacity has for the Rehabilitation Nursing. In addition, the systematization of care based on the Fonseca Self-Care Model [4], allowed the development of an intervention plan, based not only on the needs of self-care, but also on the functional

capacity and knowledge of the patient and, in the conditions and context of the same, including the caregiver. For this, besides partially and totally compensatory interventions, an educational support system based on the therapeutic relationship nurse-patient/career was implemented, and it was possible to obtain sensible results from rehabilitation nursing care, which translated into gains both in self-care and in general functionality.

References

- Instituto Nacional de Estatística [INE] (2011). Censos: Resultados provisórios. Lisboa: INE (2011). https://censos.ine.pt/xportal/xmain?xpid=CENSOS&xpgid=ine_censos_public acao_det&contexto=pu&PUBLICACOESpub_boui=122073978&PUBLICACOESmodo= 2&selTab=tab1&pcensos=61969554
- Martins, R., Mesquita, M.F.: (jan/jun, 2016). Fraturas da Extremidade Superior do Fémur em Idosos. Revista Millenium, 50: 239–52. Avaliable from http://www.ipv.pt/millenium/Millen ium50/14.pdf
- Tomey, A., Alligood, M.: Teóricas de Enfermagem e a Sua Obra Modelos e Teorias de Enfermagem, 5th edn. Lusociência, Loures, Portugal (2004)
- Goes, M., Lopes, M.J., Oliveira, H., Fonseca, C., Marôco, J.: A nursing care inter-vention model for elderly people to ascertain general profiles of functionality and self care needs. Sci. Rep./Sci Rep. 10, 1770 (2020). https://doi.org/10.1038/s41598-020-58596-1
- Rocha, S.; Avila, M., Bocchi, S.: Influência do Cuidador Informal na Reabilitação do Idoso em Pós-operatório de Fratura do Fêmur Proximal. Revista Gaúcha de Enfermagem 37(1), 1–9 (2016). http://web.b.ebscohost.com/ehost/pdfviewer/pdfviewer?vid=34&sid=9dbf5768-7246-4917-80fa-c466f69c85f5%40pdc-v-sessmgr03
- Doran, D., Pringle, D.: Patient outcomes as accountability. In: Doran, D. (ed.) Nursing Outcomes: The State of the Science, 2nd edn. pp. 1–27. Jones and Bartlett, Sudbury, MA (2011)
- Yin, R.: Estudo de Caso: Planejamento e Métodos (D. Grassi, Trad.), 2nd edn. Bookman, Porto Alegre (2003)
- Nascimento, V., Fonseca, C., Ferreira, R., Lopes, M., Moguel, E.: Structured proposal for rehabilitation nursing (RN) care intervention: sensitive gains to RN care for the person with self-care deficit and in the surgical process. In: García-Alonso, J., Fonseca, C. (eds.) Gerontechnology. IWoG 2019. Communications in Computer and Information Science, vol. 1185. Springer, Cham (2020). https://doi.org/10.1007/978-3-030-41494-8_27
- Goes, M.: Psychometric qualities of a core set to ascertain the functional profile of Portuguese elderly citizens. In: International Workshop on Gerontechnology, pp. 314–329. Springer, Cham (2020). 10.1007/978-3-030-41494-8_31. First Online 29 February 2020. Print ISBN 978-3-030-41493-1. Online ISBN 978-3-030-41494-8
- Fortin, M.F.: Fundamentos e Etapas do Processo de Investigação, 1st edn. Lusodidacta, Loures, Portugal (2009)
- Sousa, L., Carvalho, M.: Pessoa com Fratura da Extremidade Superior do Fémur, pp. 421–31.
 In: Marques-Vieira C & Sousa L. Cuidados de Enfermagem de Reabilitação à Pessoa ao Longo da Vida, 1 edn. Lusodidacta, Loures (2016)
- Cruz, A., Oliveira, L., Conceição, V.: Enfermagem em Ortotraumatologia, 2.ª ed. Formasau, Coimbra
- Graça, T., Bocchi, S., Fusco, S., Avila, M.: A Experiência do Cuidador Informal à Luz da Teoria Geral de Enfermagem. Online Braz. J. Nurs. 16(3), 355–365 (2018). http://web.b.ebscohost.com/ehost/pdfviewer/pdfviewer?vid=29&sid=9dbf5768-7246-4917-80fa-c466f69c85f5%40pdc-v-sessmgr03



Have People Over 64 Used Technological Devices During COVID-19?

Sara Chimento-Díaz^{1,3(\omega)}, Pablo Sánchez-García^{2,3}, Cristina Franco-Antonio^{2,3}, Esperanza Santano-Mogena^{2,3}, and Sergio Cordovilla-Guardia^{2,3}

Computer and Telematic Systems Engineering Department, Polytechnic School, University of Extremadura, Cáceres, Spain

schimento@unex.es

Nursing Department, Nursing and Occupational Therapy College, University of Extremadura,

Abstract. The percentage of older adults has not stopped increasing in our country. In rural Spain, the data on ageing is even more worrying. If we look at Extremadura, we see that the percentage of the population over 64 is higher than the national average, with 20.7% of the total population over 64. For the human being, occupation (the activity of the person) has direct implications on physical and psychological health. The therapeutic alliance between health professional and patient is essential because it is based lies in the achievement of cooperation. The objective of this study was to analyse use of new technology and technological devices during the months of lockdown. The interview was carried out by a specific researcher, during the months of September-October 2020 in the Autonomous Community of Extremadura to people who lived in their homes or a residential centre. A qualitative interpretative study of a phenomenological nature carried out. A total of 14 participants were included in the study (9 lived in the residential centre). Finally, we could observe that one factor determine the perception that people over 64 have about the use of new technologies and technological devices, is influenced by the social and emotional factor.

Keywords: Elderly · Isolation · Technology · Rehabilitation

1 Introduction

The percentage of older adults has not stopped increasing in our country. According to the projections of the National Institute of Statistics, in 2068 29.4% of the population will be over 64 [15]. In rural Spain, the data on ageing is even more worrying. If we look at Extremadura, we see that the percentage of the population over 64 is higher than the national average, with 20.7% of the total population over 64 [16].

With the limited information currently available, it appears that both older adults and people of any age with underlying medical conditions may be at greater risk of

Cáceres, Spain

³ Health and Care Research Group (GISyC), University of Extremadura, Cáceres, Spain

serious illness from COVID-19 [21]. The risk of Covid-19 infection and death in the adult population [8] and that in the region is a very high rate of ageing. It is essential to pay attention to those who live in residences centres that exist in Extremadura [13], o users of day centres, focused on covering the needs of older people as a whole, from care and personal attention to the promotion of autonomy [10].

Nearly one-third of the world's population is in isolation or mandatory quarantine. The Covid-19 pandemic has posed many challenges to maintaining standards of care and treatment for patients while addressing the growing anxieties of patients, caregivers and the general public [23], without forgetting the additional impact of this lockdown, accelerating, in many cases, the process of regression of many patients [20].

For the human being, occupation (the activity of the person) has direct implications on physical and psychological health. Through participation in different activities, human beings exercise and facilitate the development of their motor, psychological and sensory functions. Any restriction of any of these functions, together with an inaccessible environment, can create a loss of significant roles for the person, negatively impacting their social participation and sense of life [5].

The term therapeutic alliance was developed throughout the 20th century by the Austrian physician Sigmund Freud. He raised the importance of the analyst maintaining interest and an understanding attitude towards the patient to allow the healthier part of the patient to establish a positive relationship with the analyst [7].

Despite a growing body of research on how various technologies support relationships between people, the ability to keep the unique aspects of the therapeutic alliance at arm's length remains a concern for many professionals [18]. This therapeutic alliance is nothing more than the interpersonal relationship between patient and therapist. Since the emotional and relational quality of the bond between them is an essential part of the rehabilitation process, it can be a determining factor in the effectiveness of the therapy [7]. The therapeutic alliance is essential because it is based lies in the achievement of cooperation, demonstrated by both the client and the health professional. It is the result of three components: agreement on the tasks to be performed during treatment, agreement on objectives and goals, and the emotional bond between therapist and patient, i.e., the possibility of developing an attachment through mutual acceptance and trust [14]. A situation that, relatively a few months ago, was practically unthinkable to happen telematically.

In 2018, more than 920 people over the age of 64 died in Extremadura due to progressive dementia, with Alzheimer's disease being one of the leading causes, with almost 350 deaths [17]. Considering loneliness as a risk factor (1.58 times greater) in the development of dementia of those with an established social network [11].

Throughout the life cycle, many changes occur, both at the biological, behavioural and cultural levels, based on the context and environment of the person, which is why we can say that the human being is a holistic being. One of the biological changes that occur throughout life is the process of ageing. To aged involves changes in the brain that imply modifications in cognitive and functional functioning, memory visuospatial, relationships, and the speed of information processing can be reduced. At the same time, verbal skills seem to be better preserved [4]. Dementia implies a loss of these cognitive capacities, due to dysfunction or brain damage of organic cause, producing a

decrease in personal autonomy, making it difficult to carry out activities of daily living (ADLs), and which are often accompanied by alterations in affectivity and behaviour. More than 90% of dementias are due to chronic neurodegenerative or vascular processes associated with ageing for which no curative treatment is available [22]. Mood and mental health are fundamental. As a consequence of being in lockdown for an extended period, the person becomes a little more vulnerable. For this very reason, we must support the carers, who also have their familiar surroundings [2]. Health professionals such as occupational therapists are responsible for ensuring that the person achieves the highest level of personal autonomy through the recovery, achievement and maintenance of the user's lost abilities. The role they play in the field of geriatrics is present in different areas of daily life, from the most basic activities linked to self-care such as dressing, eating, mobility or grooming, to the development of communication and relationship skills with other people Health professionals estimate that, due to the pandemic, users have had a 75% reduction in the hours in which they have received face-to-face treatment. 41.94% of occupational therapy professionals estimate that the percentage of users with the possibility of accessing and managing telematic care is less than 25% [3]. Social networks are gaining strength in terms of the implementation of rehabilitation techniques with patients, facilitating communication between patients and users, and facilitating communication between residents of nursing homes and their families, thus reducing the lack of communication due to the prohibition of visits in these centres [2]. However, it is essential to control these social networks given their direct relationship with possible problems such as anxiety, given the constant exposure to information that is available [12].

2 Materials and Methods

A qualitative interpretative study of a phenomenological nature carried out. The data collection based on the following issues:

- 1. Have you been in the situation of receiving cognitive rehabilitation telematically?
- 2. What are the technological resources you have at your disposal?
- 3. Do you need help to use the technological devices?
- 4. Has it made it easier for you to maintain your activity because professionals have looked for alternatives based on new technologies?

The interview was carried out by a specific researcher, during the months of September-October 2020 in the Autonomous Community of Extremadura.

As criteria of inclusion, it was taken as a reference that the person was older than 64 years old, resided or has resided in the last year in a residential centre or is a user of someday centre. As criteria of exclusion, it was taken into account an average of three errors or more in the Short Portable Mental Status Questionnaire (Pfeiffer Questionnaire) for people who can read and write and four errors for people without studies [19].

The method of data collection was through life stories, thus allowing a perspective of the present reality of the person who participated in the study. The interview focused on allowing the user to comment on their experience. In case they have made video calls or some other activity that allows them to be in contact with their relatives, or case none of these activities have been carried out, what they think about it. Another of the activities carried out during the state of alarm created by the COVID-19 health crisis was to hold rehabilitation and cognitive stimulation sessions using video call platforms or to send activities in the form of a pdf via e-mail. Allowing the person to do them out from the computer or on paper if they could print the document.

The use of other technological devices such as smartphones, smartwatches and computers with or without an internet connection assessed.

The qualitative analysis was carried out using the webQDA platform. It is it follows a structural and theoretical design of other programmes available on the market, favouring collaborative work online and in real-time and allowing qualitative data to be analysed, individually or in collaboration, synchronously or asynchronously [1].

The variables that have been taken into account are sex, the socio-economic level of the person, accessibility to technological resources and whether they have used any technological device before the new technologies.

The predisposition to participate in the study was also collected.

3 Results

Eighteen interviews were conducted which, after a first screening and following the criteria of the Pfeiffer questionnaire (SPMSQ), more than three errors or four if the person does not know how to read or write, finally a total of 14 participants were included in the study (Table 1).

| Grade of institutionalisation | Men (9) | Women(5) |
|-------------------------------|---------|----------|
| Residential centre | 4 | 5 |
| Day centre | 4 | |
| Rehabilitation at home | 1 | |

Table 1. Grade of institutionalization of participants

Initial question "Have you ever been in the situation of receiving cognitive rehabilitation telematically? Allows us to know the situation that each participant depending on the grade of institutionalisation in which they are. Inpatient in a residential centre or living in the family home and going to a day centre. We can see that all the participants who were admitted to residential centres during the months of lockdown did not need to receive telematic treatment. However, they did rate the reduction in the frequency with which they received services. At the same time, the 5 participants who were not in residential centres were offered the possibility of receiving these therapies telematically. In order to do this, it was necessary to have access to a technological device (computer, tablet, smartphone), an internet connection, an e-mail account and, if the user required it, a printer to be able to print out the activities recommended by the professional in question. We find, therefore a significant limitation, 5 of the participants with the option

to rehabilitation sessions in a telematic way, only one subject affirms to have used the resources without the aid of a relative.

D: «I use the computer a lot because I communicate with my grandchildren, one is in Barcelona and another in Germany. The activities sent to me by the occupational therapist were printed out and then made on paper because I had to use a pencil. But I did everything without help»

On the opposite side, one of the participants states that he could not carry out the activities unless the professionals themselves take him home, as he had no access to any of the necessary devices or knowledge about how to use them

J.Z: \ll I live here near the association. I was called by the occupational therapist to come down and pick up the book that she left in my letterbox. I do not have a computer or anything, and I live with my wife who does not know how to handle these things very well either \gg

This reflection leads us to ask ourselves the following question: What are the technological resources that they have? We can observe that only 1 participant has access to computer equipment and internet connection at home. Three of the participants belonging to the group of people living in the family home claim to have access to technological devices of close relatives, such as children, grandchildren and nephews. On the other hand, 4 of the respondents admit to having a smartphone but only use it to make calls and have their relatives set alarms to remind them of pills.

Beyond the proximity or the possibility of accessing a technological device, we find, above all, in users belonging to residential centres a certain reticence to use some devices such as computers and intelligent clocks:

A: «We cannot leave everything to the machines.»

D: \ll I already have a radio, why do I want a mobile phone? If they give me the big device when my niece calls me. \gg

However, we discovered that many of the people interviewed had needed devices such as tablets to be able to make video calls with their relatives during the months of lockdown. They demand the need to learn how to use these devices because they do not want to lose contact with their relatives if they find themselves in the same situation of isolation and lockdown.

 $M:\ll I$ would like to know how to use a computer to feel happier. \gg

By asking the participants about the autonomy with which they use the devices, we asked ourselves the following question: do they need help to use the technological devices? We found almost unanimously that 13 of the 14 participants stated that they needed and required help from a relative, either a wife or daughter, in the case of people living at home and from the occupational therapist in the case of people living in nursing homes.

We can observe that, in this way, a situation of the dependence of the user is indirectly generated about the person he or she has as a reference in order to be able to use technological devices.

Despite the possible dependence that is created, we wondered if it was worthwhile to need a reference person to lean on whenever the participant needs or wants to use some device. So, with the following question: Has it made it easier for you to maintain your activity because professionals have looked for alternatives based on new technologies? It is the subjects themselves who recognise the need for meaningful occupation, the importance of maintaining a routine and are aware that the break in the face-to-face rehabilitation sessions has reduced the capacity for recovery and maintenance of skills, especially on a cognitive level.

J.M: «Here, although we find it difficult to do so, because the professionals know what is best for us, however, in my house, when I felt like, I did it and when I did not, I did nothing.»

4 Discussion

Interpreting the results, we can observe a bifurcation in two lines of action depending on the degree of institutionalisation that each participant has had.

On the one hand, we find how the person's social participation and the need to relate to their peers have influenced the perception of new technologies and technological devices as necessary.

Klund (2020) found that individual social participation is closely related to the recovery process [9]. Social interaction is a very influential factor in the individual.

We can find out how all the subjects who have been admitted to residential centres during the months of lockdown, despite not having technological devices, recognise the need and usefulness of new technologies. However, this position is not so exact in users who live in their homes, since the emotional factor of seeing a relative has not been triggered.

M: \ll Sometimes, when I saw my wife on the Tablet, I would burst into tears, I had never been so long without being able to see her or hug her \gg

 $J: \ll We$ have a house in the country with a vast garden, my wife, my daughter and I left, and we have been there during the whole lockdown \gg

Another line that emerges after the analysis of the results is the relation between carrying out the activities proposed by the professional at home or not, making evident the relationship between the intention of doing and the occupation.

Christiansen stated that the term occupation refers to the involvement or commitment in the performance of activities, tasks or roles with a productive purpose, of self-maintenance. In contrast, when talking about occupational performance, we are referring to the daily performance of occupations that organise our lives and satisfy our needs [6]. This theory gives rise to the pyramid of occupations, referring to levels of occupation as hierarchies or levels.

Levels of occupation were organised on a pyramid, where the activities are the base, and the roles are the top.

At the bottom of the pyramid are the activities, understood as the specific behaviour aimed at achieving a specific goal. At the second level are the tasks, which are the set of activities that share the same purpose, and finally, in the highest position, the roles, which are defined as the distinctive places in society [6].

For this process to be carried out, essential factors and functions are needed, influenced by the context, the volitional capacity and the intention of the person, among others. The same subject can have many roles at the same time, and he can have the role of a parent, a sibling, a worker's role and even the role of a sick person. A set of activities and tasks accompanies each role. In some cases, in different contexts, for example, for people who are active in the labour market, the role of the worker was developed in a specific and delimited environment, the centre and workplace.

During lockdown we were forced to bring all roles together in one location, our home. Maybe it may have distorted reality, making the assimilation of some roles difficult and preventing the achievement of occupational balance [23].

To conclude, we could say that one of the factors that could determine the perception that people over 64 have about the use of new technologies and technological devices, is influenced by the social factor. We observed that patient who had been isolated and separated from their families during the lockdown months. They recognise the need and usefulness of new technology and even appeal to the need to learn to use technological devices to help maintain the relationship with their loved ones without the need to resort to a person who facilitates this contact.

On the other hand, we observe how those people who have been in their homes during lockdown, do not perceive the use of technological devices as a vital need, beyond being able to remain active with their respective rehabilitation treatments.

It would be interesting to be able to measure the impact of the reduction of rehabilitation services within the residential centres. Furthermore, we would like to see the relationship between how it has been able to influence the intrinsic motivation of the person to carry out all the proposed activities on all the online sessions. Due to the current situation, some limitations those we have encountered are the problematic access to the participants. Not being able to enter residential centres or day centres have been subject to the character of the centre (public, subsidised or private) and above all of the professionals in it, the latter being a determining factor.

Acknowledgments. This work was supported by 4 IE+ project (0499_4IE_PLUS_4_E) funded by the Interreg V-A España-Portugal (POCTEP) 2014–2020 program.

Conflict of Interest. The authors declare that they have no conflict of interest.

References

- Costa, A.P., Moreria, A., de Souza, F.N.: webQDAlwebQDA (2010). https://www.webqda.net/o-webqda/?lang=es. Accessed 15 Oct 2020
- 2. Araya, P.R.: Covid-19: who cares for an elderly person? El Obs (2020)

- Arenas, J., Emeric, D., Amézaga, M., Blázquez, M.P., Chimento, S., Martínez, A.I., Maeztu, O., Rienda, J.J., Sadia, L., Valverde, M.: Impact of COVID-19 on occupational therapy. Talavera de la Reina (2020)
- Calatayud, E., Plo, F., Muro, C.: Analysis of the effect of a cognitive stimulation programme on people with normal ageing in primary care: randomised clinical trial. Atención Primaria 52, 38–46 (2019). https://doi.org/10.1016/J.APRIM.2018.09.007
- 5. Carreño-Acebo, M.E., Cañarte-Mero, S.B., Delgado-Bravo, W.M.: The occupational therapist and his role with geriatric patients. Dominio las ciencias **2**, 60–71 (2016)
- Chistiansen, C., Baum, C.: Occupational therapy: overcoming human performance deficits, 1a. USA (1991)
- Corbella, S., Botella, L.: View of therapeutic alliance: research and assessment. An. Psicol. 19, 205–221 (2003)
- 8. D'cruz, M., Banerjee, D.: 'An invisible human rights crisis': the marginalization of older adults during the COVID-19 pandemic an advocacy review. Psychiatr. Res. **292** (2020)
- Eklund, M., Tjörnstrand, C.: Associations between occupational and social interaction factors and well-being among people with psychiatric disabilities living in supported housing in Sweden. J. Occup. Sci. 27, 54–68 (2020). https://doi.org/10.1080/14427591.2019.1620121
- Esteban Herrera, L., Rodríguez Gómez, J.Á.: Dependency situations in elderly people's homes in Spain. Ene 9 (2015). http://dx.doi.org/10.4321/S1988-348X2015000200007
- 11. Freedman, A., Coe, C., (FCFP), Nicolle, J.: Social isolation and loneliness: the new geriatric giants approach for primary care
- Gao, J., Zheng, P., Jia, Y., Chen, H., Mao, Y., Chen, S., Wang, Y., Fu, H., Dai, J.: Mental health problems and social media exposure during COVID-19 outbreak. PLoS One 15 (2020). https://doi.org/10.1371/journal.pone.0231924
- 13. García, A.A., Del Pilar, M., Nieto, A., Fariñas, D.R.: Residential statistics: distribution of residential centres and places by province (2019). Data from April 2019
- 14. Germain, V., Marchand, A., Phane Bouchard, S., Phane Guay, S., Drouin, M.-S.: Assessment of the therapeutic alliance in face-to-face or videoconference treatment for posttraumatic stress disorder
- INE: Population Projections 2018 (2018). https://www.ine.es/prensa/pp_2018_2068.pdf. Accessed 15 Feb 2020
- INE: Population by community and age (2019). https://www.ine.es/jaxi/Tabla.htm?path=/t20/e245/p08/I0/&file=02002.px. Accessed 8 Feb 2020
- 17. INE: Extremadura. Deaths by province of residence, causes (reduced list), sex and age (2019). https://www.ine.es/jaxi/Datos.htm?path=/t15/p417/a2018/l0/&file=02012.px#!tabs-tabla. Accessed 18 Sep 2020
- Lopez, A., Schwenk, S., Schneck, C.D., Griffin, R.J., Mishkind, M.C.: Technology-based mental health treatment and the impact on the therapeutic alliance. Curr. Psychiatry Rep. 21, 1–7 (2019)
- Martínez De La Iglesia, J., Herrero, R.D., Vilches, M.C.O., Taberné, C.A., Colomer, C.A., Luque, R.L.: Cross-cultural adaptation and validation of Pfeiffer's test (Short Portable Mental Status Questionnaire [SPMSQ]) to screen cognitive impairment in general population aged 65 or older. Med. Clin. (Barc) 117, 129–134 (2001). https://doi.org/10.1016/s0025-7753(01)720 40-4
- Mediavilla, R., Fernández-Jiménez, E., Rodríguez-Vega, B., Gotor-Martínez, L., Rivelles-Sevilla, R.V., Rojano-Capilla, P., Bravo-Ortiz, M.F.: Adapting mental health care after the COVID-19 outbreak: preliminary findings from a public general hospital in Madrid (Spain). Psychiatry Res. 289, 113077 (2020)

- 21. Muñoz Valverde, M.V., Martínez Zujeros, S., Acosta Benito, M., Ariza Vega, M.P., Arribas Pérez, A.M., Verónica, B.T., Lastres Paredes, A., Pérez Corrales, J., Sancho Castillo, C., Fernández Huete, J., Incio González, M.J., Gómez Calero, C., Herrera Gálvez, D., Moreno Ramírez, M.P., Martínez Monge, N., Martín Del Cañizo, M.: Clinical guide for occupational therapy intervention in patients with COVID-19. 47 (2020)
- 22. Olazarán, J.: Can dementia be diagnosed in primary care? Aten. Prim. 43, 377–384 (2011). https://doi.org/10.1016/j.aprim.2010.09.004
- Usman, M., Fahy, S.: Coping with the COVID-19 crisis: an overview of service adaptation and challenges encountered by a rural psychiatry of later life (POLL) Team. Ir. J. Psychol. Med. (2020). https://doi.org/10.1017/ipm.2020.86



Awareness of Intangible Cultural Heritage Through Videos Promoting Active Ageing

Juan Francisco Ortega Morán¹(⊠), José Luis Moyano García-Cuevas¹, Francisco Manuel Esteban Gómez¹, Carolina Vila-Cha², Nuno Serra², Debora Zamillo³, Aurelia Curaj⁴, Francisco M. Sánchez Margallo¹, and J. Blas Pagador¹

1 Centro de Cirugía de Mínima Invasión Jesús Usón, Cáceres, Spain jfortega@ccmijesususon.com

² Instituto Politécnico da Guarda, Guarda, Portugal

Abstract. Elderly population is constantly increasing and ageing is causing demographic, epidemiological and anthropological changes such as to make active and healthy ageing increasingly pivotal. With the objective to extend life expectancy in good health, it is important to raise awareness about the adoption of those factors that favor active ageing, such as a healthy lifestyle with proper nutrition, regular physical activity, a good management of stress, sleep and emotion, but also with an active participation in the social, economic, cultural, spiritual and civil issues of the community. Cultural heritage is the set of physical artifacts and intangible attributes of a past group or society, maintained in the present and left as a legacy for future generations. But it is important to raise awareness among the older population to promote intangible cultural heritage linked to active ageing. This work details the design and development of videos created for this purpose. Through interviews to older people about intangible cultural heritage, active ageing and quality of life, six categories of the first one have been selected: traditional games, handcraft, dance, folklore and traditional festivals, classical literature, painting and poetry. Eight videos within these categories have been created, with subtitles translated into five languages and descriptive metadata. Elder people have a fundamental role in maintaining and passing cultural heritage down, as they have past memories of the socio-cultural environment (things, places, people and experiences) and can be an important source of information for the sharing and disseminating their knowledge to new generations.

Keywords: Active ageing · Awareness · Intangible cultural heritage · Videos

1 Introduction

Ageing is an inherent process of life. It is not possible to avoid ageing, but it is possible to postpone and control impairment. Successful ageing is related to active ageing, which is defined by the World Health Organization as the process of optimizing opportunities

³ Centro Sportivo Educativo Nazionale, Rome, Italy

⁴ Geron Foundation, Bucharest, Romania

 $[\]ensuremath{\mathbb{O}}$ The Author(s), under exclusive license to Springer Nature Switzerland AG 2021

J. García-Alonso and C. Fonseca (Eds.): IWoG 2020, LNBE, pp. 177–183, 2021.

for health, participation and security in order to enhance quality of life as people age. To be an older "active" person means to participate in social, economic, cultural, spiritual and civic life, not just to be physically active or to participate in the labor force. On the other hand, Cultural Heritage is a concept that can be seen as a transfer of societal or individual values from the past to the future with benefits in the present. The heritage means, actually, a healthy life style promoted by long-live people, as traditions and customs of living. Cultural Heritage can be divided into distinct topics:

- (1) Tangible cultural heritage: physical artefacts produced, maintained and transmitted in a society, between generations [1]. Therefore, buildings and monuments, artistic creations and other tangible products of human creativity with cultural significance in a society are included.
- (2) Intangible cultural heritage (ICH): includes five domains (oral traditions and expressions, including language as a vector; performing arts; social practices, rituals and festive events; knowledge and practices on nature and the universe; traditional craftsmanship) [2].
- (3) Natural heritage: cultural landscapes, biological and physical formations.

The 2003 UNESCO Convention [3] recognizing the role of ICH as a source of cultural diversity driving sustainable development. Transmitted from generation to generation, manifestations of ICH are constantly recreated by communities and groups, instilling in them a sense of collective identity.

The key issue in the composition of the ICH is people awareness, which is a process of active engagement with experience. It may involve an increase in skills, knowledge, understanding, values, feelings, attitudes and capacity to act. Effective awareness leads to change, development and the desire to learn more about living longer. In the AGEment project [4], a European Cultural Heritage catalogue for the awareness of Active Ageing has been developed, which can be seen as we learn, not just about, but through culture and heritage.

Using information and communication technologies to support innovation and disseminate Cultural Heritage can be a huge advantage in developing knowledge for those who cannot physically access it. With the advent of digital technology, many institutions create and maintain digital repositories that comprehend different media formats, such as audio or video accompanied by registries and protocols for classifying, preserving and retrieving data, and are content that can be accessed remotely via networks [6]. In this sense, the awareness catalogue developed in the AGEment project includes a collection of videos within different cultural heritage and active ageing areas. The aim of this work is to detail the design and development of the created videos for the awareness of intangible cultural heritage linked to active ageing.

2 Methods

An ICH element must be recognized by its communities, groups or individuals. Without this recognition the element cannot be imposed or documented as so. Therefore, gather information on this topic necessarily involves the communities, groups or individuals

whose heritage is to be identified and defined. Documentation of the ICH elements follows several overlapping stages, such as information gathering, data processing and production of informational material. These stages have been constructed taking in consideration participatory approaches and state of art information technology, allowing the data collection with a diversity of digital devices.

2.1 Information Gathering on Elderly Related Healthy Lifestyles

Information gathering refers to the process of recording observations, experiences and knowledge of the community members about the ICH elements. For that, a semi-structured interview was performed to gather information on ICH, active ageing and quality of life.

The interviewed population was active people, mentally and physically, participants in the community life, but also active in designing their lives, with clear life motivation. They were as aged as we found in the area of each partners country (Spain, Portugal, Italy and Romania) and awarded of their healthy lifestyle, living in their homes and keeping their autonomy. Healthy lifestyle doesn't mean diet and exercises only, but also stress management, relaxation, sleep quality and emotions (how we deal with negative emotions). Moreover, their appreciation and awareness about their status as active people was asked to let them the opportunity to describe their active life.

2.2 Selection of Contents

All data collection has been used to develop the contents that establish a connection between cultural heritage and active ageing dimensions. These contents aim to raise awareness of young and old adults to lifestyles that are encouraging a healthy ageing process, prolonging life with autonomy and social inclusion of the population as they get old.

After analyzing the interviews performed to several older adults in the countries of each partner, the following ICH categories have been selected:

- Traditional games: transfer of happiness and memories to new generations. Promotion of moderated physical activity that can support awareness messages about daily movement of adults interacting with others.
- Handcraft: traditional jobs and social customs of small villages. They put rural life
 in value and attract people to their surroundings. Both social relationship and healthy
 food habits are promoted with this case.
- Dance: couples dancing is a low-impact physical activity that is very common among
 the elderly and able to stimulate social relations between peers and between different
 generations.
- Folklore and traditional festivals: experience and knowledge in music, dance and other topics related to regional folk. Awareness messages have both physical and cognitive implications, but always enhancing social importance of these festivals.
- Classical literature: gender aspect and gastronomy in classical literature. They promote mental wellness exposing several points of important women appearance in the Spanish literature, i.e. the Quixote.

Painting and poetry: a reality made up of adults and old people that try to redevelop
their neighborhood through painting and poetry, coloring the buildings with drawings
and verses of poetry.

2.3 Production of Videos

During this stage, data are transformed in useful information through the creation of videos on the selected ICH elements embedded on a didactic context to encourage preservation of cultural heritage and simultaneously promote active ageing.

The videos have been produced following technical information:

- Video resolution: 1920x1080 (Full HD).
- Shooting orientation: horizontal.
- Audio quality: maximum quality available, at least stereo.
- Length: From 1' minimum to 5' maximum.
- Language: any.
- Subtitle: mandatory and in English.
- Camera shootings: the shot should be fixed, no zoom and no pan.
- Graphics: the video have to use the same banner and boxes graphics.
- Font: the texts and title have to use the same font.
- Boxes: three boxes to emphasize the relevant aspects of the project:
 - personal/relevant information about the interviewee;
 - aspects of active ageing particularly accentuated in the video;
 - cultural heritage area linked to the active ageing of the video.
- Opening: project logos, title of the video.
- Closing: the same for each video, with project logos.

These technical criteria have not been based on any standards for video creation, but have been established to maintain coherence in the application of the procedures to create the videos by any project partner.

3 Results

As a result of the above-mentioned procedure, eight videos have already been developed in the following categories of ICH:

- Folklore and traditional festivals:
 - Folklore: Pilgrimages in Cáceres (Spain). A great connoisseur of Caceres describes
 two of its oldest popular festivals: the pilgrimage of the Saint Martyrs and the
 pilgrimage of Saint Blaise. He identifies their origin, gastronomy, costumes or
 dances. He invites the elderly to preserve them and participating in them to be
 active and autonomous.

- Heraldry: Origin, meaning and interpretation. A member of the Institute of Heraldry gives a brief overview of the study of heraldry. Specifically, he explains its origin and teaches how to interpret and identify some of the shields of the families of Cáceres. He shows the importance for the elderly to continue studying and researching different subjects, to keep their minds active and delay their deterioration.
- Legends: Monumental City of Cáceres. An amateur guide to the monumental city
 of Cáceres describes some legends related to the origin of the city and its citizens.
 Specifically, he tells us about the legend of the reconquest of the city by the Arabs
 and about some historical figures of the city and their relationship with the French
 monarchy. He highlights the benefits of transmitting this immaterial knowledge as
 a guide for his physical and mental well-being.
- Folklore: Candelas pilgrimage in Cáceres. An active housewife who narrates the
 tradition of the Candelas pilgrimage in Cáceres. She details the hairstyle and the
 typical regional costume worn by the women, and also the popular gastronomy.
 She encourages older people to not miss out on the traditions and instill them in
 their descendants.
- Folklore: Pilgrimage of the Virgin of the Mountain in Cáceres. The same woman narrates the tradition of the pilgrimage of the Virgin of the Mountain in Cáceres. It is celebrated on the first Sunday of May, coinciding with Mother's Day. Many people take part in this pilgrimage and it strengthens the social relationship between the participants. She recommends that all the people walk up the mountain to keep fit.

• Handcraft:

Handcrafts: Embroidery. An embroidery enthusiast talks about different embroidery techniques, but specifically she explains the Petit Point technique. She also emphasizes the importance of not remaining inactive after retirement and encourages older people to go out and socialize, as social relationship is vital and necessary.

• Classical Literature:

- Classical Literature: Gastronomy in Don Quixote. A teacher of literature and passionate about Don Quixote and Miguel de Cervantes talks about gastronomy in Don Quixote and therefore, in 16th century in Spain. She indicates the importance of continuing to cook your own food for the quality of life of the elderly, because in addition to being healthier, it is fun.
- Classical Literature: Woman in Don Quixote. The same person talks about the situation of women in Don Quixote and, therefore, in 16th century in Spain. She indicates the importance of keeping the mind active through reading, whether Don Quixote or any other book.

All videos have subtitles in the languages of all partners of the project (Spanish, Italian, Romanian, Portuguese) and in English. The created videos include the following descriptive metadata:

- Title.
- Description.
- TAGs for searching.
- Resolution.
- Duration.
- Registration date.
- Active Ageing topics.
- Cultural heritage area.
- Active ageing messages.

4 Conclusions

The AGEment project aims to disseminate and raise awareness among the population, especially adults and elderly people, towards the concept of active ageing, linking it to cultural heritage, a topic relevant to the target audience and able to increase their motivation to receive and understand the messages. To do this, it has developed as awareness raising material some video interviews describing one or more elements of cultural heritage that can motivate the interviewed people to lead an active life. During the storytelling, the various factors of Active Ageing that characterize each experience are also highlighted.

This work proposes an innovative approach to raising awareness about Active Ageing among older people as it uses multimedia content with high motivational content thanks to the relationship between European cultural heritage and the promotion of well-being in the adult age. Elderly people are not only the target audience of the developed contents, but they are the protagonists and have been an active part of the whole material development process.

New videos are being developed within the different cultural heritage categories defined in this study. All these multimedia content will be disseminated to the elderly community once they have been finished. For that, they will be available to the general public in the webpage of the AGEment project. Moreover, new technologies will be used concretely apps for both Smartphones and SmartTVs, since they are widely used. They have been designed taking into account the limitations of access and use of elderly. During the validation of such apps with end-users, contents evaluation will be included to assess if the videos are successful in promoting a healthy lifestyle.

This project will directly contribute to generate "Ageing Literacy" that promotes a positive and successful ageing, emphasizing the need for continuous health literacy and ensuring the intergenerational ties joined under the same European Cultural Heritage. It is expected not just develop materials with direct impact on ageing well promotion, but it expects to generate discussion in the community that can lead the authorities to develop sustainable measures on active ageing. Results from this project can be transferred to other areas by helping to minimize social issues such elderly isolation in rural contexts.

References

- 1. Tangible and Intangible Cultural Heritage. https://resources.riches-project.eu/glossary/tangible-and-intangible-cultural-heritage/. Accessed 10 June 2020
- 2. UNESCO. Browse the Lists of Intangible Cultural Heritage and the Register of Good Safeguarding Practices. https://ich.unesco.org/en/lists. Accessed 10 June 2020
- 3. UNESCO. Convention for the Safeguarding of the Intangible Cultural Heritage. http://portal.unesco.org/en/ev.php-URL_ID=17716&URL_DO=DO_TOPIC&URL_SECTION=201. html. Accessed 10 June 2020
- 4. AGEment Project. https://agement-project.eu/. Accessed 10 June 2020
- The Digital Library Reference Model. https://www.coar-repositories.org/files/D3-2b-Digital-Library-Reference-Model.pdf. Accessed 10 June 2020



Pictograms - A Useful (Digital and/or Physical) Tool to Assist Elderly Patients in Understanding Medication Instructions? - A Systematic Review

Sara Faustino¹ , Sofia Oliveira-Martins²,³ , and Ana Margarida Advinha¹,²(☒) ,

Abstract. The aging process has been and is still a concern for humanity. Although some may consider old age as the peak of wisdom and tranquility, this process is accompanied by the development of various diseases, contributing to increased polypharmacy. In this age range, due to pharmacokinetic and pharmacodynamic changes, polypharmacy becomes complex due not only to physiological declining but also to decreased cognitive abilities that are crucial in a correct medication management.

Pictograms are particularly useful for conveying information related to medication especially for patients with low health literacy. Several studies confirm that its inclusion in informative materials positively influences the patient's attention, understanding, recall and adherence to treatment, demonstrating its potential for medication management in the elderly. This study describes and analyzes the results of the use of pictograms on medication management and adherence by elderly patients, through a systematic literature review based on the predefined methodological approach described in the Preferred Reporting Items for Systematic reviews and Meta-Analyzes (PRISMA).

In total, fourteen studies that met the defined inclusion criteria were included in the review. The studies were heterogeneous regarding the study design, population size and types of results. The interventions showed positive results promoting greater patient adherence to treatment and controlling problems related to the incorrect use of medication, however, the specific results reinforce the need for further studies in this area to provide a more complete approach about the use of pictograms in health care, namely digital devices, especially in this age range.

Keywords: Digital use · Elderly · Health literacy · Medication adherence · Medication therapy management · Pictograms

1 Background

Today's society is characterized by demographic aging and, despite improvements, both in health care and socioeconomic conditions that led to increased longevity, it was found

¹ Faculdade de Ciências e Tecnologia, Universidade do Algarve, Faro, Portugal anamma@uevora.pt

² CHRC – Comprehensive Health Research Centre, Universidade de Évora, Évora, Portugal
³ Faculdade de Farmácia, Universidade de Lisboa, Lisbon, Portugal

that the aging process is still accompanied by the development of several diseases, contributing to increased polypharmacy. Polypharmacy in this population becomes complex due to the pharmacokinetic and pharmacodynamic changes associated with physiological aging, but also due to the decline in physical and cognitive abilities, essential for the correct medication management [1].

The ability of elderly patients to understand information about their therapeutic regimens is a critical point for the correct use of medication. Low health literacy and high medication burden in the older adult population are contributing factors to the misunderstanding of medication instructions, leading to an increased risk of poor adherence and adverse events [2].

Although ageing is characterized by a natural and progressive loss of functionality, it is known that it is still possible to delay it and improve performance, either through the intervention of caregivers, health professionals or specific devices designed for this purpose. From this perspective, the functional ability of the elderly to manage their medication can be interpreted through the theory of self-care deficit, since medication management is an activity that individuals perform for their own benefit to maintain their health, well-being and quality of life [3, 4].

Pharmacists generally provide counselling about prescribed medications just once, when a prescription is initially filled, even though some medications are taken for many months or virtually indefinitely [5]. On the other hand, medication use instructions, such as the leaflets accompanying medicinal products, are often written at a high readability level, that potentially lead to the misuse of certain medications, low treatment adherence, and as a result, worst treatment outcomes [6]. Therefore, it is important to develop tools to help older adults to understand the instructions for taking their medications. One of the methods used to increase the degree of understanding of drug-related information is through the use of pharmaceutical pictograms.

Pictograms are graphic representations of objects or actions conveying a meaning which should be independent of any particular culture or language [7]. Pictograms consist of appropriately designed visual forms of health-related information, illustrating various aspects associated with the use of medicines, for example the dosage form or specific precautions [8].

Several studies demonstrate that pharmaceutical pictograms are useful tools to reinforce both comprehension and recall of medicines-related information, attract attention and reduce misunderstandings regarding a drug treatment, especially for patients with low literacy [9, 10]. One explanation for why pictographs may work is the Dual Coding Theory, first proposed by Paivio in 1971 [11]. The theory essentially holds that human memory uses two interactive stores "verbal" representations and mental images. When exposed to an image, the verbal memory may be triggered reinforcing memory traces and subsequent recall [12].

However, it is important to understand if these pictograms can also be useful to help elderly population to manage and adhere to the prescribed medication regimen.

This study aims to conduct a systematic literature review, to describe and analyze the use of pictograms in the process of adherence and medication management, specifically focused on elderly patients.

2 Methods

A systematic literature review was performed, based on the pre-defined methodological topics described in the Preferred Reporting Items for Systematic reviews and Meta-Analyzes (PRISMA) [13].

The research question was defined as: what is the importance of using pictograms in the medication adherence and management process by the elderly population?

To develop the search query, the PICO method was adapted and used:

- Population elderly people (individuals aged 60 or over in developing countries and individuals aged 65 or over in developed countries).
- Intervention use of pictograms as tool to help medication management and adherence.
- Outcomes two outcomes were considered: i) pictograms identification and characterization; and ii) results obtained with pictograms use.

The search was conducted in PubMed/MEDLINE database on 23rd May 2020, with the following search strategy: (((elderly) OR ("older people") OR ("older adult") OR (elder) OR (olders) OR (seniors) OR (aged) OR ("aged, 80 and over") OR ("frail elderly")) AND ((pictograms) OR (picture) OR (pictograph) OR (pictorial)) AND ((("medication adherence") OR ("medication compliance") OR ("patient compliance") OR ("frail elderlication adherence") OR ("medication therapy management") OR ("drug therapy management") OR ("medication self-administration") OR ("medication taking") OR ("medication competence") OR ("medication self-management")) OR ("patient medication knowledge"))).

The selection criteria were pre-defined according to the study objective. *Inclusion Criteria*

- Phenomenon of interest: use of pictograms to support medication management.
- Type of studies: primary studies (experimental or observational).
- Type of participants: elderly population (individuals aged 60 or over in developing countries and individuals aged 65 or over in developed countries).
- Type of results: identification and characterization of pictograms, their impact in terms of therapeutic adherence and main difficulties identified.

Exclusion Criteria

Studies in which at least one of the following criteria was verified were excluded.

- 1. Phenomenon of interest: studies whose title is not entirely related to the phenomenon of interest.
- 2. Language: publications in a language other than Portuguese, English or Spanish.
- 3. Type of participants: studies that do not include the elderly population (as previously defined).
- 4. Type of studies: secondary studies.

All search records/studies were exported to Microsoft OfficeTM Excel and Mendeley Desktop®. The screening process using the pre-defined selection criteria was performed separately by two reviewers. Any disagreements regarding the eligibility of studies were reconciled at the final step by consensus.

Additionally, a forward tracking references was performed to retrieve additional relevant studies.

3 Presentation and Discussion of Results

Our search obtained 132 records, without duplicates. A total of 102 studies were excluded based on their title or abstract, while 20 studies were excluded upon full-text review. By forward tracking references, 4 additional studies were included. At the end, fourteen studies that met the pre-defined inclusion criteria were included in the review [10, 14–26].

The study selection flowchart is presented below (Fig. 1), identifying the different screening stages, as well as the results obtained in each phase. The reasons for exclusion of the records are identified accorded the numerical identification previously presented in the method section.

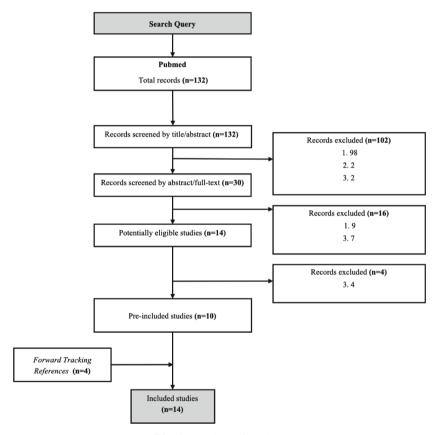


Fig. 1. PRISMA flowchart

Regarding geographic location, seven studies were conducted in United States of America (USA), three in Canada, two in South Africa, one in Japan and one in United Kingdom (UK), all published between 2001 and 2019.

Selected records were analyzed and the elements about publication, namely authorship, year, country and objective are presented in Table 1. Regarding the methodology and content, the study design, sample, and results are presented in Table 2.

Table 1. Description of study publications included in the systematic literature review

| Authors (Year) Country | Objective |
|---|---|
| Berthenet <i>et al.</i> (2016) Canada [14] | To evaluate and validate a set of pictograms depicting medication instructions for use among the elderly to support health literacy. Improve pictogram by redesigning them based on participant's feedback |
| Dowse & Ehlers (2001) South Africa [15] | To evaluate and compare pharmaceutical pictograms developed locally and culturally adapted, with pictograms from USP (1991 edition), in a black population with low literacy. Investigate the effectiveness of these pictograms in a simulation recall of medical instructions |
| Dowse & Ehlers (2005) South Africa [10] | To determine the influence of medicine labels incorporating pictograms on the understanding of instructions and on adherence Design labels with pictograms for selected drugs and compare their understanding with conventional labels (text only) and assess the influence of pictographic labels on therapeutic adherence in patients with low literacy |
| Fukuda <i>et al.</i> (2019) Japan [16] | To determine the usefulness and effects of a pictogram for alerting patients about drugs that affect driving to prevent traffic injury and maintain good adherence |
| Gazmararian <i>et al.</i> (2010) USA [17] | To evaluate a 3-part intervention (automated telephone reminder calls to refill prescriptions, picture prescription card, and clear health communication training for pharmacists) intended to increase refill adherence |
| Hawkins & Firek (2014) USA [18] | To evaluate the efficacy of a pictorial medication sheet to improve adherence in veterans with heart failure and cognitive impairment and describe the acceptance of the intervention |
| Kim <i>et al.</i> (2016) Canada [19] | To test the effectiveness of the health pictograms created based on United States Pharmacopeia's (USP) pictogram composite rule. Test its understanding on senior volunteers |
| Leong <i>et al.</i> (2017) USA [20] | To determine if pictograms improved patients' ability to correctly fill a pillbox |
| Poureslami et al. (2012) USA [21] | To explore the effectiveness of different formats of culturally relevant information and its impact on asthma patient's self-management within the Punjabi, Mandarin, and Cantonese communities |
| Cordasco <i>et al.</i> (2009) USA [22] | To improve medication adherence in cardiac patients, in partnership with a safety-net provider, this research team developed and evaluated a low-literacy medication education tool |

Table 1. (continued)

| Authors (Year) Country | Objective |
|---|---|
| Schillinger et al. (2005) USA [23] | To assess concordance between patient and clinician reports of patient warfarin regimens |
| Kripalani <i>et al</i> . (2007) USA [24] | To develop, implement and pre-evaluate an illustrated medication schedule ("pill-card") that indicates daily medication using icons and images of pills |
| Kripalani <i>et al</i> . (2012) USA [25] | To test the effect of two interventions on medication adherence in a low literacy sample |
| Knapp et al. (2005) UK [26] | To compare the understanding of two sets of pictograms related to instructions or warnings (from USP and South Africa) in adults in the United Kingdom; and to assess 1) the interpretation of USP pictograms among the elderly, 2) the effect of the size of the pictogram on interpretation, and 3) any change in the rate of interpretation in the repetition of the presentation after explaining the correct meaning in the first presentation |

Most of the selected studies [10, 16, 17, 19, 20, 22–26], evaluated the usefulness of pictograms as a tool to support medication management, in order to improve therapeutic outcomes.

Some of the studies included in this review, although not involving only a sample made up of elderly patients, verified the influence of age on the interpretation of pictograms. In the study developed by Dowse & Ehlers (2005) [10], the age of the sample was not considered as a variable in understanding the meaning of pictograms. However, since the study involves a population with limited reading skills, in a society with different cultural contexts, the results present a positive influence of pictograms on medication management and adherence. This factor, especially associated with medication management, has been described in other studies, such as Advinha *et al.* (2016, 2018) [27, 28]. The authors further demonstrate that pictograms should rarely be the only source of communication, since they do not convey the level of detail necessary for the proper understanding of pharmaceutical information, showing that they are an effective aid to understanding and remembering, if combined with text, demonstrating the need for contextualization (previous explanation of the meaning), as mentioned in the studies by Kripalani *et al.* [24, 25].

Studies using pill-card or medication sheet interventions with pictograms have shown the importance of this tools for medication-related information flow between different languages and cultures, since pictograms can be more easily understood than the traditional medication labels. However, the authors do not neglect the importance of a previous evaluation of the images, to ensure that they are easily interpreted, culturally appropriate and that they must be accompanied by an explanation [18, 24, 25]. In fact,

the combination between the illustration and a textual caption, is also found in studies developed by multidisciplinary teams constituted by pharmaceutical and design experts [6, 29].

Berthenet *et al.* (2016) [14] in their study on the use of 76 pictograms from International Pharmaceutical Federation (FIP) in the elderly population, suggest that they should be validated in seniors, even though they have already been validated in young populations, as referred also by Kim *et al.* (2016) [19], where the authors emphasize the importance of taking age and health literacy into account when validating and applying pictograms.

Both studies by Dowse & Ehlers (2001, 2005) [10, 15] were carried out in South Africa, a multicultural and polyglot society, with eleven official languages. The first study revealed that the patient's literacy has a great influence on the ability to understand the pictograms and highlighted the importance of a follow-up in testing phase, namely if the results related to comprehension were significantly better after a second interview [15]. In the second study, comprehension and adherence was assessed using text-only (control) or text with pictogram (experimental) labels for antibiotics [10]. Understanding was measured through interviews and adherence was assessed by counting pills, three to five days after enrollment. The use of pictograms has proved to be particularly helpful for transmitting medication schedule and additional instructions (e.g., to take the medicine before meal, the importance of taking the complete antibiotic pack). In addition, medication adherence was greater in the group that used the support of pictograms.

The study by Fukuda *et al.* (2019) [16] investigated the possibility that the use of existing pictograms in Japan may have different effects on patients' medication-taking behavior, specifically assessing the extent to which a pictogram with a warning message can change patients' behavior. The results obtained suggest that, especially in the elderly population, the addition of this type of pictograms has shown the potential to promote safe behaviors and at the same time promote the medication adherence.

Gazmararian *et al.* (2010) [17] implemented an intervention with three components: 1) telephone call reminders to replace medication; 2) personalized pictographic prescription with the appearance, indication, daily dosage for each medication; and 3) training sessions for pharmacists on the principles of health communication, as well as on the use of pictographic prescriptions as a counseling tool. About 80 to 90% of the participants stated that this tool, together with the telephone call reminder, helped them to remember their medication and prescriptions refill.

In their study, Hawkins & Firek (2014) [18] obtained two important conclusions: 1) the medication sheet with pictograms improved adherence, and 2) the intervention was positively received as a tool for improving adherence and that it makes therapeutic reconciliation easier, although in general adherence to medication was low. Regarding the use of medication sheets with pictograms, 74% considered the intervention to be a great help in medication management, with 90% considering it as an especially useful tool for newly diagnosed patients. Participants also report that this tool allowed other caregivers, namely from family, to help them in pillbox refill without fear of failure.

Kim et al. (2016) [19] designed a set of seven new pictograms and tested their understanding on senior volunteers at a wellness center. The results showed that compared

to the USP pictograms, the new pictograms have lower rates of correct interpretation, namely due to 1) misinterpretation of the main action represented 2) ignoring conditional information, and 3) making an incorrect semantic association between the main information and the conditional information. This study reported important considerations about health pictograms design.

In the pilot study by Leong *et al.* (2017) [20] although the use of pictograms did not significantly improve the participants' ability to correctly refill a pillbox, 77% of the participants indicated that the pictograms helped them to understand the medication instructions, and 67% gave preference to pictograms. About 93% agreed that pictograms should be used on all drug labels.

The results obtained by Cordasco *et al.* (2009) [22], reported that the pictograms increased patient knowledge about his medication and seemed to improve adherence, as well as the clinical accuracy.

In the study by Schillinger *et al.* (2005) [23] the researchers assessed the agreement between reports of long-term warfarin users, with the physician's reports, in which patients were asked to: 1) verbalize their prescribed weekly warfarin regimen, and 2) identify that same regimen from a digitalized color menu of warfarin pills. Approximately 50% of patients achieved verbal agreement with the medical report, while 66% obtained visual concordance with the weekly warfarin regimen reported by the doctor (p < 0.001). When patients changed the reporting of their regimen from verbal to visual, there was a greater patient-physician concordance in all subgroups. This improvement appeared to be greater in patients with communication barriers. The use of visual aid elements has been shown to be effective in improving the accuracy of these reports and, consequently, improving agreement between doctor and patient over time, particularly in older patients.

In Poureslami *et al.* (2012) [21], it was found that the technique of using inhalers in patients with asthma improved significantly in intervention groups in which instructions were given in the form of educational videos or in pictographic pamphlets. In this study, it was also shown that younger individuals with higher levels of education demonstrated a more significant improvement in knowledge about asthma, compared to older participants with a lower level of education. These findings suggest that the interaction between age, education level, gender and knowledge may influence the correct use of the inhaler in controlling asthma, suggesting the realization of new studies that explore the role of aging and cognitive decline in the learning styles of different ethnic-cultural groups.

In Kripalani's study (2007) [24] an illustrated pill-card was developed as an intervention for a randomized controlled trial – Improving Medication Adherence through Graphically Enhanced Interventions in Coronary Heart Disease (IMAGE-CHD) [25] between 2004–2005. At initial presentation, a pharmacist explained the pill-card and performed a pharmacotherapeutic review, according the illustrated regimen. Furthermore, the card contained also the information about important side effects and other special instructions for administration (e.g., taking with food, take at bedtime). After three months of intervention, a follow-up was carried out, providing information about the effectiveness. The patient's responses varying especially with literacy level. More than 80% of patients (n = 173) reported the frequent use of the pill-card. About 40% reported using it every day, and more and 25.8% used it at least once a week. The use

Table 2. Description and characterization of the studies included in the systematic literature review.

| Study | | Study design | Sample | | | Main results |
|-------------------------------------|------------|--------------------|---------------|----------------|---|--|
| | | | Dimension (n) | n _i | Age $(y = years)$ | |
| Berthenet <i>et al.</i> (2016) [14] | | Quasi-experimental | 135 | 135 | 79.3 y (SD = 7.7) | There were no significant differences in the general understanding between the two age groups (older and younger than 80 years old), however, age influenced the interpretability and translucency of certain pictograms. The level of education did not influence the general understanding when all pictograms were included in the analysis (p = 0.09). However, there was a statistically significant difference in translucency when comparing low and high levels of education in the study population (p = 0.01). Compared to participants with less than 12 years of schooling, participants with 12 or more years of schooling, participants with 12 or more years of schooling, participants with 12 or more years of schooling had higher scores for transparency |
| Dowse & Ehlers (2001) [15] | 2001) [15] | Prospective cohort | 46 | Not reported | Sample of interest >60 y 41-65 y: 26 (56.5%) >65 y: 3 (6.5%) | The results of the literacy tests indicate that when having completed between 5 to 7 years of schooling, there is a strong probability that the understanding of written information is incomplete. In the 1st interview, only 7 (30%) of the "Local" pictograms and 2 (8.7%) completed the ANSI criterion of understanding ≥85%, and these results improved in the 2nd interview to 20 and 11 pictograms, respectively |

 Table 2. (continued)

| Study | | Study design | Sample | | | Main results |
|-------------------------------------|-------------|--------------------------|---------------|--------------|--------------------------|--|
| | | | Dimension (n) | nj | Age $(y = years)$ | |
| | (2005) [10] | (2005) [10] Case-control | 87 | 7 | Sample of interest >65 y | The pictograms seem to contribute to improve comprehension since no participant in the experimental group obtained such a low score as the control group, and the majority in this group (72%) had a high level of understanding (>90%). The mean score for comprehension was significantly better in the experimental group (95.2%) than in the control group (69.5%) |
| Fukuda <i>et al.</i> (2019) [16] | | Not reported | 1200 | Not reported | 49.58 (SD = 16.21) | Regarding age, the perception of risk was significantly higher in respondents in their 50's and 60's than in young people around 20 years old. Older participants rated the pictogram as more useful: specifically, those interviewed in their 50s and 70s compared to those aged ≈20 years 63.2% of the interviewees would adopt desirable behaviors both for the prevention of accidents and for their treatment |

 Table 2. (continued)

| Study | Study design | Sample | | | Main results |
|--------------------|--------------|---------------|---------------------------|-----------------|--|
| | | Dimension (n) | ni | Age (y = years) | |
| Gazmararian et al. | Intervention | 275 | 50-64 y (I = 70 C = 4) | ≥65 y | Adherence to medication was significantly |
| (2010) [17] | | | ≥65 y | | different between the intervention group (mean |
| | | | (I = 32 C = 19) | | CMG (cumulative medication gap) = 0.25) and |
| | | | | | control (mean CMG = 0.18) (p = 0.004). This |
| | | | | | difference was not significant when assessed |
| | | | | | during follow-up (p = 0.57) |
| | | | | | Participants in the intervention group $(n = 173)$ |
| | | | | | were subjected to several questions during the |
| | | | | | 6-month follow-up survey to determine their |
| | | | | | satisfaction when receiving the prescription |
| | | | | | with images and telephone intervention. The |
| | | | | | feedback from both techniques was very |
| | | | | | positive, with more than 80% of the |
| | | | | | intervention participants indicating that the |
| | | | | | prescription with images helped them "a lot" to |
| | | | | | remember the names of the drugs, indication, |
| | | | | | and when and how much to take of the |
| | | | | | medication. Approximately 80% of the |
| | | | | | intervention participants felt that the use of the |
| | | | | | prescription with images improved the |
| | | | | | pharmacy's advice and affected their overall |
| | | | | | satisfaction |

 Table 2. (continued)

| Study | Study design | Sample | | | Main results |
|--------------------------------|---|---------------|---|-------------------------------|---|
| | | Dimension (n) | n _i | Age $(y = years)$ | |
| Hawkins & Firek (2014) [18] | Pilot study Interventional within-subjects | 27 | Not reported | Mean age 65.3 y (SD = 8.2) | In general, medication adherence was low, however, there were improvements in pre-intervention adherence (M = 79.74, SD = 16.98) to post-intervention adherence (M = 84.74, SD = 10.00) 20 participants (74.1%) accepted the pictographic intervention, 20 (74.1%) considered it useful for themselves and others, and 24 participants (88.9%) considered it useful for themselves and others. |
| Kim et al. (2016) [19] | Transversal | 24 | $\leq 70 \text{ y} = 28$ > $70 \text{ y} = 14$ | Not reported | The USP pictograms showed a higher rate of correct interpretation in relation to the new pictograms developed in this study. The general rate of correct interpretation was 61.56% (SD = 22.41%) for the 7 USP pictograms while for the new pictograms it was only 40.48% (SD = 20.67%) being this afference statistically significant (p < 0.005) when using the Wilcoxon test. Higher rates of correct interpretation were observed in groups of participants with higher education, male, under 70 years old and white |

 Table 2. (continued)

| Study | Study design | Sample | | | Main results |
|---|-----------------------------------|---------------|----------------------|--------------------------------|--|
| | | Dimension (n) | nj | Age (y = years) | |
| Leong <i>et al.</i> (2017) [20] | Randomized controlled pilot study | 30 | 30 | Mean age 54.9 y (SD = 15.6) | 21 participants passed the PT Text (PillBox Text) and 19 on the PT Pictogram. Two participants passed the PT pictogram, but not the PT text; 4 participants passed the PT text and not the PT pictogram. There was no difference in the approval of the text with text or pictograms. PT results using pictograms did not show a significant improvement in medication understanding Older and unemployed participants were more likely to fail the PT |
| Poureslami <i>et al.</i> (2012) [21] | Randomized controlled trial | 85 | $Group 4$ $B_1 = 22$ | Mean age 62.9 y (SD = 15.3) | Adequate use of inhalers improved significantly between all experimental groups over time (CI = 1.79 ± 0.52 , p < 0.001), as well as the participants' knowledge about asthma symptoms (CI = 0.83 ± 0.53 , p < 0.01) Patients with a higher level of education and patients under 60 years of age showed significant improvements in knowledge of asthma symptoms and factors that aggravate the condition The four groups showed improvement in their knowledge of asthma "triggers" over time |

 Table 2. (continued)

| Study | Study design | Sample | | | Main results |
|---------------------------------------|-----------------------------|-------------------------------|----------------|---|--|
| | | Dimension (n) | n _i | Age (y = years) | |
| Cordasco <i>et al.</i> (2009) [22] | Randomized controlled trial | 210 INT = 100 CTR = 110 | Not reported | Mean INT = 55.7 y (SD = 11.6) Mean CTR = 55.7 y (SD = 11.6) | Among the 166/210 eligible participants (79%) who completed the 2-week interview, reported that medication adherence was 70% (CI ₉₅ %: 62%, 79%) in the intervention participants and 78% (CI ₉₅ %: 72%, 84%) in the control group (p = 0.13). Among the 85 participants (31%) who completed the 4-week interview, self-reported pill counts indicated high adherence (greater than 90%) that did not differ adherence (greater than 90%) that did not differ with the self-reported pill count by the intervention participants (R = 0.5; p = 0.004), but not in the control group (R = 0.07; p = 0.65) |
| Schillinger <i>et al.</i> (2005) [23] | Transversal | 220 | 107 | Sample > 60 Mean age 59 y | 66% of patients' visual reports about their therapeutic regimens agreed with the doctor's reports Unlike verbal agreement, visual agreement did not differ between individuals who speak Cantonese and individuals who speak English (14% vs. 66%) or individuals who speak English (62% vs. 66%). Among individuals who speak Spanish and individuals who speak English (62% vs. 66%). Among individuals who speak Spanish and English, agreement was lower for patients with inadequate versus adequate health literacy (57% vs. 74%) |

 Table 2. (continued)

| Study | | Study design | Sample | | | Main results |
|------------------------------------|-------------|---|-----------------------------------|---|-----------------------------------|--|
| | | | Dimension (n) | nj | Age (y = years) | |
| Kripalani <i>et al.</i> | (2007) [24] | Intervention | 209 | Not reported | Mean age 63.7 y (SD = 10.3) | Among the 209 respondents, 173 (83%) reported using the pill-card when they first received it, although use has decreased to 60% approximately 3 months later. Patients with low literacy, less than high school education or cognitive impairment are more likely to consult the card regularly at the beginning and at 3 months (p < 0.05) and to understand, and 94% found it useful to remember important information about medications, such as name, indication or time of administration |
| | (2012) [25] | Randomized controlled trial | 435 | >65y: 203 | Mean age 63.7 y | Overall, adherence did not differ significantly between groups: 31.2% in the group that received usual care, 28.3% with replacement reminders, 34.2% with medication schemes illustrated with pictograms, and 36.9% with both interventions |
| Knapp <i>et al.</i> (2005) [26] | | 1st part: Randomized controlled trial part: Randomized controlled trial | 1st part 160 2nd part 67 | 1^{84} part ≥ 65 years $(n = 31)$ 2^{104} part $65-96$ y $(n = 67)$ | 65–96 years Mean age 79.3 y | In the 1 st part of the study, only 3 of the 20 pictograms met the criteria of 85% correct interpretation as defined by ANSI. The effects of age on the interpretation rate demonstrated that the average score decreased significantly with increasing age: among the four age groups 17–24 (n = 38), 25–34 (n = 39), 35–64 (n = 52), and \geq 56 (n = 31) the scores obtained were 6.7, 6.5, 5.7 and 39, respectively. The results of the 2 rd part of the study show that participants are more likely to correctly interpret larger pictograms (p = 0.037) and after a second presentation (p < 0.001) |

of the pill-card was greater among patients with lower literacy and/or cognitive impairment. Regarding the IMAGE-CHD, there were no statistically significant improvements regarding adherence.

Finally, the study by Knapp *et al.* (2005) [26] suggests that some existing pictograms are not correctly interpreted, and they should be carefully applied in practice. The size of the pictogram had a significant effect on interpretation by elders, and in this population, it could be beneficial to use of life-size versions to transmit information.

In several studies, elderly participants considered the pictograms to be useful in medication management [16–18, 20, 21, 24] and in improving adherence [10, 16, 18, 22, 24]. In addition, they can constitute an efficient tool in overcoming language barriers [23]. However, numerous studies have considered that the use of these auxiliaries must be taken care of and implies their validation since sociodemographic factors such as age, level education and health literacy influence the understanding of the pictograms [10, 14, 15, 19, 21, 24–26], being mentioned that they must be applied together with text, contextualized [15, 20] and must be previously explained to patients by the health professional who accompanies them (doctor, nurse or pharmacist) [15, 16, 21, 26].

4 Conclusion

Globally, the founded studies were heterogeneous with regard to the study design, population size and types of results, facts that are limitations to this review but, in general, the interventions showed positive results promoting greater patient adherence to treatment and controlling problems related to the incorrect use of medication.

However, as many types of pictograms still produce low levels of comprehension, the specific results reinforce the need to use evaluated, adapted and validated country-specific pharmaceutical pictograms, among each age group and setting.

This systematic literature review represents the first step that needs to be done for testing pictograms in the Portuguese elderly population, namely the one that attends to community pharmacies. The second step will be the prior training through patient counseling on the intended meaning.

Finally, in a world of constant technological advances, it is essential to test the use of these pictograms in mobile applications or digital devices to assist elderly patients in medication management, aiming to improve adherence and consequently positive health outcomes. Mobile applications play an important role in mHealth, as they allow users to access information quickly, at the touch of a finger, even in the elderly population, as already broadly demonstrated.

References

- Galvão, C.: O idoso polimedicado Estratégias para melhorar a prescrição. Rev. Port. Med. Geral e Fam. 22(6), 747–752 (2006)
- Vaillancourt, R., Giby, C.N., Murphy, B.P., Pouliot, A., Trinneer, A.: Recall of pharmaceutical pictograms by older adults. Can. J. Hosp. Pharm. 72(6), 446–454 (2019). PMID: 31853145
- Maddigan, S.L., Farris, K.B., Keating, N., Wiens, C.A., Johnson, J.A.: Predictors of older adults' capacity for medication management in a self-medication program: a retrospective chart review. J. Aging Health 15(2), 332–352 (2003)

- 4. Renpenning, K.M., Taylor, S.G.: Self-Care Theory in Nursing: Selected Papers of Dorothea Orem. Springer, New York (2003)
- 5. Puspitasari, H.P., Aslani, P., Krass, I.: A review of counseling practices on prescription medicines in community pharmacies. Res. Soc. Adm. Pharm. **5**(3), 197–210 (2009)
- Merks, P., Świeczkowski, D., Balcerzak, M., Drelich, E., Białoszewska, K., Cwalina, N., Krysinski, J., Jaguszewski, M., Pouliot, A., Vaillancourt, R.: The evaluation of pharmaceutical pictograms among elderly patients in community pharmacy settings – a multicenter pilot study. Patient Prefer. Adherence 12, 257–266 (2018)
- 7. Kolers, P.: Some formal characteristics of pictograms. Am. Sci. **57**, 348–363 (1969)
- 8. Barros, I.M.C., Alcântara, T.S., Mesquita, A.R., Santos, A.C., Paixão, F.P., Lyra Jr., D.P.: The use of pictograms in the health care: a literature review. Res. Social Adm. Pharm. **10**(5), 704–719 (2014)
- 9. Davies, S., Haines, H., Norris, B., Wilson, J.R.: Safety pictograms: are they getting the message across? Appl. Ergon. **29**, 15–23 (1998)
- 10. Dowse, R., Ehlers, M.: Medicine labels incorporating pictograms: do they influence understanding and adherence? Patient Educ. Couns. **58**, 63–70 (2005)
- 11. Paivio, A.: Imagery and Verbal Processes. Holt, Rinehart, and Winston, New York (1971)
- 12. Dual Coding and Common Coding Theories of Memory (2014). http://plato.stanford.edu/entries/mental-imagery/theories-memory.html. Accessed 28 Sept 2020
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G.: Preferred reporting items for systematic reviews and meta-analyses: the PRISMA Statement. Syst. Rev. 4 (2009). p. 1. https://doi.org/ 10.1186/2046-4053-4-1
- Berthenet, M., Vaillancourt, R., Pouliot, A.: Evaluation, modification, and validation of pictograms depicting medication instructions in the elderly. J. Health Commun. 21, 27–33 (2016)
- Dowse, R., Ehlers, M.S.: The evaluation of pharmaceutical pictograms in a low-literate South African population. Patient Educ. Couns. 45(2), 87–99 (2001)
- 16. Fukuda, Y., Ando, S., Saito, M.: Effect of a Japanese drug alert pictogram on medication-taking/driving behavior. Traffic Inj. Prev. **21**(1), 18–23 (2019)
- Gazmararian, J., Jacobson, K.L., Pan, Y., Schmotzer, B., Kripalani, S.: Effect of a pharmacy-based health literacy intervention and patient characteristics on medication refill adherence in an urban health system. Ann. Pharmacother. 44(1), 80–87 (2010)
- Hawkins, L.A., Firek, C.J.: Testing a novel pictorial medication sheet to improve adherence in veterans with heart failure and cognitive impairment. Heart Lung 43(6), 486–493 (2014). 100
- 19. Kim, J., Fnu, V., Bell, E., Kim, H.: Feasibility of the rule-based approach to creating complex pictograms. Stud. Health Technol. Inform. **225**, 397–401 (2016)
- Leong, M., Tam, V., Xu, T., Peters, M.: Understanding medication schedules: do pictograms help? J. Patient Saf. 14(2), e19–e24 (2017)
- Poureslami, I., Nimmon, L., Doyle-Waters, M., Rootman, I., Schulzer, M., Kuramoto, L., et al.: Effectiveness of educational interventions on asthma self-management in Punjabi and Chinese asthma patients: a randomized controlled trial. J. Asthma 49(5), 542–551 (2012)
- Cordasco, K.M., Asch, S.M., Bell, D.S., Guterman, J.J., Gross-Schulman, S., Ramer, L., et al.:
 A low-literacy medication education tool for safety-net hospital patients. Am. J. Prev. Med. 37(6), S209–S216 (2009)
- 23. Schillinger, D., Machtinger, E.L., Wang, F., Chen, L.-L., Win, K., Palacios, J., et al.: Language, literacy, and communication regarding medication in an anticoagulation clinic: are pictures better than words? In: Henriksen, K., Battles, J.B., Marks, E.S., Lewin, D.I. (eds.) Advances in Patient Safety: From Research to Implementation (Volume 2: Concepts and Methodology). Agency for Healthcare Research and Quality (US), Rockville (2005)

- 24. Kripalani, S., Robertson, R., Love-Ghaffari, M.H., Henderson, L.E., Praska, J., Strawder, A., et al.: Development of an illustrated medication schedule as a low-literacy patient education tool. Patient Educ. Couns. 66(3), 368–377 (2007)
- Kripalani, S., Schmotzer, B., Jacobson, T.A.: Improving medication adherence through graphically enhanced interventions in coronary heart disease (IMAGECHD): a randomized controlled trial. J. Gen. Intern. Med. 27(12), 1609–1617 (2012)
- Knapp, P., Raynor, D.K., Jebar, A.H., Price, S.J.: Interpretation of medication pictograms by adults in the UK. Ann. Pharmacother. 39(7–8), 1227–1233 (2005)
- Advinha, A.M., Henriques, A., Guerreiro, M.P., Nunes, C., Lopes, M.J., Oliveira-Martins, S.: Cross-cultural validation of the drug regimen unassisted grading scale (DRUGS) to assess community-dwelling elderly's ability to manage medication. Eur. Geriatr. Med. 7, 424–429 (2016)
- Advinha, A.M., De Barros, C.T., Guerreiro, M.P., Nunes, C., Lopes, M.J., Oliveira-Martins, S.: Cross-cultural validation and psychometric evaluation of the self-medication assessment tool (SMAT) for assessing and optimizing medication therapy management of older people. Eur. J. Pers. Centered Healthc. 6, 655 (2018)
- Camacho, B.: Design e avaliação de pictogramas farmacêuticos. Ph.D. thesis. Universidade de Aveiro, Aveiro (2013)



Impact of Socialization on Active Aging in the Geriatric Population: A Systematic Literature Review

Andreia Plexa¹(⋈), Helena Gonçalves², Rosa Castanheira², Sofia Marçal³, Olga Valentim⁴, César Fonseca^{5,6}, and Lara Guedes de Pinho^{5,6,7},

¹ Centro Hospitalar Psiquiátrico de Lisboa, Lisbon, Portugal

² Agrupamento de Centros de Saúde de Cascais, Administração Regional de Saúde Lisboa e Vale do Tejo, Cascais, Portugal

³ Department Manager, Primark, Lisbon, Portugal

⁴ Instituto Politécnico de Leiria - Escola Superior de Saúde, NursID, CINTESIS (Centro de Investigação em Tecnologias e Serviços de Saúde), Porto, Portugal

⁵ Universidade de Évora, Évora, Portugal

 $^{\rm 6}$ Comprehensive Health Research Centre (CHRC), Évora, Portugal

⁷ Instituto Politécnico de Portalegre, Portalegre, Portugal

Abstract. Background: Aging is a current concern of societies. The changes that it requires, not only from the health teams as their management, inspired this article across the elucidation of socialization effect on the aging process. New technologies are fundamental, but they do not replace the human relationship.

Methods: systematic literature review. The descriptors "healthy aging" AND "socialization or interpersonal relations" AND "geriatrics or older adults or elderly" were searched between December 3 to 4, of 2019, on the EBSCO and B-on platforms. Article selection performed according to criteria predefined: sample older than 60 years; an object of study related to the research question; ten-year time limit; and Portuguese and English languages.

Results: Article analysis comprised 9 out of 73 articles. Social interactions with family, friends, peers, and community influences successful and healthy aging in the elderly population. The level of well-being, optimistic spirit, development of physical activity, maintenance of independence, and cognitive function are factors that also affect this aging process.

Conclusions: It would be enriching to reach a consensual definition regarding active aging in the literature. The use of new technologies, such as video calls, are an important tool in social relationships, when close contact is not possible.

Keywords: Aging · Elderly · Socialization · Interpersonal relations

1 Introduction

The aging of the population is nowadays considered an emerging social problem in many countries. Data from the United Nations (UN) predicts a 46% increase in the world population over 60 years of age, up to 2030. This growth will occur at a higher

rate in developing countries, which may represent one of the most important social transformations. Portugal is in the 4th place of European Union countries with the highest percentage of seniors [1].

The increase in average life expectancy and the decrease in birth rates are associated with Portugal's condition. Together, these aspects encourage reflection on the profound transformations and consequent impact on people's lives. On this account, begins the pursuit of more appropriate responses and strategies for this new reality.

According to data from PORDATA (2015, cited in Serviço Nacional de Saúde (SNS), 2017), the aging rate in Portugal suffered a tremendous increase from 27.5% in 1961 to 143.9% in 2015. A considerable impact on society can be noted consequently, which requires adaptations and solutions at different levels, particularly regarding support systems, such as health, social security, education, justice, and transport systems.

The Portuguese case is not insulated, going along with other European countries. Contemporary society experiences one of the most striking phenomena: the demographic revolution characterized by the lower number of births and the magnification in longevity. Hereupon, a comprehensive set of factors are associated, not merely related to health but also highlighting better education, access to employment, income, and social security [2].

The Portuguese Nacional Statistic Institute – *Instituto Nacional de Estatística (INE)* – points to the further aging of the population. Demonstrated through the data, one out of three residents will be elderly by 2050. Thus, Portugal will occupy the third place as the country with the most elderly population in the world, right after Japan and Spain [3].

As previously known, the third objective outline in the Health and Well-being area of the UN Plan of Action for Sustainable Development aims to ensure a healthy life and promote well-being for all, throughout all ages. The World Health Organization (WHO) transmits several recommendations regarding changes in current health policies and service delivery to aged populations. Adding to this, WHO reinforces the importance of healthy aging, emphasizing the influence of life choices and individual trajectories in aging, which contribute to personal health and well-being [4].

Concerning active and healthy aging, Portugal is committed to the WHO Strategy and Global Action Plan for Healthy Aging, besides the fundamental values and objectives of the European Union (EU). Collectively, these directives support the promotion of active aging, which is observable in initiatives such as the EU Proposals for Action to promote Active and Healthy Aging and Solidarity between Generations (Decision No. 940/2011/U, of the European Parliament and of the Council, of September 14). This document points out the importance of technological evolution in monitoring the aging of the population, since it can provide an opportunity for optimizing the functional capacity of elderly, along with their well-being [5].

Active and healthy aging defines itself as the process of optimizing not only opportunities for health, social involvement, and safety, but also the development and maintenance of functional capacity to improve the quality of life as people age. Thereby this contributes to the well-being of the elderly, considering functional capacity as the result of the interaction of the person's intrinsic capacities (physical and mental) with the environment. The promotion of active aging requires a multidimensional approach in the light of accountability and permanent support among all generations [4, 5].

A way to overcome the challenges related to longevity and aging of the population has been associated with active and healthy aging promotion throughout the life cycle [5].

The term "active" refers to continuous participation in social, economic, cultural, spiritual, and civic life. In other words, it goes heavily beyond the concept of being physically and professionally active.

Although health conditions are decisive in active aging, its promotion is not restricted to the practice of healthy behaviours. On the contrary, is crucial to consider environmental and personal factors, such as economic, social and cultural determinants, physical environment, health system, sex, and other determinants [5].

The main goal is well-being, a holistic concept that includes all the elements and components of life with high value to the person. Consequently, further than success and individual motivation achievements, healthy aging reflects life habits, support and opportunities based on society's effort to maintain the functionality of the elderly and to allow them experience what they worship [5].

Additionally, active and healthy aging can also suffice as an economic enhancer through the dynamism of entrepreneurship, co-creation, and co-development. Likewise, it is possible to generate added value through a positive impact for elderlies' life quality. It includes aspects such as greater satisfaction of health professionals and caregivers, better family members and other informal caregivers' overall life and financial security quality, along with higher efficiency and increased productivity of health and social security systems [5].

Currently, we are witnessing a new paradigm on aging, with an anticipation of a significant increase in average life expectancy worldwide. From this standpoint, it would possibly result in profound changes in the current way of facing this stage of development. Nowadays, do not only want people to live longer, but a lifetime with more quality, which collectively underlines the importance of active aging.

This reality is accompanied by the integration of new technologies, enhancing novel lifestyles. In contradiction to a significant increase in chronic and degenerative diseases, society adopts new habits of sport and healthy eating practices, which promotes socialization among people who forward-looking for an extended and higher quality life.

Socialization is fundamental in all life stages. However, it has an outstanding importance when reaching old age, especially to allow autonomy, life experience value, and to motivate for quality and well-being.

The reflection on this reality led us to the central question that guides our research: Impact of socialization on active aging in the geriatric population.

According to the method for elaborating the research question recommended by the Joana Briggs Institute (Population, Intervention, Comparison and Outcomes (PICO)), was first identified: the study population (geriatric population), the intervention (socialization), and results (active aging), leading to the research's question: "What is the impact of socialization on active aging in the geriatric population?" [6].

As a common concern for this study researchers, we consider essential the study of socialization effects on the active aging of the geriatric population. However, given the time limit, it was necessary to focus on the study's question, prioritizing socialization/interpersonal relationships in this current theme that we would like to deepen. After reading some articles the researchers found that this social component is less studied, returning more evidence about the cognitive and physical dimensions. Accordingly, this study aims to map the existing knowledge produced in the scientific evidence concerning this social component in active aging and apply this knowledge in the practice of the researchers.

This question corresponds to an attempt to obtain answers that meet this current problem, embarking on a systematic review of the literature as the most suitable method in the current academic context.

The research development in accordance to achieve the following objectives: Analyse the importance of a worldwide aged population effect; Reflect on the need for active aging in the geriatric population; Investigate the impact of socialization on active aging in the geriatric population.

Most of the authors perform functions in the health team management area, and in their professional performance, are confronted with the issue of population aging. For this reason, they consider it an asset to carry out this research since the results obtained may be disseminated by the health professionals of the teams they manage. These actions promote projects and intervention strategies for the population over 60 years old, which provide more quality of life in this phase.

2 Methods

The applied methodology was a systematic literature review. The selection of articles and data extraction throughout the research process was implemented by at least two of the authors of the present review to reduce the error chance.

The research was performed from December 3 to 4, of 2019. The descriptors "healthy aging" AND "socialization or interpersonal relations" AND "geriatrics or older adults or elderly" were searched on the EBSCO platforms (databases CINAHL and SPORTD data) and B-on.

The selection of healthy aging descriptor had into account health descriptors and the lack of one option for active aging. This term is defined by "Development and maintenance of well-being and ideal physical, mental, spiritual, and social functions with the advancement of age." (http://decs.bvs.br/cgi-bin/wxis1660.exe/decsserver/).

Respecting the eligibility criteria for the selection of articles, the following was determined: sample structure with people over the age of 60, as it seeks to verify the evidence concerned to the intervention in the geriatric population; studies targeting socialization and/or interpersonal relationships in active aging; the time limit of the last ten years, to determine the most recent evidence; and articles written in Portuguese and English, as they are languages understood by the researchers.

The authors adopted the 60 years of age limit of the participants after no global consensus on the age of onset of the elderly life stage. In Portugal, the legislation establishes 65 years. However, other countries may have 60 years old as the age of the elderly life stage beginning. Consequently, when applying the Portuguese criterion, crucial scientific evidence could be ruled out.

It is worth mentioning that the studied articles referring to diverse concepts such as successful and healthy aging are also related to well-being in the elderly. The researchers took into consideration the existence of yesilarity and shared matter, whereby analysed in the review.

3 Results

The search resulted in a total of 73 articles – 31 from the EBSCO platform and 42 from B-on. After the removal of duplicates, 69 remained for analysis. Initially, their titles were read, which led to excluding articles that did not address the subject under study. By reading the summary, those with unfulfilled requirements regarding the language, study subject, and age of the target population, as well as the paid access factor, resulted in dismissing. Finally, the selection of articles took place through full reading. It is noteworthy that the selection process occurred in parallel with the validation of at least two of the researchers independently. At the end of this screening, 9 articles were ultimately chosen for review (Fig. 1).

Of the studies included, two of them took place in China [7, 8], another two in the USA [9, 10], one in Singapore [11], followed by one in Thailand [12], one in Japan [13], one in Canada [14], and finally, one in South Korea [15]. After article selection, the study's relevant information was systematically retrieved, which is available in Fig. 1.

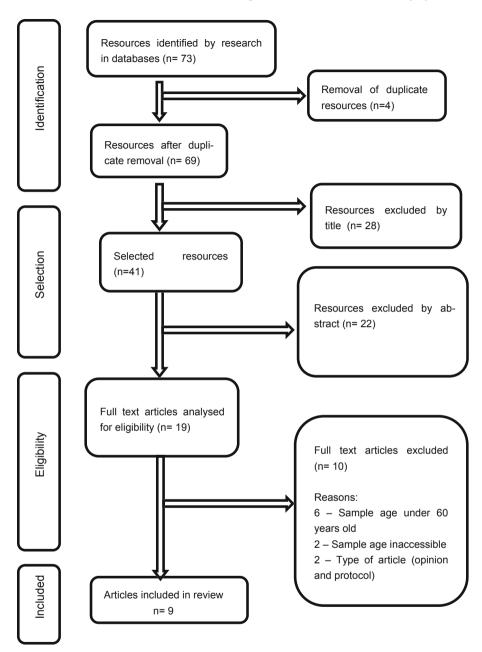


Fig. 1. PRISMA flowchart of the article selection process.

| Reference | Sample | Evaluated dimensions | Objective | Results | Conclusion |
|---|---|--|---|---|---|
| Junling Gao, Scott R. Weaver, Hua Fu, Yingnan Jia, Jiang Li 2017 [7] | 2719 people with more than 60 years of age | Dimension: subjective well-being Evaluated variables: gender, age, marital status, education, years living in the neighbourhood, health condition, chronic diseases, and leisure and physical activity | Examine the relationship between the social and physical components in a neighbourhood using the subjective well-being (SWB) assessment scale | After controlling for each covariate, social cohesion at the individual level and social interaction positively correlate with the SWB. Aesthetic quality at the individual and neighbourhood level also shows a positive correlation with the SWB | The creation of aesthetic and cohesive neighbourhoods can encourage elderly Chinese people to take part in social activities, promoting their SWB |
| Lee et al., 2017 [9] | 550 elderly over 65 years of age | Dimension: successful aging. Variables: socio-demographic (gender, age, etnia, health perception, and education level): presence of positive symptoms and depressive symptoms, satisfaction with social life, limitations in activities of daily living | Develop a brief multidimensional questionnaire to assess successful aging (SA), evaluate its psychometric properties and the relationship between age and the dimensions of SA | Proactivity, well-being, a positive spirit, and established relationships influence successful aging, having been confirmed in both groups. The results also suggest that the Successful Aging Inventory scale may be a useful predictor of successful aging | It is important that successful aging models include social relationships and proactive involvement |
| Xu et al., 2016 [11] | 122 elderly recruited from 10 senior activity centers | Variables analysed: social anxiety, socialization, and loneliness | Examine how "exergaming" influences social anxiety, socialization, and loneliness in the elderly. Additionally, analyse different effects of exergaming by different types of games and in different age cohorts | The results are inherent in a significant effect on the psychosocial well-being of the elderly. Sociability has improved to complement the elderly participants who played with their peers. Despite some disyesilarities found between the different types of games or age groups, a decrease in loneliness after the exergame play is perceptible | The findings contributed to the research on active aging and how to promote social interaction among the elderly |
| Li e Zhang, 2015 [8] | 4190 people from China's Longitudinal Longevity Study | Socio-demographic variables: Age, gender, residence, household, education, employment before retirement, financial support, smoking, relationship with alcohol; Daily life activities; Instrumental life activities; Cognitive function | To verify the impacts of social networks on the health of the older population (physical, cognitive, psychological, and general), and the relationship between the health of the elderly population and the type of social network chosen | The results demonstrate that there is an association between the types of networks (diverse, friends, family, and restricted) and health (physical, cognitive, psychological, and well-being). The diverse social network benefits the health of its users | Social interaction improvement in the elderly can reduce the vicious circle between social isolation and poor health conditions |

| con | itimi | red) |
|-----|-------|------|

| Reference | Sample | Evaluated dimensions | Objective | Results | Conclusion |
|---|--|---|---|--|---|
| Friedman et al., 2019 [10] | 217 Individuals aged 60 or over from three different communities | Dimension: Eudemonic well-being. Variables: Mental health measures (hedonic and eudaimonic well-being, depression, anxiety, and loneliness) and physical health (sleep, somatic symptoms) | Evaluate the "Lighten Up!" program as a promoter of eudaimonic well-being | Participants reported an increase in eudaimonic well-being, and there is a maintenance of these changes for 6 months. Additionally, they showed a significant decline in depressive symptoms, anxiety, and hostility | The program has positive effects to improve well-being in the elderly who live in various community settings |
| Thanakwang, & Soonthorndhada, 2015 [12] | 469 Thai seniors from Nan province | Dimension: Healthy aging. Variables: Physical functioning, cognitive functioning, active involvement with life and positive spirituality and religiosity | Examine relationships between family, friendship network and support, health-promoting behaviour, and healthy aging | Family networks do not directly influence health-promoting behaviours but work as indirect support. Friendship networks have a direct effect on health promotion. Health promotion behaviours had a powerful influence on healthy aging, especially playing a significant role in mediating family relationships, supporting friendship, and healthy aging | Intervention programs should be designed to include collaborative approach involving family and friends |
| Tanaka e Johnson, 2010 [13] | Study in Japan: Japanese aged 65 or over divided into two phases, the first with 4997 people and the second with 4044. Study in the USA: 2200 people over 60 years old | Dimension: Healthy aging. Variables: Social integration, physical disability, psychological health, gender, age, education, and pension value | Relationships between gender and the rural environment can have cultural effects on healthy aging | The results show that social interaction decreases the likelihood of depression and physical disability. Also, living in a house where there is more than one generation reduces symptoms of depression. Older men are less likely to have symptoms of depression than women. Elderly people living in rural areas are more likely to be physically disabled due to daily tasks, but less likely to experience depressive symptoms | If mental health is more important than physical health in increasing life expectancy, older people living in rura areas have a greater expectancy of surviving, as occurs in the USA |

(continued)

(continued)

| Reference | Sample | Evaluated dimensions | Objective | Results | Conclusion |
|----------------------------|--|---|---|--|---|
| Bacsu et al., 2014 [14] | 40 rural seniors over 65 | Dimension: Healthy active aging in rural areas. Variables: Social integration, physical activity, independence, mental vision, optimism, and cognitive health | Describe the meaning of healthy rural aging and which factors influence it | The results agree with research on culture's importance and the need to address perceptions of healthy aging among different populations | Policymakers and researchers must develop more effective interventions to support healthy rural aging, considering their knowledge, experiences, and understandings of rural older people |
| Cha et al., 2012 [15] | 350 Korean elderly people aged 60 and over | Dimension assessed: Successful aging. Variables: Self-esteem, competence, aging scale, self-efficacy scale, interpersonal relationship scale, the instrument of self-realization, and instrument of success | Examine and identify the factors that influence the degree of successful aging among older Korean adults | The results showed that the factor that most influenced successful aging was self-esteem, followed by self-realization, interpersonal relationships, and self-efficacy | Self-esteem is a major predictor of successful aging among Korean elderly people. Thus, health professionals must promote a sense of self-esteem and achieve greater adaptability to aging |

| Referência | Q1 | Q2 | Q3 | Q4 | Q5 | Q6 | Q7 | Q8 | Q9 | Q10 | Check list |
|---|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----------------------|
| Junling Gao, Scott R. Weaver, Hua Fu, Yingnan Jia, Jiang Li | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | _ | Transversal analytic |
| Jeong Eun Lee, Boaz Kahana, Eva Kahana | Yes | Yes | Yes | Yes | No | No | Yes | Yes | _ | _ | Transversal analytic |
| Xuexin Xu, Jinhui Li, Tan Phat Pham, Charles T. Salmon, Yen-Leng Theng | yes | No | No | Yes | Yes | Yes | Yes | Yes | N/A | _ | Quasi experimental |
| Ting Li, Yanlong Zhang | Yes | No | No | Yes | Yes | No | No | Yes | N/A | _ | Transversal analytic |
| EM Friedman, C. Ruini, CR Foy MS, L. Jaros, G. Love, & CD Ryff | Yes | Yes | Yes | No | Yes | No | Yes | Yes | Yes | _ | Quasi experimental |
| Kattikã Thanakwang, & Kusol Soonthorndhada, | Yes | Yes | Yes | Yes | No | N/A | Yes | Yes | _ | _ | Transversal analytic |
| Kimiko Tanaka e Nan E. Johnson | Yes | Yes | Yes | Yes | Yes | Yes | N/A | Yes | _ | - | Transversal analytic |

(continued)

| / | | 1) |
|-----|-------|----|
| 100 | ntinu | od |
| | | |

| Referência | Q1 | Q2 | Q3 | Q4 | Q5 | Q6 | Q7 | Q8 | Q9 | Q10 | Check list |
|---|------|-----|-----|-----|-----|-------------|----------------|------|-----|------|----------------------|
| Juanita Bacsu, Bonnie Jeffery, Sylvia Abonyi, Shanti Johnson, Nuelle Novik, Diane Martz e Sarah Oosman, | Yes | Yes | Yes | Yes | Yes | Pouco claro | Pouco claro | Yes | Yes | Yes | Qualitative research |
| Nam Hyun Cha, Eun Ju Seo e Sohyune R Sok | Yes | Yes | Yes | Yes | No | No | Yes | Yes | _ | _ | Transversal analytic |
| Y% | 100% | 78% | 78% | 89% | 67% | 22% | 67% | 100% | 60% | 100% | |

4 Discussion

In the subject "What is the impact of socialization on active aging in the geriatric population?" two fundamental concepts arise - active aging and socialization. However, it is not possible to find a clear definition of active aging, exhibited with yesilar notions, such as successful aging and healthy aging. Socialization appears in our research, combined with other concepts such as social relationships and social interaction.

The concept of successful aging does not have a consensus in the literature, given its subjectivity [9]. It varies from person to person, as well as its influencing conditions. Some authors define it as adding life to the years, rather than adding years to life, embracing the person's satisfaction with their present and past life. In the quantitative study performed, a multidimensional survey was used to assess successful aging, in which the authors concluded that this concept is also multidimensional, influenced by some variables associated with health and the psychological, behavioural, and social domains [9]. On the other hand, from the perspective of the participants who answered the survey, successful aging is influenced by well-being (physical health, cognitive functioning, and independence), positive spirit and the relationships established. This study provides preliminary contributions to the development of a successful aging inventory. Even so, in the opinion of the authors further studies are needed, namely of a longitudinal type, which allow generalizing the results achieved [9].

Rowe and Khan (1987, cited in Cha, Seo and Sok, 2012, p. 3) [15] define successful aging as the way an older adult, and the people around him, achieve maximum physical, mental and emotional satisfaction, demonstrating an active potential in each of these areas. For successful aging, the person must not have any disability or disease [15]. This definition is a little more comprehensive than the previous description since it includes people who relate to the elderly. Moreover, they are incisive regarding the physical and health conditions of the elderly, when stating that these conditions cannot be affected.

The factors that influence successful aging/healthy aging are targets of study, and in this review, were found three studies that demonstrate which components can influence successful aging and healthy aging. In the first study [15], authors evidence that

self-esteem, self-realization, interpersonal relationships, and self-efficacy are predictors related to successful aging. At the same time, the second study [14] highlights social interaction, physical activity, independence, optimism, and cognitive health as factors to consider. On the other hand, another study [11] presents an investigation about exergaming (interactive game combined with physical activity), where it became clear that well-being and socialization are highly related to healthy aging.

Cha et al. (2012) applied surveys to elderly South Koreans concluding that successful aging can be explained through the variables: self-esteem, self-realization, interpersonal relationships, and self-efficacy. The main predictor of successful aging is considered self-esteem, with strong bonds to life satisfaction. For the elderly to see themselves positively, they must focus on their strengths and not their weaknesses, as well as psychologically adapt to situations and optimally perform all social and family functions. Self-realization is the second predictor of active aging influence. This allows older people to have confidence in their performance, improving their psychological well-being. The desire for self-realization impels the elderly to demonstrate their abilities, thus reaching a higher level of psychological well-being and satisfaction with life. Interpersonal relationships are the third leading predictor that influences the well-being of the elderly. Self-efficacy reveals that the elderly believe they can still achieve their goals, allowing themselves to better manage the crises they may experience. The authors' concern with the well-being and satisfaction of the elderly is perceptible, relating these feelings to successful aging [15].

Another study [14] identified five areas related to healthy aging: social interaction, physical activity, independence, optimism, and cognitive health, through reports from people over 65 years of age. Elderly identify their circle of friends, neighbours, and family members as social interaction, valuing the relationship with their peers through experiences sharing. The elderly would like to establish connections with younger people, although their difficulties in initiating this interaction. Relationships established with family members are an essential factor in healthy aging. Social interaction is facilitated by technology, the telephone, and the internet, which are vital to maintaining contact between people. At the same time, they identify mobility as a significant element in social interaction. There must be adequate infrastructures for the elderly, such as ramps and with appropriate ambient conditions. Physical activity is noted as relevant to active aging. Participants identified the elderly center and churches as promoters of physical activity, underlining the need to try keeping themselves busy and involved in the community. Independence description referred to the ability to make their own decisions, to have self-sufficiency and freedom over their life. Interviewees further state that optimism is essential to allow and achieve healthy aging. It is necessary to have a positive outlook to accept the aging process. The spouse's lack of health and his are aspects that can impair this positive outlook. Additionally, they affirm that it is important to have care services, access to information about available services, and support to mental health to maintain a positive mind. Respecting cognitive health, respondents showed concern and anxiety regarding the cognitive decline and its impact on active aging. Thus, they fear losing the ability to meet their needs and take care of themselves. The authors alert to the study limitation that the elderly who live in nursing homes and those who have cognitive impairment have not representation. In this study, we can see that seniors heavily emphasize mobility and its importance in maintaining their independence and activity. Mental health is also not neglected, and they report the importance of maintaining a healthy and positive mind. Social interaction makes it possible to combat loneliness, remaining active, allowing seeking healthy aging [14].

For other authors, promoting social interaction and improving psychosocial well-being are components of healthy aging. Therefore, they studied exergaming to social interaction promotion among the elderly [11]. Exergaming combines physical exercise and video games, constituting one of the ways to promote healthy and active aging according to the literature addressed by the authors of the article. The impact on social anxiety, loneliness, and sociability was then examined using exergame. Another analysis targets are differences regarding different types of games and different elderly cohorts. The authors concluded the psychosocial well-being of older adults had improved, with a decrease in anxiety-related to social interaction, remarkably when the game was played with others, especially with their peers instead of alone and with young people. By participating in games with others, social interaction is encouraged, decreasing loneliness. As limitations to the study, the authors point out that they mobilized a sample through convenience, of reduced size, and without random effect in elderly allocation to groups. Having said this, they could already know their gaming partners, which facilitates social interaction between them [11].

When comparing these three studies, it is possible to see that they all address the theme of social interaction as key elements for successful/healthy aging. Cha et al. (2012) [15] and Xu et al. (2017) [11] demonstrate that physical activity influences healthy aging and can be used as a tool to avoid loneliness. Besides, the reduction in the risk of diseases and disabilities occurs with the increase in physical activity [10]. On the other hand, the concept of well-being is implied in the studies mentioned above [11, 14, 15].

Another of the studies analysed in this review [7], evaluated subjective well-being in a sample of the Chinese population. This dimension stands out as a key point life quality, which can be defined as mental well-being and includes all the evaluations and perceptions, both positive and negative, that the individual has about his life. Subjective well-being is seen as an indicator of society's progress and as an objective to be achieved by health systems. Owing to the need for health care increase with age advancement, well-being maintenance at an older age has particular importance. The researchers sought to understand the impact of the physical and social attributes of the community on the subjective well-being of the Chinese. Research suggests a relationship between these attributes and the population's health, which is why they imply more aesthetic and cohesive neighbourhoods to increase social interaction and social activities promotion, mobilizing efficient and instrumental resources of the community [7].

The Longitudinal Study analysis upon the Japanese Aging at Nihon University [13], reports that social interaction decreases physical disability or depression among Japanese seniors, bearing in mind that an increased number of social roles (intra and extra-family) lead to a lower chance of disability or depression.

As a tool for studying social relationships, some researchers decided to mobilize social networks to understand their impact on the health of the elderly.

Social networks are related to social support and can result in health promotion through behaviours influence, thereby providing healthy aging. One of the studies [12] measured healthy aging, health-promoting behaviours, family support, support for friendship, family networks, friendship networks, and the way they correlate. The findings show that the indirect effects of family and friends support in healthy aging are statistically significant. Thus, this type of support works through health promotion behaviours influencing their promotion, leading to healthy aging. These behaviours allow individuals to increase control over health-determining factors and incite beneficial choices, having in mind the goal of healthy living. Another result obtained in the study indicates that the family circle addresses subjects closer linked to specific diseases, such as diet and medication. At the same time, friends offer more informative and emotional support to promote behaviours such as physical activity [12].

Other authors [8] assume that social relationships have an impact on the health of the elderly and have studied this impact in several dimensions: physical, psychological, social, and general. They also intended to know the effect of the social network type chosen on the health of the elderly. They concluded that the social network related to friends has more physical benefits for the elderly than social networks based on family. Moreover, the results evidence a vicious circle that must have a stop, in which the deterioration of the physical and psychological health of the elderly leads to increased social isolation, which limits social networks and results in further health problems [8].

Both studies demonstrate that social networks have a positive impact on the health of the elderly, constituting themselves as health promoters, either through the network of friends or family.

Besides, policymakers should further develop recreational centers for older people to interact with friends in the community and promote group activities [12].

To promote successful aging is necessary to have supporting and productive educational programs, enabling the elderly to participate actively, applying their skills, and promoting their well-being along with their self-realization. The adoption of cognitive development and psychological satisfaction promotion initiatives are possible to develop in senior centers, as well as alumni associations, and religious gatherings, through social activities among the elderly. Nurses can include these data in their professional practice, fostering a positive outlook with a greater degree of adaptability promoted, and supporting self-esteem development across the elderly [15–18].

5 Conclusion

Through this systematic literature review, it was possible to analyse the impact of socialization on active aging. Although the concept of active aging is not a consensus in the scientific evidence, it took place an analysis of yesilar terms, such as successful aging and healthy aging. Ultimately, the successful and healthy aging process presents itself as multidimensional, strongly related to the person's physical and mental well-being. This process is influenced by the establishment of interpersonal relationships and social interaction, as well as through characteristics such as optimism and optimistic spirit, development of physical activity, maintenance of independence, and cognitive function. The use of new technologies, such as video calls, are an important tool in social relationships, when close contact is not possible.

Technological evolution has introduced new opportunities in order to maximize functional capacity, stimulate cognitive function and enhance new lifestyles, contributing to the well-being of people at older ages.

Today, social networks are also a reality present in the lives of these people and constitute an excellent social support, in addition to bringing them closer and updating them, they can also influence healthy behaviors.

The implementation of online courses, workshops and even the exergaming that consists of combining physical exercise with video games, are pointed out as methodologies that promote healthy and active aging.

The results evidenced in the studies analysed in the review cannot be generalized due to limitations presence. Thus, it is important to carry out studies, namely a longitudinal type with larger and more representative samples of the population. On the other hand, studies are scarce regarding the Portuguese on this subject, so its development would be crucial to confirm the applicability of these conclusions in our population.

As limitations to this review, the researchers point out the time limit of its occurrence. Additionally, there was not an evaluation of the methodological quality of the studies analysed, which is also a limitation since it would enrich the evidence synthesized in this article.

Implications for Clinical Practice

Although the findings of this review cannot be generalized, the knowledge appropriation presented allows researchers to analyse the measures implemented in the health services they integrate, including the health care they provide, adjusting them to the needs of the elderly and their family. We consider important to continue the study of this theme, and to carry out more studies with samples of the Portuguese population to improve the care provided to the elderly, thus promoting an active aging in the population we attend daily.

References

- UN United Nations: UN United Nations. Published 2019. https://news.un.org/pt/story/ 2019/10/1689152
- Quaresma, M.D.L.B., Ribeirinho, C.: Envelhecimento–Desafios do Séc. XXI. Rev Kairós Gerontol. 19(3), 29–49 (2016). https://doi.org/10.23925/2176-901X.2016v19i3p29-49
- INE Instituto Nacional de Estatística: Estatísticas Da População Residente, Portugal 2016 (Estatística IN de, ed.) (2017)
- WHO World Health Organization: World Report on Ageing and Health. Published online 2015. https://apps.who.int/iris/bitstream/handle/10665/186468/WHO_FWC_ALC_ 15.01_por.pdf;jsessionid=4F483B83FABD1F8620DC78134954C1E1?sequence=6
- SNS Serviço Nacional de Saúde (ed.): Estratégia Nacional Para o Envelhecimento Ativo e Saudável 2017–2025 – Proposta de Grupo de Trabalho Interministerial (2017). https://www.sns.gov.pt/wp-content/uploads/2017/07/ENEAS.pdf
- Aromataris, E., Munn, Z. (eds.): Joanna Briggs Institute Reviewer's Manual. The Joanna Briggs Institute (2017). https://reviewersmanual.joannabriggs.org/
- Gao, J., Weaver, S.R., Fu, H., Jia, Y., Li, J.: Relationships between neighborhood attributes and subjective well-being among the Chinese elderly: data from Shanghai. Biosci. Trends 11(5), 516–523 (2017). https://doi.org/10.5582/bst.2017.01170

- Li, T., Zhang, Y.: Social network types and the health of older adults: exploring reciprocal associations. Soc. Sci. Med. 130, 59–68 (2015). https://doi.org/10.1016/j.socscimed.2015. 02.007
- 9. Lee, J.E., Kahana, B., Kahana, E.: Successful aging from the viewpoint of older adults: development of a brief successful aging inventory (SAI). Gerontology **63**(4), 359–371 (2017). https://doi.org/10.1159/000455252
- Friedman, E.M., Ruini, C., Foy, M.S.C.R., Jaros, L., Love, G., Ryff, C.D.: Lighten UP! A community-based group intervention to promote eudaimonic well-being in older adults: a multi-site replication with 6 month follow-up. Clin. Gerontol. 42(4), 387–397 (2019). https://doi.org/10.1080/07317115.2019.1574944
- 11. Xu, X., Li, J., Pham, T.P., Salmon, C.T., Theng, Y.-L.: Improving psychosocial well-being of older adults through exergaming: the moderation effects of intergenerational communication and age cohorts. Games Health J. **5**(6), 389–397 (2016). http://search.ebscohost.com/login.aspx?direct=true&db=mnh&AN=27976953&site=ehost-live
- 12. Thanakwang, K., Soonthorndhada, K.: Mechanisms by which social support networks influence healthy aging among thai community-dwelling elderly. J. Aging Heal. **23**(8), 1352–1378 (2011). https://doi.org/10.1177/0898264311418503
- Tanaka, K., Johnson, N.E.: Social integration and healthy aging in Japan: how gender and rurality matter. J. Cross Cult. Gerontol. 25(2), 199–216 (2010). https://doi.org/10.1007/s10 823-010-9118-6
- 14. Bacsu, J., Jeffery, B., Abonyi, S., et al.: Healthy aging in place: perceptions of rural older adults. Educ. Gerontol. **40**(5), 327–337 (2014). https://doi.org/10.1080/03601277.2013.802191
- Cha, N.H., Seo, E.J., Sok, S.R.: Factors influencing the successful aging of older Korean adults. Contemp. Nurse J. Aust. Nurs. Prof. 41(1), 78–87 (2012). https://doi.org/10.5172/ conu.2012.41.1.78
- Goes, M., Lopes, M.J., Oliveira, H., Fonseca, C., Marôco, J.: A nursing care intervention model for elderly people to ascertain general profiles of functionality and self care needs. Scientific Reports/Sci. Rep. 10, 1770 (2020). https://doi.org/10.1038/s41598-020-58596-1
- Moguel, E., Berrocal, J., Murillo, J.M., García-Alonso, J., Mendes, D., Fonseca, C., Lopes, M.: Enriched elderly virtual profiles by means of a multidimensional integrated assessment platform. Paper Presented at the Procedia Computer Science (2018). https://doi.org/10.1016/ j.procs.2018.10.009
- 18. Jiménez, B.R., Caballero, D.C., González, B.M., García-Alonso, J., Fonseca, C., Juárez, L.M.: Los enfoques culturales en la alimentación de personas mayores rurales. Una necesidad multidimensional para la agenda del cuidado. INDEX DE ENFERMERÍA 28(3), 125 (2019). (SCImago Journal Rank SJR: 8 H Index. Quartiles: Q4. SCOPUS INDEX)



Promotion of Self-care Management in the Person with COPD: Systematic Literature Review

Nelson Esteves^{1,2,3}(⋈), Carla Basílio¹, Pedro Costa¹, Mauro Lopes¹, Célia Nicolau¹, Rogério Ferreira²(⋈), Manuel Agostinho Fernandes³, and César Fonseca³

¹ ULSBA, Beja, Portugal

Abstract. The evolution of health, is defined not only by changes resulting from behaviors, but mainly by how the person becomes more active in the role they play for their health, promoting an increase in quality of life and well-being. For this, it becomes imperative the implementation of norms and strategies that guide the self-care process of people with Chronic Obstructive Pulmonary Disease. In this sense, the rehabilitation nurse develops a crucial action, implementing teachinglearning strategies, planning and executing his interventions, in accordance with the expectations, preferences and needs of the person with COPD. Objective: To know the strategies and gains of self-care management of the person with COPD. Method: Systematic literature review using the PubMED and EBSCO Host platforms (in the CINAHL Complete, MEDLINE Complete and MedicLatina databases), conducted between December 2019 and January 2020. The descriptors used ("COPD") AND ("patient") AND ("self-management") AND (nursing care) AND (empowerment). Results: Sample of 6 studies, after exclusion of several articles, for not obeying the inclusion criteria and objectives defined. Telerehabilitation is fundamental in the patient's empowerment process, improving their quality of life as it allows them to trust and develop a self-management plan. Conclusions: The results found demonstrate the importance of defining and applying strategies that promote the self-care management of people with COPD, defining strategies that target the empowerment and self-management of their disease as fundamental pillars for reducing hospitalizations, increasing selfconfidence, reducing anxiety and greater self-responsibility in complying with the management of the therapeutic regimen and thus obtaining more health gains.

Keywords: DPOC · Patient · Self-management · Nursing care · Empowerment

1 Introduction

COPD is a preventable and treatable respiratory disease characterized by persistent and progressive airway limitation and is associated with an inflammatory response of the respiratory tree resulting from the inhalation of harmful substances, which may

² Polytechnic Institute of Beja, Researcher POCTEP 0445_4IE_4_P, Beja, Portugal ferrinho.ferreira@ipbeja.pt

³ Researcher POCTEP 0445_4IE_4_P, University of Évora, Évora, Portugal

[©] The Author(s), under exclusive license to Springer Nature Switzerland AG 2021

J. García-Alonso and C. Fonseca (Eds.): IWoG 2020, LNBE, pp. 217–231, 2021.

evolve into chronic bronchitis, obstructive bronchiolitis and pulmonary emphysema [1]. There are several risk factors that condition the appearance of the pathology, as well as its exacerbation. The use of tobacco is the main factor, having a smoker 80 to 90% probability of developing the disease. Air pollution, gender, age, repetitive respiratory infections and bronchial hyperreactivity are also factors to be taken into account for the appearance of COPD [2]. In Portugal, according to the National Health Service (NHS) records, COPD has no less impact compared to the world panorama. In 2017 136 958 cases of this pathology were registered in our country, thus having a high prevalence rate, being responsible for 19% of deaths and one of the main causes of hospitalization. It is estimated that in 2020 the number will increase, being worldwide one of the respiratory diseases that cause the highest number of deaths and with an expected rise to 12 million deaths worldwide [5]. However, Portugal is the OECD country with the lowest number of hospitalizations for COPD. These admissions can be avoided based on preventive measures adopted, use of therapy and follow-up by Primary Health Care, these measures being an incentive focus based on Health Policies [6]. COPD is a pathology with great implications at several levels, which compromises the person in his/her well-being and at the level of self-care, as well as has an incapacitating character in the participation of social life. In the person with COPD, the progression of the pathology implies the appearance of physiological deficits such as airflow limitation and hyperinflation, leading to episodes of dyspnea and in turn to fatigue, intolerance to physical exertion, impairment in ADL and alteration of physical condition [3]. Therefore, this change in physical condition, directly related to stress tolerance, accompanies the decrease in the ability to perform most of the daily activities, thus leaving the person with COPD committed to the ADL and with a greater degree of vulnerability to the changes that the pathology conditions [7, 8]. It is therefore necessary that the person with COPD receives support in order to restructure their entire routine, especially in self-care, reducing the conflict that the disease itself brings, because it is a cause of change/transition, sometimes drastic, spontaneous, generating insecurity, stress and instability.

The nurse is a health professional trained to anticipate, evaluate, diagnose and help the person to deal with these changes [8]. It is up to the nurse to promote the maximum autonomy and well-being of the person, so that he/she adopts behaviors and holds a notion of self-meaning in his/her family and social context, being able to accomplish this "transition". According to the same author and according to her "Theory of Transition" this process requires the person to use resources and mechanisms that support the adaptation to this new status/crisis. This context reinforces the importance of teaching in the change of behaviors, regarding autonomy and self-determination. It is essential to monitor and guide in order to enable adaptation to the new reality, ensuring self-care and independence [9]. In COPD the person suffers this transition, thus having their daily habits affected, not only by the alteration of its functionality, but also by the limitations that are felt in basic and instrumental activities. This transition-generating status can affect more than the self-care of the person with COPD, but it also influences a whole family dynamic and/or life of the caregiver [4]. In this perspective, the intervention of the rehabilitation nurse should meet a care approach concordant with a theoretical model that provides the fundamental basis for the practice of care. Thus, it is imperative to approach the theory of self-care of Dorothea Orem, which advocates the concept of nursing

care in a relationship between the capabilities of action of the person in the face of the requirements of self-care. "The promotion of health through educational interventions of the nurse, which enhances the individual and/or population groups self-care (...) related to the advancement of chronic conditions of illness and the needs of particular care (...) as ways of caring for oneself." [10] (p. 2).

This theory guides the nursing care provision according to the patient's needs in relation to his self-care, becoming of great use for a good practice. Since it allows the elaboration of functional and educational intervention plans, outlining goals together with the patient, empowering the person and promoting support and education strategies by providing capabilities and tools to deal with the self-care deficit. The nurse provides care in order to lead the patient to independence, fostering his or her involvement in his or her well-being and state of health-disease [9]. Orem's theory is the basis to reach the conditions and limitations of the action that the person can reach with the contribution of nursing, being very important that there is a point of balance between what is really necessary and what is excess, all this so that the person can achieve self-care [11]. Thus, the provision of specialized nursing rehabilitation care to the person with COPD should focus on implementing and evaluating specialized plans for quality of life, training and promotion for self-care, always based on a reintegration into society and sharing in their usual habits of life [12]. The nursing intervention is then necessary when the person has needs greater than the capacities of accomplishment of the self-care, occurring an alternation in the intervention of the nurse in the compensation (total or partial) or in the educational intervention. COPD, as a chronic and progressive disease, implies difficulties in the achievement of self-care. The National Program for Respiratory Diseases aims at maximizing the health gains of people with COPD, with the intervention of all social sectors in the application of strategies based on citizenship, equity of access to specialized care and health policies. Also in this context, the DGS has prepared the "Health Literacy Action Plan" for the triennium 2019–2021, in which it contemplates an approach throughout the entire life cycle "(...) promoting the informed choices of citizens" [13] (p.n.p.). This plan emphasizes the importance of developing, defining and implementing strategies among professionals and populations that aim to achieve objectives that promote health literacy and thus boost new opportunities to encourage the adoption of healthy behaviors, with a view to informed self-management and better health outcomes in the population.

Within the scope of respiratory rehabilitation, there are three important pillars for rehabilitation of the person with COPD: respiratory functional re-education, airway permeability and energy conservation techniques [7]. In functional re-education, it is based on relaxation techniques, breathing techniques and global exercises that the rehabilitation nurse achieves health gains from the point of view of controlling dyspnea, being the symptom that brings more disability for the realization of ADL and its independence, always having the attention to educate the person in order to acquire skills that allow him/her to be autonomous in a crisis situation. Thus, the rehabilitation nurse should challenge the person with COPD to be the manager of his health condition [14]. If the informal person/caregiver demonstrates aptitude for self-management, it will be crucial to develop strategies based on knowledge and instrumental skills, the result of skills

education, that can contribute to effective management of COPD. These skills associated with "facilitating awareness of the "changes" in daily life can add confidence and sustain effective self-care over time". [14] (p. 38). It is through health education that rehabilitation nursing is a facilitator in empowering and promoting the autonomy of the person/family, through the development of capabilities inherent to self-care, acquisition of behaviors adapted to the health condition and through the provision of information [6]. This educational aspect enables the person/family to be the self-manager of their disease and in a certain way enables them to prevent complications.

2 Methodology

In this SLR, the main objective is to know the strategies and gains of self-care management of the person with COPD and the research question is what are the strategies and gains of self-care management in the person with COPD. To build it, we followed the guidelines of the Joanna Briggs Institute (JBI) [15] Based on the PICO method (P-Participants; I - Intervention; C - Context/Control; O - Outcomes), we selected studies to be included in this literature review, using the same method to define the inclusion and exclusion criteria, as follows (Table 1).

| Selection criteria | Inclusion criteria |
|--------------------|--|
| (P) Participants | People with COPD in an unhealthy situation |
| (I) Intervention | Strategies to promote self-management in people with COPD |
| (C) Context | COPD without acute exacerbation |
| (O) Outcomes | Gains from promoting self-management in the person with COPD |
| Keywords | COPD; person; self-management; nursing care; empowerment |

Table 1. Definition of criteria for selection of studies

The following descriptors were selected for the research: MeSH (Medical Subject Heading), COPD; patient; self-management; nursing care; empowerment, using the Bolean AND; and, to meet the inclusion criteria, using the Bolean NOT, acute disease.

The electronic database PubMED (US National Library of Medicine and National Institutes of Health) was searched, and the Discovery Service of the Polytechnic Institute of Beja was used, based on EBSCO Host and accessing the CINAHL Complete, MED-LINE Complete and MedicLatina databases, using the keywords above. The research was limited to the years 2014–2019, peer-reviewed, published in academic journals and providing access to the full text. The languages of the articles used in the research were English and Portuguese, the search words were used in English. In total, 280 studies were found in the databases (PubMed and EBSCOhost), of which, after removal by duplication of results, there were 171 records for analysis, which was carried out through the title of the study and whenever the analysis of the abstract was justified. According to the reading of the titles/summaries presented, 154 records were excluded for revealing little

interest and/or not presenting thematic criteria that fit the theme of our work, resulting in 17 studies of interest. After reading and full analysis of the text, 11 articles were removed because they did not fit the inclusion criteria. In total 6 articles were selected for detailed analysis and used for systematic literature review. The researches were carried out between December 2019 and January 2020. In a syntactic way, we describe the methodology through the diagram below:

Prisma Statement

See Fig. 1.

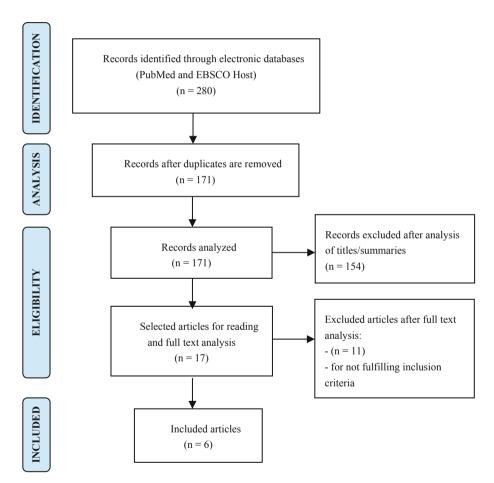


Fig. 1. Research Methodology Diagram, PRISMA type [16]

3 Results and Discussion

See Tables 2, 3 and 4.

| Article Checklist | (| Q1 | Ç | 2 | Ç | 23 | Q | 14 | Q | 5 | Q | 96 | Q | 7 | Q | 98 | Q | 9 | Q | 10 |
|--|---|------|---|--------|---|--------------|----|------|---|-----------------------|---|-------|---|---|--------|--------|---|--------|------|----|
| Participatory action research: A strategy for improv- ing self-care management in chronic obstructive pulmonary disease patients ²⁷ | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | N | Y | |
| Oximetry-supported self-management for chronic obstructive pulmonary disease: mixed method feasi-bility pilot project ²⁸ | Y | Y | Y | Y | Y | Y | Y | N | Y | Y | U | Y | Y | Y | Y | Y | Y | N | Y | |
| The empowerment of elderly patients with chronic obstructive pulmonary disease: Managing life with the disease ²⁹ | , | Y | , | Y | , | Y | , | 7 | , | č | Y | č | , | 7 | , | Y | Y | Y | , | č |
| Breathing through a troubled life – a phenomenologi- cal-hermeneutic study of chronic obstrutive pulmo- nary disease patients' livel experiences during the course of pulmonar rehabilitation ²⁰ | , | Y | , | Y | , | Y | , | Ĭ. | , | ľ | Ţ | J | , | ľ | , | Y | 3 | Y | , | ľ |
| Barriers to and factors facilitating empowerment in elderly with COPD ³¹ | | Y | , | Y | , | Y | `` | č | , | ľ | τ | J | 1 | 1 | , | Y | , | Y | , | 7 |
| Experiences of a health coaching self-management program in patients with COPD: a qualitative content analysis 32 | | Y | , | Y | , | Y | Ŋ | í. | , | ľ | Ţ | J | , | 7 | , | Y | Y | Y | , | ľ |
| Key | | Y: 1 | | titati | | N: N most | | rime | | <i>Incle</i> Study | | ı-Ran | | | ot Api | licabi | | tative | Stud | у |

Table 2. JBI critical appraisal checklist (results)

Table 3. Levels of evidence and recommendation

| Reference | Levels of evidence | Methodological quality |
|---|--|------------------------|
| Padilha, J.M., Sousa, A.P., Pereira, F.M. (2015) [17] | 2 - qualitative or mixed methods synthesis | Strong |
| MacNab et al. (2015) [18] | 2 - qualitative or mixed methods synthesis | Strong |
| Fotoukian, Z., Shahboulaghi, F.M., Khoshknab, M.F., Pourhabib, A. (2017) [19] | 3 - unique qualitative study | Strong |
| Simony, C., Andersen, I. C., Bodtger, U., Birkelund, R. (2019) [20] | 3 - unique qualitative study | Strong |
| FotouKian et al. (2014) [21] | 3 - unique qualitative study | Strong |
| Wang, L., Martensson, J., Zhao, Y., Nygardh, A. (2018) [22] | 3 - unique qualitative study | Strong |

The analysis of the results of this work is based on three assumptions, the symptoms and barriers felt by the person with COPD, the strategies used in the promotion of self-care management to overcome these barriers/difficulties and the gains/outcomes obtained after the implementation of these same measures. In order to obtain a more detailed knowledge of the daily reality experienced by the person with COPD, a standard outpatient pulmonary rehabilitation program was implemented [20], which allows to verify the presence of dyspnea, other comorbidities and the feeling of despair, which determined the influence of the participation of people with COPD in the respiratory

Table 4. Extraction of results from articles

| ye cords and degge of nursing dia anagement and it delivery model I that focuses on an of nursing can of nursing can of nursing can ge of informatic ity and safety of also made in the weet the achieven on of the health, with well to identify an in the preserval on CODD. Through the CODD. Through also made in the weat the achieven on of the health, with well to identify an it in the preserval on CODD. Through the CODD. Through and allowed: | organization of care, nursing records and decision making, evaluating for 0 months, the results through the change of nursing diagnoses of the people under study and their impact on changes in self-management and self-care capabilities; - Transformation into a care delivery model focused on treatment, a nursing care planning concept and model that focuses on developing individual management skills in people with COPD; - Changes in the corganization of nursing care, such as outpatient nursing consultations, which optimized the exchange of information between professionals and health services, improving continuity and safety of care, which strengthened and facilitated access to health care, allowing them to dispel doubts and obtain necessary information. Changes were also made in the nursing records that allowed; to outline indicators that prove the achievement of results for each person, thus allowing individual evaluation of the health status of people with COPD and optimize the management of resources in health, without increasing costs; - The observed results allowed to identify an increase in the safety and quality of mursing care and an increase in the preservation of self-management, autonomy and quality of life of people with COPD. Through the provision and learning of specific contents important for the control of the disease * The continuous telemonitoring allowed: * The observed results allowed to identify a liviner self-management, in order to reduce the prominent role in the responsibility of his/her self-management, in order to reduce the |
|--|---|
| ing allowed: 's decision mak | The continuous telemonitoring allowed: to be a guide in the person's decision making, allowing the person to assume a prominent role in the responsibility of his/her self-management, in order to reduce the |
| isibility of his/h ssionals; i tallows people eople even use a lings and invest ion of their state ty, with a tender nee to act accorn ional role, since OPD, allowing on health profess ons associated v | dependency by health professionals; *become a teaching tool, as it allows people to use their daily readings to understand their state of health. Some people even use additional measures to explore associations between symptoms and readings and invest in emergency medication courses; *give an immediate indication of their state of health, reducing the level of depression, stress and anxiety, with a tendency to improve the quality of life, since it gives the person the confidence to act according to their self-management plan; - This service has an educational role, since it has given way to the self-management poncies of the person with COPD, allowing the assumption of control of their condition: - Allowed less dependence on health professionals, making people more capable in recognizing standard symptoms associated with COPD, allowing earlier emergency |

(continued)

 Table 4. (continued)

| Author of the study | Objective of the study | Total of participants | Results | Period |
|---|---|---|--|------------------------------|
| Fotoukian, Z., Shahboulaghi, F.M., Khoshknab, M.F., Pourhabib, A., (2017) | To show training or empowerment in reducing the severity or frequency of exacerbated symptoms, thus preventing hospitalization and improving the quality of life and health in older people with COPD, their family caregivers and health professionals | 24 participants (15 people with COPD aged 60 or older; 4 Family caregivers; 5 Health Professionals) | - Adopting strategies in the elderly with COPD to learn how to live with the disease, allowing a better self-management, which consists in the effort to keep up with life, prepare for the batte with the disease and help stabilize their life: - Participation in self-care through the help of health professionals in the use of medication, oxygen, respiratory techniques and BI-PAP at home, allows the assumption of the condition of independence, being fundamental health education in the development of knowledge and skills; - Socio-psychological promotion allows people with COPD to accept their disease, living happier, increasing life satisfaction: - The support and cooperation of family and professionals allows the elderly person to accept or develop skills that allow them to stabilize their life; - Focuses on the theory of "Life Management with COPD", which explains how self-management and the strategies developed by the development of the empowerment of the person, increasing their autonomy, allowing people to know what, how and when to do; - The self-management of the elderly is the result of family support and the efforts of the multidisciplinary team, namely the nurse, who helps in motivation, promoting exercise and health education, who focuses on taking medication at the right time, side effects of medication and above all, preventing and controlling COPD | March 2012 to february 2014 |
| Simony, C., Andersen, I. C., Bodtger, U., Birkelund, R. (2019) | Simony, C., Andersen, Obtain an in-depth I. C., Bodtger, U., Birkelund, R. (2019) experiences of the person with COPD following a standard outpatient lung rehabilitation program; | 21 people with COPD | - People's lives were deeply disturbed by COPD. The problems were related to dyspnea, but also seemed to be associated with several other limiting disabilities. This seems to cause a sense of desperation that seems to influence a person's perception of life and their approach to rehabilitation. In addition, the problems seemed to complicate the chances of participating fully in an engaging manner in rehabilitation. During rehabilitation, some people were guided to improve breath control through the use of the PEP (Positive Expiratory Pressure) device leading to increased well-being, confidence and hope. However, this was not won by everyone | August 2016 to march 2017 |

(continued)

 Table 4. (continued)

| Author of the study | Objective of the study | Total of participants | Results | Period |
|--|--|---|---|--|
| FotouKian et al. (2014) | Gain knowledge about the barriers and facilitators of enabling older people with COPD so that caregivers can plan interventions that effectively improve the quality of life of older people with COPD | 24 participants (15 elderly over 60 with COPD; 4 family caregivers; 5 health professionals) | - The training of the elderly with COPD can be influenced by several factors. As barriers are considered: the nature of aging, namely lack of physical capacity, existing co-morbidities, forgetfulness; difficulties inherent to the disease, being a difficult disease with complex treatments; low economic status; fears and hopes; cultural values and beliefs; deficient formal support systems, i.e., deteriorated health system, centralized support sources, lack of team work, lack of equipment, low budgets, health care not centered on the person, poor communication, negative point of view of the elderly person: - As facilitator factors are considered the incentive, confidence in health professionals, the learning capacity of the elderly and the level of experience | March 2012 to 2014 |
| Wang, L., Martensson, J., Zhao, Y., Nygardh, A. (2018) | Wang, L., Martensson, Describe the experiences 20 people with COPD I., Zhao, Y., Nygardh, of people with COPD participating in a health self-management program | 20 people with COPD | People became aware of the importance of knowledge about the disease, as well as its self-responsibility in the management of the disease and the positive impact of the program on their quality of life, considering the importance of knowing the risk factors for COPD, such as drinking, and the benefits of respiratory techniques and physical activity and food care. They valued the presence (telephone) of the "coach" nurses, because they motivate, transmit confidence and encourage them to express their emotions and feelings by enlightening them in the contacts they made, being always available when they needed it. The participants described as limitations in managing their illness: age, literacy, symptoms, professional issues and economic issues | 6 months (may 2016 to october 2016) |

rehabilitation program. It also referred to barrier factors such as aging, lack of physical capacity, physical comorbidities, forgetfulness, difficulties inherent to the disease, complex treatments, low economic status, fears and hope, cultural values and beliefs and weak health system, literacy, symptoms and professional and economic issues [21, 22]. Thus, the evolution of COPD leads to episodes of dyspnea, fatigue, intolerance to physical exertion that seriously compromises your physical condition [3]. The alteration of the physical condition, implies the decrease of the capacity in the realization of ADL's, increasing their degree of vulnerability and dependence [7, 8].

After the diagnosis of the situation, strategies were outlined, which allowed the promotion of self-management and self-care of the person with COPD. The organization of care, the development of standards, the nursing records, the decision making, are fundamental measures that promote the continuous improvement of the quality of health services, thus allowing, as this author recommends, to transform a model of care focused on treatment, in a concept and model of nursing care planning that focuses on the development of individual management skills in people with COPD [17], based on the Theory of transition [8]. Thus, the transmission of information through the help of health professionals using medication, oxygen, ventilotherapy and respiratory techniques, the promotion of socio-psychological capacity, the involvement of family members and professionals and the application of the Theory of "Life Management with COPD", are determinant in the success of the improvement of the quality of life of the person [19]. Monitoring (via pulse oximetry) was used as a guide in the control and decision making of the person, allowing him/her to assume a prominent role in taking responsibility for his/her self-management in order to reduce the dependence on health professionals [18]. This service called "Light Touch" has also become a teaching tool for people to use their daily readings to understand their state of health. As previously mentioned, the nurse is defended as a health professional trained to anticipate, evaluate, diagnose and help the person to deal with these changes, so that the person acquires concepts and capacity of autonomy in their family and social context, in order to achieve this "transition" [8]. This transition influences not only the person with this respiratory deficiency but also the whole family dynamic and/or life of the informal caregiver [4].

The implementation of a self-management program in health, through the figure of the "coach" nurse, via telephone, with total availability, transmitting feelings of trust and encouragement to the expression of emotions, clarification of doubts [22], can be a facilitating factor, since it is considered as facilitating factors the encouragement, confidence in health care providers, the learning capacity of the elderly and their level of experience [21]. Faced with the complexity of the disease, in response to imposed difficulties and structured strategies, the results show that the use of the strategies mentioned above, allows for gains in self-care and self-management of the person with COPD. Thus, there was an increase not only in the safety and quality of nursing care, but also a preservation of self-management, autonomy and quality of life of people with COPD through the provision and learning of specific contents important for the control of the disease [17] in treatment, in a concept and model of nursing care planning that bets on the development of the individual capacity of management of COPD. The optimization of information exchange between professionals and health services, the changes in nursing records that allowed to define indicators that prove the achievement of results for

each patient and optimization of health resource management without increasing costs. Changes were also made in outpatient consultations, reinforcing and facilitating access to health care for people with COPD, allowing doubts to be dispelled and necessary information to be obtained. The use of continuous telemonitoring encouraged people with COPD to invest in emergency medication courses after they were able to relate symptoms to the readings obtained [18]. This study has become a guide for the wellbeing of the person, giving immediate indication of their state of health, reducing the level of depression, stress and anxiety, thus improving the quality of life, since it gives the patient confidence to act in accordance with his plan of self-management, having an educational role, giving rise to less dependence on health professionals, making people more able to recognize standard symptoms associated with the disease. We consider that the effectiveness of nursing interventions were fundamental to the person's rehabilitation process, as it was demonstrated in the telemonitoring, evaluation and consequent improvement of SPO2 parameters, allowing to demonstrate that telerehabilitation is central to the patient's empowerment, self-management and autonomy. The results obtained [18], are in line with the outcomes obtained [19], since they defend health education as a promoter of people's independence in the development of knowledge and skills, through exercises and management of therapeutic regimes implemented by health professionals, food care, respiratory techniques and physical activity, in order to promote their training, self-responsibility, empowerment and autonomy, allowing people to accept and live better with their condition or illness, living happier, consequently increasing their level of satisfaction with life. These results are also defended by the DGS, which states that it is through health education that rehabilitation nursing enables to empower and promote the autonomy of the person/family, developing adapted self-care capabilities, enabling the person/family to be the self-manager of their disease [6]. Increased well-being, confidence and hope were noted, although without success in all participants [17–22].

The analysis of these articles is supported by functional re-education with interventions implemented by the rehabilitation nurse, who achieves health gains through the control of dyspnea, always aiming at the education of the person in the acquisition of skills that enable him/her to become autonomous in a crisis situation [7]. Facing this perspective, Dorothea Orem's theory of self-care, which bases the concept of nursing care on a relationship between the capabilities of action of the person in the face of the demands of self-care, becoming one of the main foundations in the intervention of the concept of self-care, where it advocates the conditions and limitations of action that the person can achieve with the contribution of nursing, in order to find the balance between what is really necessary and what the person wants or desires, so that the person feels independent and satisfied in their self-care [11]. The DGS suggests that it is through health education that rehabilitation nursing empowers and promotes the autonomy of the person/family, through the development of capabilities inherent to self-care, acquisition of behaviors adapted to the health condition [6]. This educational aspect enables the person/family to be the self-manager of his/her illness and in a certain way enables him/her to self-care and prevent complications.

Thus, it can be seen that in all the articles analyzed, literacy, although not mentioned directly in the articles analyzed, is implicitly associated with competence learning processes and that it underlies a model of empowerment, because it is through cognitive

skills implemented by therapeutic education strategies, which must be extremely interactive, motivating and adapted to needs [18–20, 22], in order to instill a positive attitude in the person's daily life, as it also underpins the Action Plan for Health Literacy [13]. In this context, the rehabilitation nurse plays a crucial role, providing the necessary tools for the person with COPD to be able to manage his or her own illness, thus promoting the person's self-management and decision-making capacity, supported by the principle of responsibility, From our point of view, this is the right way to promote the independence and self-care of the person, in which the rehabilitation nurse, through his interventions, is an agent of change, orienting his praxis to the provision of knowledge and empowerment of the person and family, so that they adopt behaviors that go from finding favorable and expectable results: Self-management and Self-care [9].

4 Study Limitations

The fact that this RSL presents only qualitative studies is a limitation, since, in this type of investigation, each reality depends on the individual perceptions and beliefs. The questions have an exploratory nature and aim to discover, explore, describe and understand the problems that exist in a given context and the way in which each person experiences this experience. Since age, literacy, the severity of symptoms, professional conditions and socioeconomic conditions will influence how each person develops capacities to self-manage their illness.

5 Contributions to Nursing

The realization of this scientifically based synopsis allowed to explain the knowledge of the strategies and the management gains of self-care of the person with COPD, highlighting the vital need to incorporate the rehabilitation nursing *legis artis* in this process and the assertion that in view of the complexity of this disease it is essential to outline and implement strategies that converge in the empowerment and self-management of the person due to their disease, enhancing the improvement of their autonomy and quality of life.

Following the studies analyzed in this Systematic Literature Review, the support for the success of these programs is the presence of the specialist nurse in rehabilitation, who with his body of specialized scientific technical knowledge is a motivating agent for change, allocating behaviors that culminate in the results expectable: Self-management and Self-care, justified by the measured results that were demonstrative of the improvement in the continuity and safety of health care, less dependence on health professionals as a consequence of training and self-management of the disease and, at the same time, the presence of nurses as the motivating element, trust and encouragement. We admit that the need for scientific evidence is crucial through randomized experimental studies, which corroborate the benefits and the vital role of rehabilitation nursing intervention in programs developed in the area of self-care management, thus guaranteeing the scientific quality and reliability of the results obtained.

6 Conclusion

COPD is a disease that has a great impact on the lives of people who have it. Among the various symptoms, it is the dyspnea that has the most impact on ADL, as well as all the associated comorbidities, fatigue, the feeling of disability, intolerance to effort that compromise the entire condition of the person's experiences. The increase in the degree of dependence and inability to carry out the basic and instrumental tasks that a person usually performs in daily life leads to an increase in the degree of vulnerability, dependence on self-care and dissatisfaction with life. The delineation of strategies with the objective of promoting the self-management of the pathology and self-care of the person with COPD emerges as an imperative base of a nursing action with a view to autonomy and functionality. The improvement of the quality of life of these people, the continuous improvement of health services, the use and guidance of therapy, the promotion of socio-psychological capacity and the involvement of informal caregivers/family enable desirable and expected outcomes for the person, resulting in their satisfaction and greater independence in the use of health services.

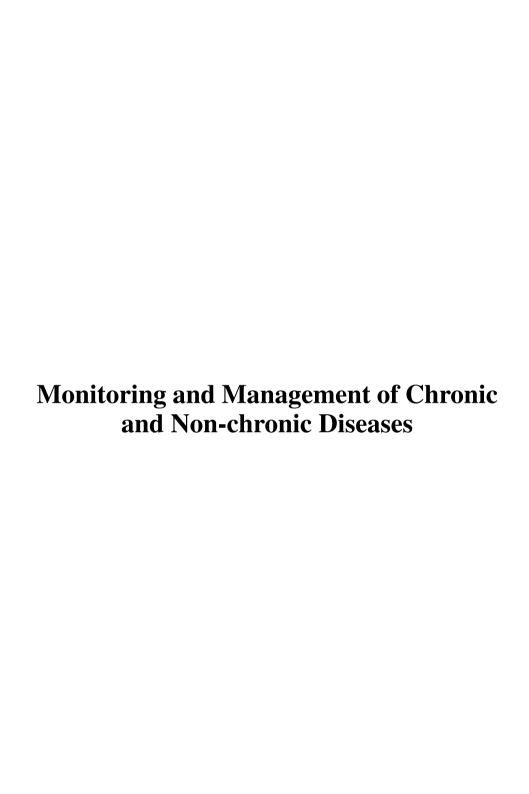
Rehabilitation nursing assumes a central role in all this dynamic of promoting self-care, self-management and functionality of the person with COPD. It is certain that there are always phenomena as barriers and facilitators of this nursing intervention. However, structured strategies and specialized care of quality are propellants of the security of the person, autonomy and of consequent quality of life. To define indicators to obtain results, in view of the individuality of each person it makes possible the optimization of the self-management of resources in health in an efficient way, possibility gained at the level of the health of the person and of economic resources. The educational role of rehabilitation nursing, literacy and functional re-education, have as objectives the development of skills and abilities, promoting not only the training of the person in self-management of the therapeutic regimen but also becomes a reducer of anxiety, stress and lack of confidence. The implementation of strategies that promote empowerment and self-management consequently brings a better and greater degree of autonomy and satisfaction of the person with COPD.

References

- Costa, A.R.V., Luz, A.P.R.G., Mestre, E.S.C.M., Silva, A.C.R.L.: O Enfermeiro e a sistematização do cuidado ao pessoa portador de DPCO. II Congresso Brasileiro de Ciências da Saúde (2017)
- Cordeiro, M., Menoita, E.: Manual de Boas Práticas da Reabilitação Respiratória: Conceitos, Princípios e Técnicas. Lusociência, Loures (2012)
- Cechetti, F., Simoni, F., Schmitt, G.: A Influência da Fadiga e da Dispneia nas Atividades de Vida Diária de Portadores de Doença Pulmonar Obstrutiva Crónica: O Papel da Reabilitação Pulmonar. Revista Brasileira de Ciências da Saúde 10(34) (2012). https://doi.org/10.13037/ rbcs.vol10n34.1753
- Nakken, N., Janssen, D.J.A., Bogaart, E.H.A., Wouters, E.F.M., Franssen, F.M.E., Vercoulen, J.H., Spruit, M.A.: Informal caregivers of patients with COPD: Home Sweet Home? Eur. Respir. Rev. 24, 498–504 (2015). https://doi.org/10.1183/16000617.00010114
- ONDR: Observatório Nacional das Doenças Respiratórias 13.º Relatório (2018). https://www.ondr.pt/files/Relatorio_ONDR_2018.pdf

- DGS: Programa Nacional para as Doenças Respiratórias. Lisboa: Direção-Geral da Saúde (2017)
- Soares, M.S.R.: A pessoa com Oxigenoterapia de Longa Duração. Estudo sobre o modelo de cuidados de enfermagem em contexto domiciliário. Tese para obtenção do grau de Doutor em Enfermagem. Universidade Católica Portuguesa (2012)
- 8. Meleis, A.: Transitions Theory. Middle-Range and Situation-Specific Theories in Nursing Research and Practice. Springer, New York (2010). https://taskurun.files.wordpress.com/2011/10/transitions_theory__middle_range_and_situation_specific_theories_in_nursing_research_and_practice.pdf
- Fernandes, S., Silva, A., Barbas, L., Ferreira, R., Fonseca, C., Fernandes, M.A.: Theoretical
 contributions from orem to self-care in rehabilitation nursing. In: García-Alonso, J., Fonseca, C. (eds.) Gerontechnology, IWoG 2019. Communications in Computer and Information
 Science, vol. 1185. Springer, Cham (2020). https://doi.org/10.1007/978-3-030-41494-8_16
- Bezerra, M.L.R., Faria, R.P.R., Jesus, C.A.C., Reis, P.E.D., Pinho, D.L.M., Kamada, I.: Aplicabilidade da Teoria do Déficit do Autocuidado de Orem no Brasil: uma revisão integrativa. J. Manage. Primary Health Care 9, e16, 1–19 (2018). https://jmphc.com.br/jmphc/article/download/538/741
- Queirós, P.J., Vidinha T.S., Filho A.J.: Autocuidado: o contributo teórico de Orem para a disciplina e profissão de Enfermagem. Revista de Enfermagem Referência, 157–164 (2014). https://doi.org/10.12707/RIV14081
- 12. dos Enfermeiros, O.: Regulamento das Competências Especificas do Enfermeiro Especialista em Enfermagem de Reabilitação. Ordem dos Enfermeiros, Lisboa (2010
- DGS: Plano de Ação para Literacia em Saúde, Portugal 2019–2021. Direção-Geral da Saúde, Lisboa (2019)
- 14. Padilha, J.M.: Promoção da gestão do regime terapêutico em clientes com DPOC: um percurso de investigação. Tese para obtenção do grau de Doutor em Enfermagem. Universidade Católica Portuguesa
- Joanna Briggs Institute: The Joanna Briggs Institute EBP Database Guide (2013). https://osp-guides.ovid.com/OSPguides/jbidb.html
- Mother, D., Liberati, A., Tetzlaff, J., Altman, D.G., The PRISMA Group: Preferred reporting items for systematic reviews and meta-analyses: the PRISMA Statement. PLoS Med. 6(7), e1000097 (2009). https://doi.org/10.1371/journalpmed.1000097. [acedido em: 15 de janeiro 2020]
- Padilha, J.M., Sousa, A.P., Pereira, F.M.: Participatory action research: a strategy for improving self-care management in chronic obstructive pulmonary disease patients (2015). https://doi.org/10.1177/1476750315606196
- MacNab, M., et al.: Oximetry-supported self-management for chronic obstructive pulmonary disease: mixed method feasibility pilot project (2015). https://doi.org/10.1186/s12913-015-1135-2
- 19. Fotoukian, Z., Shahboulaghi, F.M., Khoshknab, M.F., Pourhabib, A.: The empowerment of elderly patients with chronic obstructive pulmonary disease: managing life with the disease **12**(4) (2017). https://doi.org/10.1371/journal.pone.0174028

- 21. FotouKian, Z., Shahboulaghi, F., Khoshknab, M., Mohammadi, E., Moghaddam, H.: Barriers to and factors facilitating empowerment in elderly with COPD (2014). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4322331
- 22. Wang, L., Martensson, J., Zhao, Y., Nygardh, A.: Experiences of a health coaching self-management program in patients with COPD: a qualitative content analysis (2018). https://doi.org/10.2147/COPD.S161410





Factors Associated with Social Participation in People with Severe Mental Disorders

Sara Chimento-Díaz¹(⊠) , Pablo Sánchez-García^{2,3} , Cristina Franco-Antonio^{2,3} , Esperanza Santano-Mogena^{2,3} , and Sergio Cordovilla-Guardia^{2,3}

1 Computer and Telematic Systems Engineering Department, Polytechnic School,
University of Extremadura, Cáceres, Spain
schimento@unex.es

Nursing Department, Nursing and Occupational Therapy College, University of Extremadura, Cáceres, Spain

Abstract. Sociodemographic factors and how each person with severe mental disorder (SMD) perceives their quality of life can influence their attendance of social participation programmes. The objective of this study was to evaluate whether quality of life or other sociodemographic factors are associated with the degree of participation in a social participation programme in a sample of people with SMD. From March to June 2019, a workshop was held in which 30 people with SMD belonging to the FEAFES Cáceres association participated. Quality of life was measured using the SF-36 scale along with other sociodemographic variables. Descriptive analyses were performed, and the association of descriptive factors with attendance of the workshops was studied through a multivariate analysis. Of the 30 people evaluated (56.7% men; mean age 41.5 years), the global quality of life score in the mental domain was $45.51 (\pm 6.82)$, and in the physical domain, it was 50.66 (± 6.32). The association between the mean variables and the degree of social participation was not significant, with the exception of place of residence, with people living at home participating more often (ORa: 18.32 [1.23–272.51] p = 0.035).

 $\textbf{Keywords:} \ \ Technology \cdot Consumer \ participation \cdot Quality \ of \ life \cdot Mental \ illness$

1 Introduction

Mental health encompasses a wide range of activities directly or indirectly related to mental well-being, as indicated in the WHO's definition of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity", which touches on the promotion of well-being, the prevention of mental disorders and the treatment and rehabilitation of people affected by these disorders [1].

At the beginning of 2016 and according to the databases of the Extremadura Disability Centres (Centros de Discapacidad de Extremadura, CADEX), there were a total of

³ Health and Care Research Group (GISyC), University of Extremadura, Cáceres, Spain

24,548 people in the autonomous community with disability scores greater than or equal to 33% related to mental health disorders: 46% of these had depressive disorders, 24% had anxiety and adaptive disorders and 12% had schizophrenia and personality disorders [2]. However, these figures increases exponentially each year [3]. In fact, 9.7% of hospital stays were due to mental disorders, and 2.6% of the total population of Extremadura suffers from some type of mental disorder [4], comprising one of the most vulnerable groups. In many autonomous communities, mental illnesses are not listed as a direct cause of dependence but as a symptom of weakness of character or a punishment for immoral behaviour [5]. Therefore, the difficulty that people with severe mental illness have in participating in society is a reality [6]. There are limitations in basic activities such as leaving the house, participating in skills training activities and even having access to a suitable job; these limitations lead to a situation of vulnerability and may even evolve into social discrimination. In this way, social isolation, a lack of social networks and marginalization are characteristics that can be associated with "being alone", but the true loneliness associated with "feeling alone" entails feelings of homesickness, sadness and longing despite being around other people [7]. This feeling can be linked to lack of activity and social isolation that can lead to various affective disorders, such as depression [8]. These disorders can be disabling when they are experienced at certain life stages because of factors that amplify them, such as limited financial resources or comorbid physical diseases; in short, everything that affects social relationships and accelerates disease processes [9]. According to the WHO's, quality of life is understood as a person's perception of his or her position in life in the context of the culture and value systems in which he or she lives and in relation to his or her goals, expectations, standards and concerns [10].

2 Materials and Methods

An observational study of a group of 30 people with severe mental disorder (SMD) participating in a workshop on social networks and new technologies conducted at the FEAFES Cáceres mental health association was designed.

The activity took place between March and June 2019 and included 10 sessions in total, which generated 3 videos. The workshop was structured in 3 different phases: in the first phase, the objective of the workshop and the methodology to be used was explained, and a brainstorming meeting was held with the participants to select the topics to be covered based on their perceived needs.

The second phase was methodical and recurrent and was always structured in the same way. On the first day, the topic to be discussed was selected from the list generated during the first brainstorming session, the script was planned, and the roles that each person would adopt in the video (actors/actresses, director, producer...) were defined. To select which role each participant would play, previous knowledge about the use of social networks, technological devices, if they were users of the computer workshop was taken into account. Each participant needed to play a meaningful role for the person, favouring the assimilation of the role and enhancing the motivation to participate in the social network workshop.

In the following session, with the help of the directors and producers, the video was recorded at the chosen locations. Finally, the video was imported to iMovie. For

editing, working groups were created, and each person was responsible for editing a scene. Later, the director was responsible for assembling the video, creating transitions between scenes and producing the final cut.

All participants were clearly informed of the functions they had to perform in their roles, the factors to consider and how to behave.

For the person to acquire each role, a previous treatment of Occupational Therapy a previous was necessary. This intervention that involved performing a role analysis to describe the abilities of the person who would perform the role and how to carry it out, including skills such as basic activities of daily life, such as cleaning and bathing; instrumental activities, such as device management; and others.

Prior to the start of the workshop, information on the sociodemographic variables (age, sex, residence) of each subject was collected. Similarly, to measure quality of life, the free Spanish translated version of the original SF-36 scale licensed for unfunded research was used [11]. The SF-36 scale consists of 35 scored items divided into 8 health concepts: physical functioning, physical role functioning, emotional role functioning, social role functioning, mental health, general health perceptions, bodily pain and vitality. These dimensions form 2 main health domains: the physical health domain (QoL-P) and the mental health domain (QoL-M) [11]. Finally, as a dependent variable of the study, the attendance rate at the sessions was measured and recorded on an attendance sheet by the professional leading the workshop.

During data analysis, the variables of the sample were described. For qualitative variables, absolute values and percentages -n (%) were used. For quantitative variables, the distribution was determined using central tendency and dispersion values expressed as the mean and standard deviation (\pm SD) for variables with a normal distribution and the median and interquartile range [IQR] for those that were not normally distributed. Subsequently, the data were analysed in terms of their distribution according to the quality of life scores in the 2 main health domains: physical and mental. To do this, the sample was divided into two categories based on the mean quality of life scores: the WorseQoL group had scores below the median, and the BetterQoL group had scores greater than or equal to the median. Qualitative variables were compared using the chisquare test or Fisher's exact test for cells with fewer than 5 cases. Quantitative variables were compared using Student's t-test for variables with a normal distribution and the non-parametric Mann-Whitney U test for variables with non-normal distributions.

To measure the magnitude of the association between the quality of life of the participants and their attendance of the programme sessions, the dependent variable was dichotomized according to attendance rate as low attendance (<50%) and high attendance ($\ge50\%$).

This allowed us to carry out a multivariate analysis using binary logistic regression with attendance rate as a dependent variable and the other factors as independent variables. We obtained measures of the adjusted association between the independent variables and the dependent variable using adjusted odds ratios (ORa) and their corresponding 95% confidence intervals (95% CIs).

All analyses were performed using SPSS 25.0 for Windows (SPSS, Chicago, IL), and values of p < 0.05 were considered significant.

3 Results

Sociodemographic Characteristics

Of the 30 participants who started the programme, the median [IQR] age was 41.5 years [33.75–52.75], and 17 (56.7%) were men. The distribution in terms of the origin of the 30 participants was as follows: 9 (30%) lived at a residential rehabilitation Centre (RRC), 7 lived in group homes (GH) and 14 resided in their family homes (FH).

Quality of Life

The mean and standard deviation of the global values of the SF-36 scale with respect to the QoL-P domain was $50.66 (\pm 6.32)$ (Fig. 1).

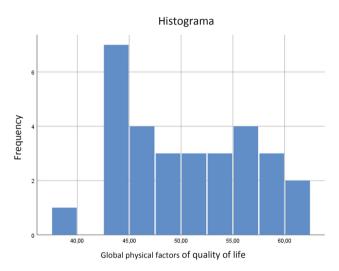


Fig. 1. Distribution of SF-36 physical component scores

The global value obtained for the QoL-M domain was 45.51 (\pm 6.8) (Fig. 2).

Figure 3 shows the quality-of-life scores broken down into the 2 domains and 8 patterns, along with the "normal" reference score.

The patterns below the normal line are all in the mental health domain, except for vitality, which is above the normal score.

After categorizing the patients into WorseQoL and BetterQoL groups according to their SF-36 scores, we found that when the variables were compared in terms of the QoL-P domain scores, there were more men in the WorseQoL group than in the BetterQoL group (n = 11 [73.3%] vs. N = 6 [40.0%] p = 0.065). The rest of the variables did differ significantly between the groups.

When the variables were compared between the groups with better and worse quality in the QoL-M domain, we found differences in median age (42 [32.2–58] years in the WorseQoL group versus 37 [32–50] years in the BetterQoL group (p=0.097)), although they were not significant. The rest of the variables were distributed similarly between the groups.

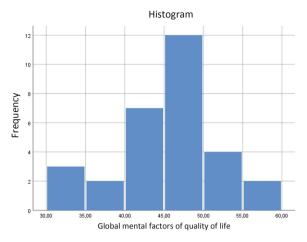


Fig. 2. Distribution of the SF-36 mental component scores

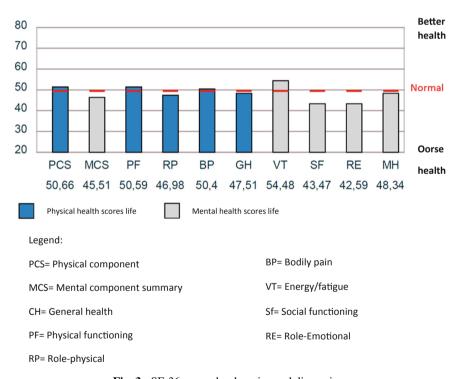


Fig. 3. SF-36 scores by domains and dimensions

Degree of Participation

Attendance of the ten sessions of the social participation programme ranged from a minimum of 10% to a maximum of 90% of sessions. The median [IQR] attendance rate (%) was 50 [10–62.5].

Of the total number of participants, 46.6% attended less than 50% of the sessions. When the distribution of the variables was examined according to workshop attendance rate, we found significantly higher workshop attendance among participants who were living at home (68% (n = 11), compared to 50% (n = 7) of RRC residents (p = 0.022). Age, sex and mean QoL-P and QoL-M scores did differ significantly between the lowand high-attendance participants.

Multivariate Analysis

When we measured the magnitude of the association between quality of life (mental and physical health) and the attendance rate at social participation workshops, we found that, adjusting for the rest of the dependent variables, the ORa of QoL-P was 3.52 (0.52-23.71), p=0.196, and the ORa of QoL-M was 1.57 (0.16-14.99), p=0.697. However, we did find significant associations in terms of place of residence, with an ORa of 18.32 (1.23-272.51), p=0.035, for FH residents.

4 Discussion

The main findings of this study are that, for the people with SMD participating in the social participation workshops, quality of life in both the mental and physical health domains was not associated with greater attendance. However, we did find a positive association between place of residence (family home) and greater attendance of the workshops.

Despite not finding a non-significant positive ORa between quality of life and participation, we cannot reject the initial hypothesis because, due to the small sample size, the statistical power may not have been sufficient; therefore, we used wide confidence intervals that include the null value. The almost-significant differences between the sexes in QoL-P and the significant differences in age in QoL-M between participants in the WorseQoL and BetterQoL groups could have influenced higher or lower attendance rates; however, after adjusting for these variables in the multivariate analysis, this possibility was discarded.

Quality of life is an individual's subjective perception of the opportunities available to them in their environment to meet their personal and work needs [12]. As a result, the need to objectively determine how each work area influences their lives and to determine whether occupational balance is a function of individual quality of life has been recognized. A person's perceived quality of life is determined by their social circle, and dependence can be created to the extent, as reflected in the qualitative study [13], that affected people themselves believe that associations should act as a bridge between "society" and the user, thus placing their occupational balance in the hands of a multi-disciplinary team. Consequently, the presence or absence of a therapeutic alliance and professional-patient trust may be considered a variable that can facilitate the achievement of goals and participation in relevant workshops. In our results, subtle distinctions were found within the studied group in terms of how involved each person was in social

participation. Although we cannot make inferences, our results suggest increased participation among people with higher mental global values of quality of life compared to physical global values, which suggests that the perception of a lower physical quality of life is not as limiting as the perception of a lower mental quality of life.

In this context, and as reflected in the book "Calidad de Vida, Inclusión Social y Bienestar Humano" (Quality of Life, Social Inclusion and Human Well-being) [14] regarding the quality of life of students, quality is perceived as fundamental to achieving high performance when student performance is understood as the student's progress towards planned goals; academic performance is not only the product of a pedagogical process of teaching and learning but is the outcome of educational action involving different elements with varying degrees of influence, the most prominent of which is the family and the social environment. This finding again emphasizes the influence and importance of context, which not only relates to high academic performance ([14]) but indirectly influences the quality of life of students as a condition that promotes academic performance.

It is understood that context is a factor that favours and/or limits quality of life and that greater community engagement decreases a person's state of anxiety and indirectly promotes their quality of life, both physical and mental [15]. Since anxiety is a mental disorder in which a person presents concern or an anxious state and has difficulty controlling fear, the difficulties and/or limitations of maintaining work-life balance in specific areas and activities, such as skills training and social participation, become more apparent among those with anxiety [16, 17]; thus, it is important to consider the relationship between this disorder and global quality of life. We can understand that a self-perception of lower mental health quality of life could limit participation in the community and all that it entails.

Cuadra, in his research on quality of life in older adults, includes the following among the most important indicators: health, living conditions, use of free time, recreation, interpersonal relationships, job satisfaction and integration into the community [18]. These results, combined with our data, suggest an association between higher quality of life and greater participation and social integration. Although the low statistical power of our study, which had a sample of 30, did not enable significant differences to be found, social participation does not appear to be limited by self-perceived mental quality of life, nor does it influence the limitations posed by innate pathology.

The workshop in which the degree of involvement and participation was measured pertained to social networks and new technologies. In this workshop, the participants were responsible for designing, recording and editing a video to be uploaded to a YouTube channel. The subject of the video arose from the concerns of the group, which gave the activity special significance since neither the theme nor the script was imposed by a professional. Currently, new technologies known as information and communications technologies (ICTs) offer important advantages in terms of their ability to reach anyone who needs it at a reasonable cost [19] and to foster relationships among peers immediately and effectively. That is why they are considered a simple and economic tool that facilitates and promotes relationship and social participation, for example, through social networks, YouTube, etc.

Different lines of research on disorders of greater clinical severity, such as post-traumatic stress disorder among children who are victims of physical and psychological abuse [20] or body image in patients with eating disorders [21, 22], show that these technologies favour complex conditions and facilitate emotional processing [20].

In our study, we observed that higher levels of autonomy and global quality of life, both physical and mental, were maintained in the studied sample among those with a greater degree of participation in the social media workshop, suggesting that ICTs offer a better way to engage in social participation. The article by Barroso discusses adulthood and new technologies, and it has been shown that ICTs offer important opportunities to improve psychological processes and the performance of activities of daily living [23].

Finally, Breton refers to ICT-based applications designed to improve interventions with children or adolescents, a population that has not received as much attention as adults in this regard [19].

We cannot forget that mental health is based on learning about reality and subsequently transforming perceptions through confrontation, management and integrative resolution of conflicts, both those internal to the individual and between the individual and his or her environment. When this learning is interrupted or fails to be resolved, we can begin to consider it an illness [24]. We cannot confirm that a decrease in global factors at the mental level favours a better quality of life. The present study presents important limitations that prevent us from drawing clear conclusions. First, the small sample size forced us to categorize quantitative variables that may have been correlated if we had had enough samples and a normal distribution. Specifically, the lack of normality forced us to use non-parametric comparison tests. On the other hand, the characterization of the sample was not sufficiently detailed; although we believe that data regarding the main variables involved were collected, the observational nature of the study prevents us from ruling out the possibility that other unmeasured factors confounded the relationship. Finally, since there is no standardized definition of what a social intervention should be or how many sessions it should include, there is no external validity. Therefore, efforts should be made to define and compare the possible applications of this type of intervention.

To conclude, we can say that it would be advisable to take into account the perception of the users of the new technologies workshop regarding the accessibility to the devices, level of knowledge and possibility of using technological devices apart from the social networks workshop. It is important to measure variables such as previous use of technological devices, the socio-economic level and the social relations of the person to have a more objective view of the results obtained. Some of the people who participated in the social networking workshop where users of a computer workshop. In this way, the basic use of technological devices was ensured. However, it is an important factor to take into account as it could favour absenteeism from the workshop if the person does not know how to handle a computer or the editing software that was chosen.

Acknowledgments. This work was supported by 4 IE+ project (0499_4IE_PLUS_4_E) funded by the Interreg V-A España-Portugal (POCTEP) 2014–2020 program.

Conflict of Interest. The authors declare that they have no conflict of interest.

References

- 1. WHO: Hablemos de la depresión. In: Salud Mental [Internet] (2017). https://www.who.int/topics/mental_health/es/. Accessed 28 June 2019
- Martín, B., Torres, I., Casado, M.P., López, M.I., Rodríguez, B., Torres, R.: III Plan Integral de Salud Mental de Extremadura 2016–2020. JUNTA DE E. Mérida (2017). https://saludextremadura.ses.es/filescms/web/uploaded_files/CustomContentResources/PLAN_SALUD_MENTAL_2016_2020.pdf
- Irarrázaval, M., Prieto, F., Armijo, J.: Prevención e intervenciones tempranas en salud mental: una perspectiva internacional. Acta Bioethica. 22(1), 37 (2016). http://dx.doi.org/10.4067/ S1726-569X2016000100005
- 4. INE: Encuesta de Morbilidad Hospitalaria. EMH, p. 10 (2015). www.ine.es
- WHO: Ciudadanos marginados. Organización Mundial de la Salud (2019). https://www.who. int/features/2005/mental health/es/
- 6. INE: Población con barreras en la participación social según las situaciones en las que señala barreras por sexo, país de nacimiento y grupo de edad (2012). https://www.ine.es/jaxi/Datos. htm?path=/t15/p470/p03/2012/10/&file=12002.px
- Rubio, R.: La soledad en las personas mayores españolas. Portal Mayores. Madrid (2004). http://www.imsersomayores.csic.es/documentos/documentos/rubio-soledad-01.pdf
- 8. Quiroz, C.O.A., Quintana, J.T., Flores, R.G., Castro, S.B.E., García, J.J.V., Rubio, L.R.: Soledad, depresión y calidad de vida en adultos mayores mexicanos. Psicol y Salud. 27, 179–188 (2017). http://psicologiaysalud.uv.mx/index.php/psicysalud/article/view/2535
- 9. Moss, K., Scogin, F., Di Napoli, E., Presnell, A.: A self-help behavioral activation treatment for geriatric depressive symptoms. Aging Ment Health. **16**, 625–635 (2012). https://doi.org/10.1080/13607863.2011.651435
- Mendieta M. Calidad de Vida y Sentido de Comunidad en la Ciudad. Uciencia Rev Divulg científica la Univ Malaga (2010). Available: https://riuma.uma.es/xmlui/bitstream/handle/ 10630/4057/38_revistauciencia03.pdf?sequence=1
- 11. Vilagut, G., Ferrer, M., Rajmil, L., Rebollo, P., Permanyer-Miralda, G., Quintana, J.M., et al.: El Cuestionario de Salud SF-36 español: una década de experiencia y nuevos desarrollos. Gac. Sanit. 19, 135–150 (2005). https://doi.org/10.1157/13074369
- 12. Vera, M.: Significado de la calidad de vida del adulto mayor para sí mismo y para su familia. An la Fac. Med. **68**, 284 (2013). https://doi.org/10.15381/anales.v68i3.1218
- Cilleros, M., Gómez, M.: Análisis cualitativo de tópicos vinculados a la calidad de vida en personas con discapacidad. Cien Saude Colet. 21, 2365–2374 (2016). https://doi.org/10.1590/ 1413-81232015218.04182016
- 14. Robledo, P., García, J.: El entorno familiar y su influencia en el rendimiento académico de los alumnos con dificultades de aprendizaje: revisión de estudios empíricos. Aula Abierta. 37, 117–128 (2009). file:///Users/sarachimento/Downloads/Dialnet-ElEntornoFamiliarYSuInfluenciaEnElRendimientoAcade-3000179.pdf
- 15. Dieterich, M., Irving, C.B., Bergman, H., Khokhar, M.A., Park, B., Marshall, M.: Intensive case management for severe mental illness. Cochrane Database Syst. Rev. 1 (2017). https://doi.org/10.1002/14651858.cd007906.pub3
- 16. Hagman, G.: Trastorno de ansiedad generalizada. Salud (i) Ciencia (2011). https://medlineplus.gov/spanish/ency/article/000917.htm
- 17. Campagne, D.M.: El terapeuta no nace, se hace. Rev la Asoc Española Neuropsiquiatría. **34**, 75–95 (2014). https://doi.org/10.4321/s0211-57352014000100005

- Cuadra, A., Cáceres, E., Guerrero, K.: Relación de Bienestar Psicológico, Apoyo Social, Estado de Salud Física y Mental con Calidad de Vida en Adultos Mayores de la Ciudad de Arica. LÍMITE Rev. Interdiscip Filos y Psicol. 11, 57–68 (2016). http://limite.uta.cl/index. php/limite/article/view/175
- 19. Bretón, J., Mira, A., Castilla, D., García, A., Botella, C.: Revisión de aplicaciones de las tecnologías de la información y la comunicación en psicología clínica y de la salud en infancia y adolescencia. Rev. Psicol. Clínica Con. Niños y Adolesc. **4**, 11–16 (2017)
- López, C., Castro, M., Botella, M., Álcantara, M.: Sistema de realidad virtual EMMA-Infancia en el tratamiento psicológico de un menor con estrés postraumático. Rev. Psicopatología y Psicol. Clínica. 16, 189–206 (2011). https://doi.org/10.5944/rppc.vol.16.num.3.2011.10361
- Ferrer, M., Gutierrez, J., Treasure, J., Vilalta, F.: Craving for food in virtual reality scenarios in non-clinical sample: analysis of its relationship with body mass index and eating disorder symptoms. Eur. Eating. Disord Rev. 23, 371–378 (2015). https://doi.org/10.1002/erv.2375
- 22. Marco, J.H., Perpiñá, C., Botella, C.: Tratamiento de la imagen corporal en los trastornos alimentarios y cambio clínicamente significativo. An Psicol. **30**, 422–430 (2014). http://dx.doi.org/10.6018/analesps.30.2.151291
- Barroso, C.L., Abad, M.V., Valle, M.S.: Mayores e Internet: La Red como fuente de oportunidades para un envejecimiento activo. Comun Rev científica Iberoam Comun y Educ. 29–36 (2015). https://dialnet.unirioja.es/servlet/articulo?codigo=5133305
- Montealegre, R.: La solución de problemas cognitivos. Una reflexión cognitiva sociocultural.
 Av en Psicol Latinoam. 25, 20–39 (2007). http://www.scielo.org.co/pdf/apl/v25n2/v25n2a3.pdf



Digital Technology Scale to Coach People with Chronic Diseases: Evidence of Psychometric Validity in Four European Countries

Pedro Parreira¹ , Rafael A. Bernardes¹ (☒) , Paulo Santos-Costa¹ , João Graveto¹ , Paulo Alexandre Ferreira¹, Anabela Salgueiro-Oliveira¹ , Liliana B. Sousa¹ , Beatriz Serambeque¹ , Lisete Mónico¹ , Marija Milavec Kapun², Tina Gogova², Pirjo Vesa³, Hilde Vandenhoudt⁴, Dorine Nevelsteen⁴, and Raija Kokko⁵

Health Sciences Research Unit: Nursing, Nursing School of Coimbra, Coimbra, Portugal {parreira, rafaelalvesbernardes, paulocosta, jgra-veto, palex, anabela, baptliliana, beat-rizprazserambeque}@esenfc.pt, lisete.monico@fpce.uc.pt

² Faculty of Health Sciences, University of Ljubljana, Ljubljana, Slovenia {marija.milavec,tina.gogova}@zf.uni-lj.si

³ North Karelia University of Applied Sciences, Karelia, Finland pirjo.vesa@karelia.fi

⁴ Thomas More Kempen, Turnhout, Belgium

{hilde.vandenhoudt,dorine.nevelsteen}@thomasmore.be
5 Department of Nursing, Tampere University of Applied Sciences, Tampere, Finland
raija.kokko@tamk.fi

Abstract. Noncommunicable diseases (NCDs) bring new challenges for the healthcare sector, demanding a paradigm shift on healthcare deliverance. In this sense, information and communication technologies (ICTs) are being more and more used, implying a change in educational programs of nursing schools. The application of ICTs in healthcare is often linked with concepts like 'patient engagement' or 'patient empowerment', implying an active participation of the patient in the therapeutic process. Although coaching in a context where NCDs are present is well studies, nursing curricula seems to lack consistent content for future nurses. This study aims to develop a tool to explore nursing student's perceived easiness of use and perceived utility of potential ICTs in the coaching of people with chronic diseases. The scale's items list (n = 45) emerged from a recent study published in the nursing students' digital competencies area. The scale was developed based on the Technology Acceptance Model (TAM) and other conceptual models. The scale was reviewed and discussed by a panel of experts and then translated into four languages (Portuguese, Slovenian, Flemish, and Finnish). The scale was applied to undergraduate nursing students from five universities from Portugal, Finland, Belgium and Slovenia. A total of 874 students were enrolled, with a mean age of 22.38 years (SD = 5.49), being 621 (71.1%) females. The most significant dimensions were Professional Performance, Relationship and Patient Empowerment. DTS-NCD constitutes a good tool to explore nursing student's perceptions relating the use of ICTs.

1 Background

With the increase of chronic diseases as a global burden and a major public health challenge [1, 2], namely in the elderly population, there seems to be a need for a paradigm shift when it comes to healthcare deliverance. In fact, there's a need to rethink organizational strategies and nursing interventions [3] in order to be capable of answering new challenges that arise from noncommunicable diseases (NCDs).

Nowadays, information and communication technologies (ICTs) are being more and more incorporated into healthcare systems [4, 5], followed by routine practices changes, also implying progressive educational programs for professionals and for patients. In fact, in countries like Portugal, Belgium and Finland, nursing curricula already include disciplines like 'innovation and entrepreneurship' as an earlier preparation for future nurses.

Nonetheless, and although current ICT solutions are vast, the complex disease management implied by NCDs is still an important challenge for most healthcare systems, generating significant barriers. Some of the most frequent are 'the complexity of communication among the care team', 'the burden of regular review and follow-up' and 'the limited means of providing support for patient self-management' [6].

In such context, the application of ICTs in healthcare is often linked with concepts like 'patient engagement' or 'patient empowerment' [6], which imply the active participation of the patient in his own therapeutic process. A recent study [8] concluded that when empowerment measures are present, patient's health seemed to improve and get an active attendance in their self-care, a better self-governing of their health and a higher personal control.

Although the importance of coaching in a context where NCDs are present is well studied in the literature, nursing curricula seems to lack consistent content for future nurses [9, 10].

Taking into consideration the preceding information, this study aims to develop a tool to explore nursing students' perceived easiness of use and perceived utility of potential ICTs in the coaching of people with chronic diseases.

2 Method

2.1 Phase 1: Scale Development

For the construction and development of the scale, dimensions used were the ones already studied and published by a recent research in the nursing students' digital competencies area [11].

An initial version of the scale was created in English, with a section with a total of 45 items. This section focuses on nursing student's perceived easiness of use and perceived utility of ICTs in the coaching of people with chronic diseases. The section

contains a scale with closed questions, answered through a Likert Scale that ranged from 1 (strongly disagree) to 7 (strongly agree).

A questionnaire entitled Digital Technology Scale to measure the competencies in digital technology to support people with chronic diseases was developed based on conceptual development sustained in Technology Acceptance Model- TAM [12–14]; Technology Readiness Acceptance Model and Unified Theory of Acceptance and Use of Technology (15-16) inspired in several instruments (System Usability Scale (SUS) [15]; USE Questionnaire[17]; After Scenario Questionnaire (ASQ) [18, 19] we highlight two major dimension: Utility perceived and easy to use [12, 13, 20].

Respondents rated each of the 45 items based on their opinion about the use of digital technologies and tools to coach people with chronic diseases (7-point Likert scale from 1-Strongly disagree to 7-Strongly agree).

2.2 Phase 2: Scale Refinement and Translation

The scale was reviewed and discussed within a panel of experts composed of 13 nursing doctorates, researchers and teachers from five European universities. Structural and semantic adjustments were performed until all experts involved were in agreement. This process resulted in the development of the pre-validated version of the Digital Technology Scale to measure the competencies in digital technology to support people with chronic diseases (DTS-NCD scale).

After this process, the DTS-NCD scale was translated into four languages (Portuguese, Slovenian, Flemish, and Finnish) following the method proposed by Beaton and associates for the Cross-Cultural Adaptation of Self-Report Measures [15]. The translation process involved four stages: i) two independent forward translations for the target language, made by bilingual translators whose mother tongue is the target language; ii) conduction of a written synthesis of the previous translations made; iii) two independent back-translation of the synthesized version by English native speakers; iv) expert consensus of semantic, idiomatic, experiential and conceptual equivalence. After this process, all local experts reported a correct and accurate translation of the DTS-NCD scale to each language.

2.3 Subjects and Recruitment Process

As inclusion criteria, students had to be 18 years of age or older, integrate the bachelor degree (first cycle), and give informed consent to their participation. First, students were approached by a senior research team member between classes and informed about the study goals. Then, students were asked about their desire to participate in completing the DTS-NCD scale. After its completion, students were instructed to place the scale form in a sealed box in a designated location within the institution's facilities.

2.4 Ethical Considerations

Following the ethical principles of the Declaration of Helsinki, students who willingly decided to participate in the study signed a written informed consent form. All forms used during this study were alphanumerically encoded to preserve students' identity.

This study was approved by the Ethical Commission of the Health Sciences Research Unit: Nursing (UICISA:E) of the Nursing School of Coimbra (ESEnfC) with the reference P665-04/2020

2.5 Data Analysis

Principal component analysis (PCA) and reliability analysis were performed in each country through the statistical program Statistical Package for the Social Sciences (version 22.0). Frequencies of answers were examined in order to eliminate items without variation, or in which the positioning of the sample deviated clearly from a normal distribution. Outliers were analysed according to Mahalanobis squared distance [21]. The normality of the variables was assured by the coefficients of skewness (Sk) and kurtosis (Ku) (|sk| and |ku| < 1).

The PCA requirements were checked according to Tabachnick and Fidell (2013) [21], namely the sample size and adequacy, normality and linearity of the variables, and R's factorability. VARIMAX rotation method with Kaiser's normalization was used, since we intend to retain independent factors.

3 Results

A total of 874 nursing students were included in the study, with a mean age of 22.38 years (SD = 5.49), being 621 (71.1%) females. The students were from four different countries: 105 from Finland, 187 from Slovenia, 131 from Belgium and 451 from Portugal.

The results of the PCA are presented in Table 1. Considering the ratio subjects per items, since we used 22 items, the ratio subjects per items found was over 5 for all the countries (excluding Finland with a ratio of 4.8), which enables, according to Gorsuch (1983) [22], a reliable utilization of PCA. Additionally, the intercorrelation matrix differed from the identity matrix, since the Bartlett's test showed significant scores for all the countries (p < .001), and the Kaiser-Meyer-Olkin (KMO) measure was over .70, indicating an adequate sampling for the four countries in analysis.

Two criteria were used for factors' extraction: eigenvalue over one and Scree plot. The combining of these two criteria lead to the extraction of three factors in each country. Some items were excluded, since their communalities (h2) and factorial loadings (s) were below .50. Other items were excluded based on high factorial loadings in more than one factor.

A final solution of the same factors with the same items for all the four countries were extracted, being responsible for 73.89% of the total variance in Belgium, 71.82% in Finland, 67.58% in Portugal, and 64.39% in Slovenia. Factorial loadings are higher than .50 for all dimensions [21]. For the four countries, Factor 1 is composed by items related o professional performance (F1 – Professional Performance), Factor 2 with the interpersonal relation based on the patient centred care (F2 – Relationship), and Factor 3 with the empowerment of the patient (F3 –Patient Empowerment). All the dimensions showed good reliability (Cronbach's alpha > .90). For the four countries, Factor 2– Relationship has received the lowest mean score and Factor 1 – Professional Performance the highest mean score.

Table 1. Principal Component Analysis, Reliability and Descriptive statistics of the Digital Technology Scale to coach people with chronic diseases; data from the three factors after Varimax Rotation for the four countries

| Country: | | Belc | Belgium | | | | Finland | | | Por | Portugal | | | | Slovenia | |
|---|------------|-------------|---------|-------------------------|--------|-------------|-----------------|-------|--------|------------|-----------------|-----|-------------|--------|-----------------|-----|
| Using digital technologies and tools to coach people with chronic diseases Items: | F1 (s) | ® E2 | (s) | h2 | (s) | (s) | (S) E3 | h2 | (s) | (s) F2 | (s) | h2 | (s) | (s) | (s) | h2 |
| 11- Allows me to complete task(s) easily. | -85 | .23 | 19 | 18. | .81 | .31 | .15 | .77 | 62: | .23 | .15 | 17. | 92. | .24 | .20 | 39. |
| 10-Increases the productivity of my work. | 25. | .31 | .15 | .83 | 7.7 | .33 | .27 | .73 | 62: | .28 | .18 | .73 | 28: | .19 | .17 | 92. |
| Facilitates the continuity of my task(s). | .82 | 91. | 34 | .82 | 17: | .36 | .27 | 02'' | .73 | 60' | .35 | 79. | .75 | .14 | .32 | 69. |
| 9- Allows me to complete task(s) quickly. | -82 | 1. | .10 | .70 | ¥. | .21 | 80' | .75 | 87. | .18 | .13 | .67 | 1. | 1. | .12 | .62 |
| Facilitates the performance of my task(s). | 8. | .25 | .26 | 1/2 | 爽 | .23 | .27 | .83 | 7. | .20 | .31 | 89. | 69. | .22 | .28 | 09. |
| 8- Reduces the possibility of errors. | 89. | .25 | .26 | .59 | .73 | .13 | .28 | .63 | 57: | 01 | .16 | 09. | 69: | 1. | = | .50 |
| 7-Increases the quality of my work. | 99. | .24 | .39 | .64 | .73 | 9. | .46 | .75 | 17: | .27 | 91. | 09. | 29. | 11 | .35 | .59 |
| 14- Allows me to control the task(s) to be performed. | .62 | .01 | .42 | .57 | .82 | .13 | 72. | .77 | 99. | .05 | .33 | .54 | 49 . | 04 | 4. | 19. |
| 23-Establishes a true relationship with the patient. | .21 | 88. | .20 | 98. | .10 | .87 | .21 | 18. | .12 | .83 | .18 | 47. | .17 | 18. | Ξ | 02. |
| 29-Promotes an open dialogue with the patient. | .12 | .82 | .31 | 2/2 | .20 | .82 | .21 | 92. | .21 | <i>TT:</i> | .32 | 74 | .18 | 1. | .23 | 29. |
| 21-Enhances my understanding of a patient's experience. | .33 | 98. | 24 | 18. | .29 | 69: | .22 | 79. | .27 | 47. | 24 | 29. | .10 | 97. | 4. | 09. |
| 32-Builds an effective relationship with the patient. | .13 | 67. | .37 | 12 | .27 | 89. | 38 | 89. | .18 | 47. | .36 | 17. | .22 | 57. | .31 | 17. |
| 20-Facilitates an empathic relationship with a patient. | .31 | 87. | 24 | 92. | 4 | 85 | 61. | 62'' | .13 | 18: | .13 | 69. | .05 | 18. | .10 | 79. |
| 26-Creates a safe environment for dialogue with a patient. | .17 | <i>TT</i> : | .29 | 17. | .31 | .80 | .21 | 62' | 41. | 92. | .27 | 29. | .20 | .78 | .15 | 79. |
| 24-Increases the patient's motivation. | .29 | .70 | 84. | 08. | .21 | 99. | .34 | .59 | 14 | 26. | 84. | 99. | 61. | 27. | .28 | .63 |
| C35-Motivates the patient to take control of his/her own health. | .22 | .39 | 92. | .78 | 91. | .35 | 92. | 7. | .26 | .22 | .80 | 92. | .23 | .36 | .70 | 79. |
| 43-Informs the patient about the importance of his/her role in self-management. | .25 | .31 | 37. | .72 | .27 | .17 | 18: | .75 | .27 | .30 | .73 | 02. | 72. | 9. | 8. | .72 |
| 37-Establishes the goals that the patient wants to achieve. | .35 | .28 | .73 | .73 | .30 | .28 | 17: | 89. | .32 | .31 | 69: | 29. | .21 | .46 | .59 | 09' |
| 38-Motivates the patient's interest in his/her own health. | 24 | .37 | 17: | 17. | .22 | .30 | <i>tt</i> : | .73 | .20 | .37 | 7. | .72 | .10 | 64. | 99. | 89. |
| 33-Supports the patient's self-management skills. | .32 | .39 | 89. | .72 | 24 | .48 | 19. | 99. | .20 | .22 | 62: | .72 | .34 | .24 | 99: | 19. |
| 44-Enhances my understanding of the basic principles of self-management support. | .31 | 4 | 99. | .72 | .24 | 91. | .73 | .63 | .36 | 36 | .63 | .65 | .29 | .15 | 29. | .56 |
| Country: | | Belc | Belgium | | | Œ | Finland | | | Por | Portugal | | | | Slovenia | |
| Using digital technologies and tools to coach people with chronic diseases Items: | F1 (s) | F2 (s) | F3 (s) | 117 | F1 (s) | F2 (s) | F3 (s) | h2 | F1 (s) | F2 (s) | E3 (s) | h2 | F1 (s) | F2 (s) | F3 (s) | h2 |
| C41-Helps to prepare a real action plan to- gether with a patient. | .51 | .26 | .57 | 99' | .25 | .23 | .74 | 99' | .43 | .31 | .55 | .58 | .31 | .26 | 19. | .62 |
| Ratio subjects per items | | | 131/ | 131/22=5.95 | | | 105/22=4.8 | 4.8 | | 451/2 | 451/22=20.5 | | | 18 | 187/22=8.5 | |
| Kaiser-Meyer-Olkin Measure of Sampling Adequacy | dequacy | | | .937 | | | .903 | | | oi. | .948 | | | | .933 | |
| Bartlett's Test of Sphericity (approx. chi-square, df=231) | ii-square, | | 2720.5 | 2720.50, <i>p</i> <.001 | _ | 21 | 2115.16, p<.001 | €.001 | | 7374.14 | 7374.14. p<.001 | | | 265 | 2651.18, p<.001 | 101 |
| Eigenvalues | 5.86 | 5.6 | 4.7 | | 5.2 | 5.6 | 7.8 | | 5.29 | 4.95 | 4.6 | | 5.13 | 4.91 | 4.1 | |
| % of explained variance | 26.61 | 25. | 21. | | 23. | 25. | 27 4 | | 24.0 | 22.5 | 21. | | 22.3 | 23.3 | 18. | |
| Cronbach's alpha | .94 | .95 | .93 | | 94 | .93 | .92 | | .92 | .92 | .92 | | .92 | .91 | 68' | |
| Mean | 4.54 | 3.4 | 5.2 | | 5.7 | ς, ∞ ∞.∞ | 4.4 | | 5.04 | 3.63 | 8 4.6 | | 4.96 | 3.42 | 8 4.5 | |
| Standard-deviation | 1.16 | 1.3 | 1.2 | | 0.1 | 1.2 | 0.10 | | 1.05 | 1.25 | = , | | 1.20 | 1.36 | | |
| | | | 4 | | 7 | o | > | | | | , | | | | r | |

4 Discussion

As a growing public health concern, chronic conditions require a close relationship between professionals and patients, with a progressive and desired self-management of one's condition. Besides, with NCDs' prevalence growing with high rates, there's a need to expand primary healthcare teams, as an important outcome of the necessary decentralization in this sector [24].

In this sense, and when it comes to 'professional performance', health coaching emerged has a widely adopted intervention within the scope of chronic disease treatment [23], and for professionals, eventually a mandatory skill. In fact, in a report about community health nursing education [25], WHO states that community health nurses must be well equipped with up-to-date community health nursing knowledge and skills. This is such that ICTs are opening new and exciting possibilities for self-care and for engagement of people and communities, thus generating a stronger primary health care (PHC) [26].

For nursing profession, and according to Kulbok & Ervin (2012) [27], public health knowledge is a strong component of the nursing curricula, but there seems to be an absence of proper curricula content in order to be more effective and efficient.

From the point of view of the patient, expanded roles in the process of disease self-management can be difficult and frustrating [7, 28, 29]. But, and from a perspective of the relation between professional and patient, when it comes to delivering a person-centred care, with self-established goals, solutions are easily found.

PHC as a new whole-of-society approach to health, among other components, requires an effective empowerment of people and communities [24, 25, 28]. In fact, 'patient empowerment' may trigger self-management components like 'focusing on illness needs', 'activating resources' and 'living with a chronic illness' [30].

Until now, from what we know of previous research, we developed a unique tool focused on what nursing students perceive of future potential ICT solutions, in terms of easiness of use and utility. Our tool showed good psychometric properties and similar results when applied to students from Portugal, Finland, Slovenia and Belgium. It's thus a strong scale to apply within Europe's cultural setting, even when nursing education differs across countries.

Our study isn't devoid of some limitations. Regarding the total number of participants (n = 874), the samples of each country isn't a representation of the entire local nursing student community. During the recruitment phase, the students' course year was not defined as an inclusion criterion, thus being a source of bias, since clinical practice isn't the same throughout course completion. For future research, these limitations should be taken into consideration.

5 Conclusion

Digital Technology Scale to measure the competencies in digital technology to support people with chronic diseases showed evidence of psychometric validity and reliability in the four European countries in analysis. Professional Performance, Relationship, and Patient Empowerment were the most significant dimensions related to the use of digital technologies and tools in the coaching of people with chronic illness.

Authors' Contributions. PP, PSC, JG, PAF, MMK, PV, HV, DN and RK conceived the study. LM and PP performed the statistical analysis. PP,ASO, PSC, BS, RAB, LBS, JG, PAF, MMK, TG, PV, HV, DN and RK collected data. PP, PSC, RAB, LM wrote the manuscript with the input from the remaining authors. All of the authors have read and approved the final manuscript.

Ethics Approval and Consent to Participate. This study was approved by the Ethical Commission of the Health Sciences Research Unit: Nursing (UICISA:E) of the Nursing School of Coimbra (ESEnfC) with the reference P665-04/2020

Funding. This study is part of the project DigiNurse - Learning ICT Supported Nursing for Self-Management of Patients, funded by the Education, Audiovisual and Culture Executive Agency of the European Comission, through the Key Action 2: Cooperation for innovation and the exchange of good practices of the Erasmus+ program.

Competing Interests. The authors declare that they have no competing interests.

References

- World Health Organization. Global action plan for the prevention and control of noncommunicable diseases 2013–2020, pp. 1–55. WHO Press, Geneva (2013). https://apps.who.int/iris/bitstream/handle/10665/94384/9789241506236_eng.pdf;jsessionid=AC86EA3943A1DAAC4D76833D05577666?sequence=1
- World Health Organization. Noncommunicable Diseases: Country Profiles 2018. WHO, Geneva (2018). https://www.who.int/nmh/publications/ncd-profiles-2018/en/
- Lisiecka-Biełanowicz, M., Wawrzynlak, Z.M.: Healthcare model with use of information and communication technology for patients with chronic disease. Ann. Agric. Env. Med. 23(3), 462–467 (2016)
- 4. García-Lizana, F., Sarría-Santamera, A.: New technologies for chronic disease management and control: a systematic review. J. Telemed. Telecare 13, 62–68 (2007)
- Lupton, D.: Critical perspectives on digital health technologies. Sociol. Compass, 1344–1359 (2014). https://doi.org/10.1111/soc4.12226
- Georgeff, M.: Digital technologies and chronic disease management. Austr. Fam. Phys. 43(12), 842–846 (2014)
- 7. Lupton, D.: The digitally engaged patient: Self-monitoring and self-care in the digital health era. Soc. Theor. Health 11(3), 156–270 (2013)
- 8. Galanakis, M., Tsoli, S., Darviri, C.: The effects of patient empowerment scale in chronic diseases. Psychology 7, 1369–1390 (2016). https://doi.org/10.4236/psych.2016.711138
- 9. Koivunen, M., Saranto, K.: Nursing professionals' experiences of the facilitators and barriers to the use of telehealth applications: a systematic review of qualitative studies. Scand. J. Caring Sci. **32**(1), 24–44 (2017)
- Eley, R., Fallon, T., Soar, J., Buikstra, E., Hegney, D.: The status of training and education in information and computer technology of Australian nurses: a national survey. J. Clin. Nurs. 17(20), 2758–2767 (2008)
- 11. Parreira, P., Costa, P., Salgueiro-Oliveira, A., Ferreira, P., Sousa, L., Marques, I., et al.: Nursing students digital competencies for the self-management of patients: development of the diginurse model's interface. In: Gerontechnology, pp. 249–256 (2019)
- 12. Davis, F.D., Bagozzi, R.P., Warshaw, P.R.: User acceptance of computer technology: a comparison of two theoretical models. Manage. Sci. 35(8) (1989)

- 13. Davis, F.D.: Perceived usefulness, perceived ease of use and user acceptance. MIS Q. 13(3), 319–339 (1989)
- 14. Mathieson, K.: Predicting user intentions: comparing the technology acceptance model with the theory of planned behavior. Inf. Syst. Res. 2(3), 173–191 (1991)
- 15. Venkatesh, V., Morris, M.G., Davis, G.B., Davis, F.D.: User acceptance of information technology: toward a unified view. MIS Q. **27**(3), 425–478 (2003)
- Bangor, A., Kortum, P.T., Miller, J.T.: An empirical evaluation of the system usability scale. Int. J. Hum. Comput. Inter. 24(6), 574–594 (2008)
- 17. Lund, A.M.: Measuring usability with the USE questionnaire. Usability Interface **8**(2), 3–6 (2001)
- 18. Lewis, J.: Psychometric evaluation of the PSSUQ using data from five years of usability studies. Int. J. Hum. Comput. Interact **14**(3), 463–488 (2004)
- Lewis, J.R.: Psychometric evaluation of an after-scenario questionnaire for computer usability studies. ACM SIGCHI Bull. 23(1), 78–81 (2007)
- Venkatesh, V., Davis, F.D.: A theoretical extension of the technology acceptance model: four longitudinal studies. Manag. Sci. 46(2), 186–204 (2000)
- Tabachnick, B.G., Fidell, L.S.: Using Multivariate Statistics. 6th edn. Pearson Education, London (2013)
- 22. Gorsuch, R.: Factor Analysis. Lawrence Erlbaum, Hillsdale (1983)
- 23. Boehmer, K.R., Barakat, S., Ahn, S., Prokop, L.J., Erwin, P.J., Murad, M.H.: Health coaching interventions for persons with chronic conditions: a systematic review and meta-analysis protocol. Syst. Rev. **5**, 146 (2016). https://doi.org/10.1186/s13643-016-0316-3
- Altman, R.B., Bankauskaite, V., Vrangbaek, K.: Decentralization in Health Care, 326 p. McGraw Hill Open University Press, New York (2007)
- 25. World Health Organization. A framework for community health nursing education. WHO, Geneva (2010). https://apps.who.int/iris/bitstream/handle/10665/204726/B4816.pdf? sequence=1&isAllowed=y
- 26. World Health Organization. A Vision for Primary Health Care in The 21st Century. WHO, Geneva (2018). https://www.who.int/docs/default-source/primary-health/vision.pdf
- 27. Kulbok, P.A., Ervin, N.E.: Nursing science and public health: contributions to the discipline of nursing. Nurs. Sci. Q. 25(1), 37–43 (2012). https://doi.org/10.1177/08943184114229034
- 28. Adams, R.J.: Improving health outcomes with better patient understanding and education. Risk Manag. Healthcare Policy 3, 61–72 (2010). https://doi.org/10.2147/RMHP.S7500
- Grady, P.A., Gough, L.L.: Self-management: a comprehensive approach to management of chronic conditions. Am. J. Public Health 104(8), e25–e31 (2014). https://doi.org/10.2105/ AJPH.2014.302041
- Shulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., Redeker, N.S., Reynolds, N., Whittermore, R.: Processes of self- management in chronic illness. J. Nurs. Sch. 44(2), 136–144 (2012). https://doi.org/10.1111/j.1547-5069.2012.01444.x



Aging and Functionality of the Institutionalized Elderly People of Alto Alentejo: Contributions to the Diagnosis of the Situation

Helena Arco^{1,2,4(⊠)}, Adriano Pedro¹, Lara Pinho^{1,3,4}, and Adelaide Proença¹

¹ Instituto Politécnico de Portalegre, Portalegre, Portugal helenarco@ipportalegre.pt ² VALORIZA, Portalegre, Portugal ³ University of Évora, Évora, Portugal ⁴ Comprehensive Health Research Centre (CHRC), Évora, Portugal

Abstract. The loss of functionality in aging process is a concern nowadays. We proposed to perform the diagnosis of the functionality of institutionalized elderly people in Portalegre city. We developed a quantitative, descriptive and transversal study with the application of three evaluation instruments (Elderly Nursing Core Set, Mini-Mental State Examination and Blessed Dementia Scale (BDS)). The sample consisted of 89 elderly people, with an average age of 86.6 years-old, most of them are female (71.9%), widowed (77,5%) and illiterate (51.7%). The average of years of institutionalization was 3.5. 45.3% showed cognitive deterioration, and 50% showed moderate to severe deficits on the BDS. It was also found that 7% of the older people had low weight and 79.4% were overweight. It was also found that 7% of them had low weight and 79.4% were overweight. 37% reported they have pain and more than 52% presented moderate to complete disability in daily life activities such as walking, washing, caring for body parts, excretion processes and dressing. However, less than 26% presented some deficiency in eating. Regarding environmental factors 88% of the elderly people reported having some kind of support from family and friends. We concluded that the sample presents functional deficits, including considered cognitive deficiencies, requiring intervention. Considering that the evaluation presented here was made before the pandemic period caused by Covid-19, it is important to re-evaluate this sample after the restrictions of social conviviality to assess the effect of the pandemic on functionality and rethink the model of care for the institutionalized elderly people.

Keywords: Aging \cdot Functioning \cdot Health of Institutionalized Elderly People \cdot Long-term care

1 Introduction

The aging process combines different factors that determine its more or less accelerated evolution, such as heredity, environment, social context and individual lifestyles [1, 2]. It is marked by biological, physical, cognitive, psychological and social changes, and also generates huge implications for the person, especially those consequences related to functionality and quality of life [3].

We often associate the aging process with the entry of an older person into a residential structure for the elderly people. The institutionalization of the elderly people is multifactorial, highlighting issues related to the family (re)configuration, which sometimes does not have the capacity to care them full time, especially when the elderly person presents, in addition to an advanced age, a greater state of fragility, isolation, existence of multi-morbidities and, consequently, greater loss of functionality. Public policies for aging, which have been adopted, are clearly insufficient to keep the older people in their family, presenting institutionalization as an alternative to the family.

Their institutionalization, which often causes their distance from family and social life, associated with a more sedentary lifestyle, contributes to the loss of their autonomy, inhibiting the construction of new life projects. If we associate this with the existence of chronic diseases, functional changes may let the elderly people more dependent [4, 5]. Multi-morbidity significantly increases the risk of needing long-term care, with dementia and stroke being the most strongly correlated with this risk [6].

The functionality expresses a new paradigm in gerontology, focusing less on clinical specificities or on the number of existing chronic diseases, and more on the elderly people's abilities to deal with the challenges of daily life that allow them to perform a set of tasks aiming at their independence and autonomy [3]. Functional capacity refers to the potential of older adults to perform activities of daily life or to perform a specific act without needing help, which may include basic and instrumental activities [1]. There are some technological innovations that can assist them when they lose their functional capacity in carrying out some everyday activities [7].

Basic activities are the tasks of self-care, such as bathing, dressing and eating [8], the greater the number of difficulties that an elderly person has in satisfying his daily life activities, the more severe is his inability. Instrumental activities are the skills in managing the environment where a person lives, including the performance of domestic chores, the use of money or the ability to use public transport. The term functionality encompasses all body functions, the ability to perform activities and their participation in society [1], so the assessment of functionality must be multi-dimensional [6]. Conversely, functional disability can be understood as the inability or difficulty in performing daily activities related to physical, psychological, social, economic or resource health, which makes an independent life impossible [6].

Since this loss of functionality is a constant concern in our day-to-day lives, which requires a thorough knowledge of the current situation and which allows for in-depth

characterization and the formulation of proposed measures that may influence the adoption of public policies, at least of a nature regional, we proposed to carry out a diagnosis of the functionality of the institutionalized elderly people in residential structures for the elders in the municipality of Portalegre. This work aims to verify if there is a correlation between the functionality of older people and the length of stay in the Residential Structure.

2 Methodology

2.1 Study Design

When we talk about aging, we are often faced with situations where the older person is not always active or successful; we see the loss of functionality that occurs in a sphere of action that is often associated with several dimensions, including multi-morbidity. Thus, within the scope of the 4iE Project, we proposed to develop a quantitative, descriptive and transversal study that took place in this first part between December 2019 and January 2020.

2.2 Setting, Sample and Data Collection

In order to diagnose the functionality of the elderly residents in Residential Structures for Elders in the municipality of Portalegre, including cognitive assessment, a sample consisting of 89 elderly people, who lived in two organizations belonging to the district, was selected. The technological platform Miape [9] was used to insert data in two institutions in the district of Portalegre, Portugal.

Three assessment instruments were applied. The Mini-Mental State assesses cognitive function and was developed by Folstein et al. (1975) [10]. It consists of six groups of questions that assess temporal and spatial orientation, memory, attention and calculation, evocation, language and constructive skills [10].

The Blessed Dementia Scale (BDS) - was developed in 1968 by Blessed and colleagues [11], with the aim of quantifying the degree of intellectual and personality deterioration in older people. It consists of 22 items that reflect: changes in the performance of activities of daily living (8 items); changes in habits, including self-care (3 items) and changes in personality, interests and impulses (11 items). Information can be obtained from someone close to the person and it is related to their behavior in the last 6 months or through clinical records, if it is available. The quotation ranges from 0 to 28 and the higher the value, the greater the degree of functional deterioration. A cutoff score was established in which values below 4 indicate no deterioration, scores from 4 to 9 indicate mild impairment, scores above 10 suggest moderate to severe impairment [12]. Stern et al. (1987) [13] also suggests that values from 10 to 15 indicate moderate impairment and higher than 15 indicate severe impairment.

Regarding the Elderly Nursing Core Set (ENCS) – it evaluates the functionality and was designed from a set of items belonging to the International Classification of

Functionality specifically for the elderly population [14, 15]. It consists of 31 questions that were categorized on a Likert scale from 1 to 5 points. The higher the score, the worse the functionality profile [14]. The study to evaluate the psychometric characteristics of the ENCS indicated four domains: Self-care with 12 items: Washing (d510), Dressing (d540), Taking care of body parts (d520), Carrying out the daily routine (d230), Maintaining the position of the body (d415), moving using some type of equipment (d465), Walking (d450), Changing the basic position of the body (d410), Care related to excretion processes (d530), Eating (d550), Use of the hand and arm (d445), Drinking (d560); Learning and mental functions with 6 items "consciousness functions" (b110), "Orientation functions" (b114), "Attention functions" (b140), "Memory functions" (b144), "Emotional functions" (b152), "Higher level cognitive functions" (b164); Communication with 3 items Speak (d330), Conversation (d350) and Communicate and receive oral messages (d310) and Relationship with Friends and Caregivers with 4 items Family relationships (d760), Health professionals (e355), Personal care providers and assistants personal (e340) and Friends (e320) [15].

2.3 Data Analysis

The data were analyzed using the SPSS program (Version 25), with descriptive statistical techniques and Pearson's correlation coefficient test in order to, on one hand, describe and summarize the information regarding the observed sample and, on the other hand, to measure the degree of association and the direction of correlation between two metric scale variables. Regarding ethical procedures, we wanted to observe the protection and respect for people, bearing in mind the Helsinki Declaration, among others. The project initially submitted by the University of Évora received approval from the Ethics Committee, in this case it was still authorized by the directors of the two organizations where the study took place. All questionnaires were applied by the nursing professionals who integrated them, after obtaining consent. All questionnaires were coded in order to guarantee confidentiality.

3 Results

The elderly people who live in the two ERPIs had an average age of 86.6 years-old, most of them are female (71.9%) and widowed (77.5%), presenting approximate values in both institutions A and B. It was found that 51.7% of these elderly people were illiterate, however in institution A, a higher frequency of elderly people who attended school emerged, only one in each institution attended higher education. It was also found that 7% of the elderly people were underweight and 79.4% were overweight.

With regard to the average number of years of institutionalization, it was 3.5 years, with a range between 0 months (newly admitted) and 82 months (about 7 years) (Fig. 1).

With regard to cognitive assessment, 45.3% showed deterioration (mini-mental state), with 50% exhibiting moderate to severe deficits on the Dementia scale.

Lenght of stay in institution A and B

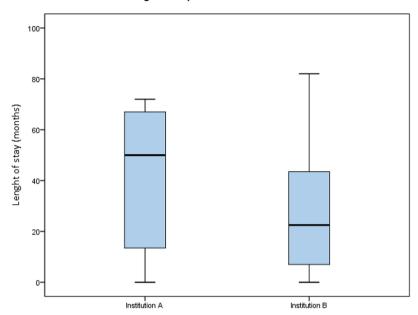


Fig. 1. Length of stay in institution A and B.

Regarding the BDS scale, we found that half of the sample presented between moderate impairment to severe (50%), with only 30% showing no impairment as shown in Table 1.

Table 1. Blessed dementia scale

| BDS | Institut | ion A | Institut | ion B | Total (2 | 2 institutions) |
|-----------------------------|----------|--------|----------|--------|----------|-----------------|
| | n_i | % | n_i | % | n_i | % |
| Without impairment (<4) | 1 | 5.00% | 19 | 41.30% | 20 | 30.30% |
| Mild impairment (4–9) | 5 | 25.00% | 8 | 17.39% | 13 | 19.70% |
| Moderate impairment (10–15) | 10 | 50.00% | 11 | 23.91% | 21 | 31.82% |
| Severe impairment (>15) | 4 | 20.00% | 8 | 17.39% | 12 | 18.18% |
| Total | 20 | 100% | 46 | ≃100% | 66 | 100% |

With regard to functionality and self-care, 54% had moderate to severe disability in the ability to perform the daily routine, 52.8% had difficulty in changing the basic position of the body, 58.4% had difficulty in moderate to complete walking, with 48.3% still having difficulty in moving around using equipment. However, only 21% expressed difficulty in using their hands and arms. With regard to hygiene, 67.4% of the elderly people showed moderate to severe difficulty in washing, with 59.5% also having difficulty in dressing. Similar data were obtained in the care of excretion processes (52.8%). Regarding "Eating", only 26% had severe to moderate disabilities, perhaps due to the difficulty of these elderly people in using hands and arms, also showing lower values.

As for Learning and Mental Functions, it was found that although the majority did not present changes in consciousness (55%), 41.9% manifested changes ranging from mild to severe deficiency in the orientation functions and 53.9% in the level of attention. These data are somewhat consistent with that found through the application of the BDS scale, previously mentioned. Communication, on the other hand, presents better results with 73% of the elderly people able to speak without disabilities and 63% also having a conversation along the same lines. With regard to the Relationship with Friends and Caregivers, it was found that about 98% of the elderly people received support from the family, between light support and punctual support. Also 88% received between one-off support and full support from friends.

If there are elderly people with different hospitalization times, we wanted to deepen their knowledge in order to check if there was a correlation between hospitalization time and functionality (Table 2). The results pointed out that there was no correlation.

| | | Total of the ENCS scale | Length of stay |
|-------------------------|-----------------------|-------------------------|----------------|
| Total of the ENCS scale | Pearson's correlation | 1 | 0.007 |
| | Sig. (Bilateral) | | 0.954 |
| | N | 89 | 79 |
| Length of stay | Pearson's correlation | 0.007 | 1 |
| | Sig. (Bilateral) | 0.954 | |
| | N | 79 | 79 |

Table 2. Correlation between length of stay and functionality

4 Discussion

With regard to sociodemographic characterization, the data in this study are identical to previous studies in the Portuguese population [16, 17], with the majority of the sample being female, which is due to the greater longevity of women to the detriment of men, according to data WHO [18]. Regarding marital status, as expected, considering the average age, most of them are widowed. In terms of education, most of the sample did not attend school nor know how to read or write, a factor that, on the one hand, is due to the difficulties in attending school when they were in school age and, on the other, it may relate to the type of institutions where the sample was collected.

By analyzing the sample's body mass index, and using the values recommended by the WHO as a reference [19], we found that the majority of the elderly population are overweight (62.35%), with 35.29% presenting obesity (BMI > 30). These data are in line with the results of other studies [20]. It is necessary to intervene since obesity is considered a public health problem, causing around 2.8 million deaths per year worldwide [20, 21].

Analyzing the results of the mini-mental, we found that 45.3% of the sample showed cognitive deterioration and with the analysis of the BDS we found that half of the sample has moderate to severe impairment (50%). Although it cannot be concluded that these 50% of elderly people have a diagnosis of dementia, as BDS only assesses cognitive and personality deterioration, it seems important to mention some international data. A systematic review of the literature reports that more than two thirds of residents in nursing homes have dementia [22]. One study found that from 33% to 50% of people with dementia in high-income countries are institutionalized [23]. In the United Kingdom, for example, this rate is much higher, with up to 80% of institutionalized elderly people estimated to have dementia [24]. A consistent conclusion in several studies, referred to in a meta-analysis [22] is that lower cognition is related to an increased risk of institutionalization.

With regard to the results of the Elderly Nursing Core Set, in the self-care domain, we found that the items "washing up" (average = 3.47) is the one with the worst results, with 56 elderly people with severe disability (n_i = 15) to complete (n_i = 41); followed by "taking care of body parts" average = 3.31) with 49 elderly people with severe disability (n_i = 10) to complete (" n_i = 39); "Dressing up" (average = 3.27) with 51 elderly people with severe disability (n_i = 11) to complete (n_i = 40); perform the daily routine (average = 2.97) with 39 elderly people with severe disability (n_i = 11) to complete (n_i = 28); and "walking" (average = 2.85) with 32 elderly people with severe disability (" n_i = 13) to complete (n_i = 19). In the field of communication, in decreasing order of results regarding functional difficulties, there are the items "communicate and receive oral messages" (average = 2.12), "conversation" (average = 1.91) and "speaking" (average = 1.65).

In the domain of learning and mental functions, the item "higher level cognitive functions" ("Average = 3.04") is the one that presents the worst results in functional terms, with 43 elderly people presenting severe disability ($n_i = 10$) to complete ($n_i = 33$); followed by "memory functions" (average = 2.46) and the item "emotional functions" (average = 1.85) is the one that presents the best functional results.

Regarding the results of ENCS, we find that similar data were obtained in other studies carried out in Portugal [16, 17]. Therefore, there is a high rate of dependency, requiring intervention, and the use of new technologies can be used as an adjunct to care.

Regarding the length of hospital stay, there was no relationship between this variable and functionality. We suggest that other studies relate these variables to a larger sample to clarify the results.

5 Conclusions

As in Europe, population aging is notorious and it has been associated with morbidities, especially in institutionalized elderly people. In this work, we proposed to carry out the

diagnosis in the context of two Residential Structures, concluding that the older people institutionalized there have presented functional deficits, which are mainly evident in the dimensions of Self-Care, Learning and Mental Functions, including cognitive impairment. In this first data collection, the length of stay and the increase in the functional deficit were not detected. But such data refer us to a care regime in waiting partially or totally compensatory, to be developed by caregivers. Perhaps because these structures are located in the interior of the country, and in the countryside, it was found that family and friendship support was still very present. However, since this evaluation was carried out before the Pandemic period caused by Covid-19 in Portugal, we think it is important to carry out a second evaluation with the old sample, in view of the restrictions of social interaction that prevailed in recent months. Such knowledge will be necessary to later promote reflection on the needs of these elderly people as well as on the reconfiguration of the care and monitoring model in the Residential Structures for the Elderly people.

References

- Costa, S., Amaral, A., Rodrigues, T., Xavier, M., Chianca, I., Moreira, M., et al.: Funcionalidade em idosos: revisão integrativa da literatura. RIASE Rev Ibero-Americana Saúde e Envelhec 2(3), 941–953 (2017)
- Paúl, C.: Envelhecimento activo e redes de suporte social. Sociol Rev da Fac Let da Univ do Porto 15, 275–287 (2005)
- Fonseca, A., Medeiros, S.: Instrumentos de avaliação da funcionalidade em idosos validados para a população portuguesa. Psicol Saúde Doenças 20(3), 711–725 (2019)
- 4. Fleg, T., Oliveira, M.: Avaliação da funcionalidade de idosos institucionalizados: relação entre a MIF e a ICF. CINERGIS **18**(3), 190–195 (2017)
- Vilela, D., Busanello, K., Oliveira, S., Fréz, A., Riedi, C.: Correlação entre o estado geral de saúde e a capacidade funcional em idosos ativos. ConScientiae Saúde 3(12), 447–454 (2013)
- Rodrigues, R., Azeredo, Z., Mendes, I., Crespo, S., Silva, C.: Os muito idosos do concelho de Coimbra: avaliação da funcionalidade na área da saúde física. Rev Port Saúde Pública 34(2), 163–172 (2016)
- Moguel, E., Berrocal, J., Murillo, J.M., García-Alonso, J., Mendes, D., Fonseca, C., et al.: Enriched elderly virtual profiles by means of a multidimensional integrated assessment platform. Procedia Comput. Sci. [Internet] 138, 56–63 (2018). https://linkinghub.elsevier.com/retrieve/pii/S1877050918316405
- 8. Orem, D.: Nursing: Concepts of Practice. 6th edn. Mosby, St. Louis (2001)
- Mendes, D.J.M., Lopes, M.J., García-Alonso, J.M., Santos, J., Sousa, L.M.M.: Resilient software architecture platform for the individual care plan. In: Mendes, D., Fonseca, C., Lopes, M.J., Garcia-Alonso, J., Murillo, J.M., (eds.) Exploring the Role of ICTs in Healthy Aging, pp. 13–32 (2020). http://services.igi-global.com/resolvedoi/resolve.aspx?doi=10.4018/978-1-7998-1937-0.ch002
- Folstein, M.F., Folstein, S.E., McHugh, P.R.: Mini-mental state. J. Psychiatr. Res. 12(3), 189–198 (1975). https://linkinghub.elsevier.com/retrieve/pii/0022395675900266
- 11. Blessed, G., Tomlinson, B.E., Roth, M.: Blessed-roth dementia scale (DS). Psychopharmacol. Bull. **24**(4), 705–708 (1988). http://www.ncbi.nlm.nih.gov/pubmed/3249772
- 12. Eastwood, M.R., Lautenschlaeger, E., Corbin, S.A.: Comparison of clinical methods for assessing dementia. J. Am. Geriatr. Soc. **31**(6), 342–347 (1983). http://doi.wiley.com/10. 1111/j.1532-5415.1983.tb05744.x

- 13. Stern, Y., Mayeux, R., Sano, M., Hauser, W.A., Bush, T.: Predictors of disease course in patients with probable Alzheimer's disease. Neurology **37**(10), 1649–1649 (1987). http://www.neurology.org/cgi/doi/10.1212/WNL.37.10.1649
- 14. Lopes, M.J., Fonseca, C.: The construction of the Elderly Nursing Core Set. J Aging Inov. **2**(1), 121–131 (2013)
- Fonseca, C., Lopes, M., Mendes, D., Parreira, P., Mónico, L., Marques, C.: Psychometric properties of the Elderly Nursing Core Set. In: García-Alonso, J., Fonseca, C., (eds.) Gerontechnology IWoG 2018 Communications in Computer and Information Science, pp. 143–53.
 Springer (2019). http://link.springer.com/10.1007/978-3-030-16028-9_13
- Goes, M., Lopes, M.J., Oliveira, H., Fonseca, C., Marôco, J.: A nursing care intervention model for elderly people to ascertain general profiles of functionality and self care needs. Sci. Rep. 10(1) (2020)
- 17. Fonseca, C.: Modelo de autocuidado para pessoas com 65 e mais anos de idade, necessidades de cuidados de enfermagem. Universidade de Lisboa (2014)
- 18. World Health Organization: World health statistics 2019: monitoring health for the SDGs, sustainable development goals. World Health Organization (2019). https://apps.who.int/iris/bitstream/handle/10665/324835/9789241565707-eng.pdf
- Direção-Geral da Saúde: Processo assistencial integrado da pré-obesidade no adulto. Direção-Geral da Saúde, Lisboa (2014)
- Shebl, A.M., Hatata, E.S.Z., Boughdady, A.M., El-Sayed, S.M.: Prevalence and risk factors of obesity among elderly attending geriatric outpatient clinics in Mansoura City. J. Educ. Pract. 6(30), 136–147 (2015). http://search.ebscohost.com/login.aspx?direct=true&db=eric&AN=EJ1081347&site=ehost-live&scope=site
- Bacsu, J., Jeffery, B., Abonyi, S., Johnson, S., Novik, N., Martz, D., et al.: Healthy aging in place: perceptions of rural older adults. Educ. Gerontol. 40(5), 327–337 (2014). http://10.0. 4.56/03601277.2013.802191
- Toot, S., Swinson, T., Devine, M., Challis, D., Orrell, M.: Causes of nursing home placement for older people with dementia: a systematic review and meta-analysis. Int. Psychogeriatrics 29(2), 195–208 (2017). https://www.cambridge.org/core/product/identifier/S10416102 16001654/type/journal_article
- Prince, M., Prina, M., Guerchet, M.: World Alzheimer Report 2013: Journey of Caring-Analysis of Long-Term Care for Dementia, London (2015)
- Alzheimer's Society: Optimising treatment and care for people with behavioural and psychological symptoms of dementia: a best practice guide for health and social care professionals, London (2011)



Gains from Nursing Care in Mobilizing the Elderly Person After Hip Arthroplasty

Iromisa Pereira¹, Rogério Ferreira^{2(⊠)}, João Vieira², Maria M. Goes², Teresa Mestre², and Henrique Oliveira^{2,3}

Algarve University Hospital Center, Faro Hospital, Faro, Portugal Polytechnic Institute of Beja, Beja, Portugal ferrinho.ferreira@ipbeja.pt
Telecommunications Institute, Lisbon, Portugal

Abstract. The thigh and proximal fracture of the femur appear as affections of the musculoskeletal system that cause a greater disability and, consequently, a decrease in the quality of life in the elderly. Hip arthroplasty is the treatment of choice in order to restore the autonomy of the elderly. However, the changes resulting from the surgery, give rise to self-care deficit. The nursing care in the mobilization at the time of surgery becomes a key element to empower the elderly and maximize the functionality of the operated limb. **Objective:** Identify the gains of nursing care intervention in mobilizing the elderly person after hip arthroplasty. Method: Research conducted in MEDLINE Complete and CINAHL Complete databases through the EBSCOhost platform in order to identify articles published between 2015 and 2020. After implementing the inclusion and exclusion criteria seven studies were selected. The evidence levels of the articles were ensured by Melnyk and Fineout-Overholt. Results: Nursing interventions in mobilizing the elderly after hip arthroplasty contribute to functional recovery, well-being and self-care, prevention of complications, health promotion, decrease in length of stay and client satisfaction. **Conclusion:** Nursing care in mobilization are essentials for the recovery of the elderly undergoing hip arthroplasty. The use of technologies, namely via WeChat, is essential to ensure the continuity of your rehabilitation process after hospital discharge.

Keywords: Osteoartritis · Fracture · Hip arthroplasty · Nursing care · Mobilization · Elderly

1 Introduction

Population ageing is a growing phenomenon all over the world. The effect of the decrease in mortality and birth rate has been changing the demographic profile of the population, whose most striking feature is its progressive aging, constituting one of the greatest achievements of society [1]. However, according to the World Health Organization [WHO] [2], the main health problems of populations associated with aging are chronic diseases, with musculoskeletal changes being the main causes of morbidity and disability, giving rise to enormous health expenditures and loss of functional capacity. The

WHO [3], highlights among these changes osteoarthrosis (OA) and limb trauma, such as femur fractures.

The hip joint (HJ), being one of the most affected by OA, appears as an indication for hip arthroplasty in the elderly. There are also indications for hip arthroplasty: femoral neck fracture and osteonecrosis of the femoral head [4].

Although arthroplasty is one of the surgical interventions with the best results in the functional recovery of the patient, it still generates some instability at the hip level, causing the elderly to experience changes in mobility, compromising their interaction with the environment, and the development of their potential to carry out daily life activities [5, 6].

In this context, one of the main objectives of the nurse is the recovery of the person in his maximum function, strength, coordination, resistance and safety, that is to say, to watch over the maintenance and promotion of well-being and quality of life, the recovery of functionality, through the promotion of self-care, the prevention of complications and the maximization of capabilities [5].

The nurse plays an extremely important role in the current health panorama, since he acts as a self-care agent in a continuum of health-disease, with the objective of providing care to all people, so that he maintains, improves and recovers health, aiming at maximum functional capacity [7]. Thus, mobilization is an important component of rehabilitation after hip arthroplasty in order to empower the elderly and maximize the functionality of the operated limb, in order to provide maximum independence and safe performance of daily life activities [8].

After the hip arthroplasty, the main objective is the functional rehabilitation of the person, regarding the mobility and independence to perform daily life activities [9]. In the immediate postoperative period, the major concern is the prevention of complications associated with early mobilization and prevention of incorrect positioning [10].

After 48 h of surgical intervention, there is a set of care restrictions in mobilization/positioning, to prevent dislocation of the prosthesis and other complications. The active mobilization of the operated lower limb, care with the lifting and transfers and use of the auxiliary means of walking integrate the strategies of intervention in nursing before the elderly person submitted to hip arthroplasty [11, 12].

The training of daily activities is also a fundamental intervention in the recovery after hip arthroplasty, because it allows to train and maximize the functionality of the patient in the performance of daily life activities, in order to allow a better re-adaptation to daily life routines, in the maximization of functionality through adaptive strategies of support [10, 12–14]. In short, these mobilization precautions should be maintained in order to avoid complications and provide a good functional recovery after hip arthroplasty.

2 Objective

Identify the gains of nursing care intervention in mobilizing the elderly person after hip arthroplasty.

3 Methods

Ethical Aspects

No opinion was requested from the Ethics Committee as this was a secondary study. In the formulation of the problem there was the concern with the respect for the principles of clarity, objectivity and precision, so that the results are assumed as an added value for nursing care in the mobilization of the elderly person after hip arthroplasty. The analysis of data extracted from the selected studies was developed in line with the principle of respect for the results obtained in these investigations and by these investigators. The reference of the authors was in compliance with the standards of good academic and scientific practice.

Type of Study

The choice of an integrative literature review had the purpose of accessing current knowledge on the problem under study and thus, contribute to the incorporation of the findings of this study in practical contexts. The methodological procedures used involved the following steps: 1) identification of the starting question; 2) definition of inclusion and exclusion criteria of studies; 3) definition of the information to be extracted from the studies; 4) analysis of the included articles; 5) presentation and discussion of the results and 6) synthesis of knowledge.

Methodological Procedures

In formulating the research question the PI[C]OD methodology was used: population (P), type of intervention (I), comparisons (C), result - outcome (O) and type of study - design (D). In order to respond to the objective previously outlined and which served as a thread for this integrative review of the literature, the following guiding question was elaborated: "What are the gains of intervention (Outcomes) in nursing care in the mobilization (Intervention) of the elderly after hip arthroplasty (Population)?

As inclusion criteria, priority was given to articles with quantitative and/or qualitative methodologies, published in their entirety (full-text), in Portuguese or English, in the area of nursing and which allowed answering the aforementioned guiding question, inserted in the databases CINAHL Complete and MEDLINE complete, with available references and publication date between January 2015 and March 2020. It was considered as exclusion criteria, articles unrelated to the subject under study, with ambiguous methodology, with publication dates prior to 2014 and repeated in both databases.

After the formulation of the research question, the collection of data on the subject under study took place during March 2020 in the MEDLINE Complete and CINAHL Complete databases through the EBSCOhost platform. The descriptors used in the research were: "Nursing", "Nursing care", "Nursing Intervention", "Nursing support", "Hip arthroplasty", "Hip prosthesis", "Hip replacement" "Mobility care", "Mobilization care", "Mobilization", "Early ambulation", Early mobilization", "Early rehabilitation" "Aged", "Elder" and "Elderly" "Geriatric". The descriptors were searched on the EBSCOhost platform in the following order:

- [(Nursing interventions) or (Nursing care) or (Nursing)] AND
- [(Hip Arthroplasty) or (Hip replacement) or (Hip prosthesis)] AND

- [(mobility care) or (mobilization care) or (mobilization)] OR [(Early ambulation) or (Early mobilization) or (Early mobilisation) or (Early mobility) or (Early rehabilitation)] AND
- [(Aged) or (Elder) or (Elderly) or (geriatric)].

The selection of studies involved the evaluation of the title and analysis of the abstract in order to verify if the articles met the inclusion and exclusion criteria. When these did not prove to be enlightening, the article was read in its entirety so as to minimize the loss of important studies.

A total of 182 articles were identified in the CINAHL Complete and MEDLINE Complete databases through the EBSCOhost platform. The evaluation of the articles was done in two phases, in a first phase 16 articles were selected after reading the titles, and in a second phase after reading the abstracts the potential of 11 articles was justified. Of these, 7 articles were selected from the full reading of the article and from the analysis of the research question and inclusion and exclusion criteria. These research stages are demonstrated in Fig. 1.

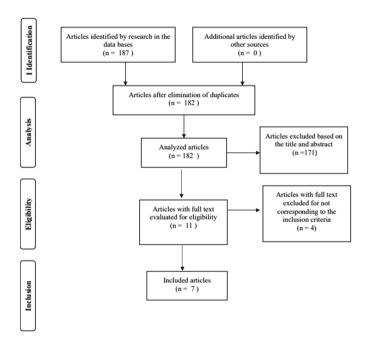


Fig. 1. Prism flow diagram

The critical analysis of the articles focused on the appreciation of the levels of evidence. The contributions of Melnyk and Fineout-Overholt [15] were used in order to identify the different types of knowledge production that are implicit in the studies. These consider the following levels of evidence:

- Level I Systematic reviews (meta-analyses, guidelines for clinical practice based on systematic reviews);
- Level II Experimental studies;
- Level III Almost experimental studies;
- Level IV Non experimental studies;
- Level V Program evaluation reports/ literature reviews;
- Level VI Opinions of authorities/consensus panels.

4 Results

After the analysis of the selected articles, the results of the integrative literature review will be presented in Chart 1.

Chart 1. Results of the integrative literature review

| Authors/Method/Level of evidence | Objective | Results |
|--|---|---|
| Luo, Dong & Hu [16] Method: Near experimental study Level of evidence: III Participants: 232 patients submitted to hip arthroplasty between January 2013 and October 2015. They were divided into two groups: group A, where 114 patients received nursing intervention by telephone and group B, where 118 patients received nursing intervention via WeChat | To evaluate the effect of nursing intervention via WeChat in the rehabilitation of patients undergoing hip arthroplasty | The results obtained with this study reveal that nursing interventions via WeChat significantly improve the effect of health education, recovery of HJ function, functional independence and quality of life of patients undergoing hip arthroplasty. The WeChat nurse performs several interventions such as: emotional support improving the patient's mood and consequently promoting mental health; reminding the patient of the importance of maintaining an adequate diet; supervising the taking of medication; performing rehabilitation training and consequently preventing various complications associated with poor mobilization. The study shows that in group B the Harris scale (used to evaluate the function of the limb) obtained higher values than in group A, and reached a score of 91 after 6 months of surgery. The prolonged nursing intervention via WeChat significantly improves the quality of life of patients undergoing hip arthroplasty. In this sense, the score of the SF-36 scale (used to evaluate the quality of life) of both groups has gradually increased. However, from 3 to six months after discharge, the score of group B was remarkably higher than group A Regarding the level of independence, more individuals were completely independent in group B than in group A, at 1, 3 and 6 months after the discharge |

(continued)

Chart 1. (continued)

| Authors/Method/Level of evidence | Objective | Results |
|---|---|--|
| Li, Ma, Huang, Xu, Sun, Yu & Zhang [17] Method: Experimental Study Level of evidence: II Participants: 100 patients with femoral neck fracture submitted to hip arthroplasty. They were divided into two groups: 50 patients in the control group who were submitted to routine nursing care, while the other 50 patients in the observation group were submitted to comprehensive nursing care | Exploring nursing interventions in the rehabilitation of patients undergoing hip arthroplasty | It was verified at the end of the study that in the observation group the Harris scale (used to evaluate the function of the limb) was higher than the control group, and six months after surgery it reached a score of 95 According to the Barthel scale (used to evaluate the ability to develop life activities) the observation group also obtained better results, reaching a score of 97.32 after 6 months of surgery It was found that the effectiveness of rehabilitation and postoperative recovery depends on several factors, such as: surgery and nursing interventions in mobilizing the patient. The nurse should encourage and guide in the performance of mobilizations and muscle strength exercises as early as possible in order to recover joint function |
| Okamoto, Ridley, Edmondston, Visser, Headford & Yates [18] Method: Near experimental study Level of evidence: III Participants: 126 patients submitted to hip arthroplasty divided into two groups. The control group (n=68) were mobilized one day after surgery, while the study group (n=58) were mobilized on the day of surgery | Determine whether mobilization on the day of surgery after hip arthroplasty reduces the length of stay in hospital | The results obtained with this study reveal that mobilization on the day of surgery after hip arthroplasty reduces the length of stay in hospital, accelerates functional recovery and reduces complications Patients mobilized on the day of surgery were 1.8 times more likely to be discharged, as they demonstrated greater independence in mobilizing in bed, in transfers and in walking with or without assistance |

(continued)

Chart 1. (continued)

| Authors/Method/Level of evidence | Objective | Results |
|--|---|--|
| Qi, Hao, Zhang, Zhao & Lian (2017) [19] Method: Experimental Study Level of evidence: II Participants: 100 patients submitted to hip arthroplasty, 50 in the control group and 50 in the observation group. The control group received routine postoperative nursing care and the observation group received comprehensive nursing care | To investigate the effect of nursing interventions on pain and functional recovery of people undergoing hip arthroplasty | According to the study, after hip arthroplasty patients should be encouraged to undergo rehabilitation training in order to recover joint function of the hip in a short period of time The nursing interventions influenced positively the pain relief, allowing improving the patients' adherence to the rehabilitation exercises and, thus, to improve the functional recovery of the HJ of the patients submitted to hip arthroplasty. In the performance of flexion, extension, abduction and the observation group presented values higher than the control group The degree of satisfaction was higher in the observation group than in the control group Regarding adverse complications, the results show that the observation group had a lower percentage of adverse complications |
| Ko, Lee, Oh, Choi, Kim, Sung & Baek [20] Method: Near Experimental Study Level of evidence: III Participants: 37 patients with hip fractures proposed for hip arthroplasty, aged over 65 years, divided into two groups: 21 patients in the experimental group were submitted to specific care and information prior to surgery and 16 in the control group who were submitted to general nursing care | To evaluate the effects of an individualized nursing care plan on the recovery of elderly people undergoing hip arthroplasty in order to reduce adverse complications | The results of this study show that an individualized nursing care plan for the person undergoing hip arthroplasty is essential for effective recovery and rehabilitation. This plan should include interventions such as: pain control, correct mobilization, muscle strength exercises, positioning and transfer, adequate walking technique and care in life activities after discharge Also according to the study, the decrease of fear of falling contributes to the adherence to rehabilitation exercises, consequently a better physical recovery The results of the study indicate that the TUG scale score (used to evaluate functional mobility of the limb and balance) after six weeks of surgery was less than 30 s in the experimental group and more than 30 s in the control group |
| Huang, Sung, Wang & Wang [21] Method: Experimental study Level of evidence: II Participants: 108 participants, 54 in the intervention group and 54 control group | Determine the effects of an educational nursing training program on elderly with hip arthroplasty | The educational training program has significantly improved the functional capacity of the elderly with hip arthroplasty, as it encourages them to explore their needs and concerns The study demonstrated that educational nursing interventions significantly improved the mobility of the elderly and consequently there was greater independence in daily life activities and an increase in the quality of life of the elderly with hip arthroplasty |

(continued)

Chart 1. (continued)

| Authors/Method/Level of evidence | Objective | Results |
|--|---|---|
| Zhang & Xiao [22] Method: Experimental study Level of evidence: II Participants: 70 patients diagnosed with osteonecrosis of the femoral head treated with hip arthroplasty, divided into two groups: 35 people in the control group, who received routine care, and 35 people in the intervention group, who received rapid surgery combined with nursing interventions | To evaluate the effect of rapid surgery combined with nursing interventions in the rehabilitation of patients undergoing hip arthroplasty | The study showed that there is a positive effect in rapid surgery combined with nursing interventions in the rehabilitation of patients undergoing hip arthroplasty, since there is an increase in the physical function and range of motion of patients undergoing hip arthroplasty The effective treatment of pain has proved to be very important in the recovery after hip arthroplasty, since it allows the earliest rehabilitation exercises, bringing benefits such as increased range of motion, muscle strength, quality of life and reduces the length of hospital stay Regarding the prevention of complications, the result of the study showed that there was a lower incidence rate of deep venous thrombosis in the intervention group of the control group (2.86% vs. 8.57%) Also a structured care plan effectively improves the confidence and satisfaction of the patients and their relatives in the team, thus increasing the adherence to rehabilitation exercises |

5 Discussion

After reading the articles, health gains resulting from nursing interventions in mobilizing the elderly after hip arthroplasty were evidenced (Chart 2).

In all studies, a comparison between two groups was made. Intervention groups received intensive or earlier rehabilitation care while control groups received general or usual care.

The descriptive statements of the Regulation of Quality Standards of Nursing Care [23] served to support the definition of categories for the discussion of data. The indicators that emerged from the analysis of the articles were mostly regrouped into different categories. This operation allowed the indicators to be differentiated and regrouped by analogy to the statements. This process was determinant for the analysis of sensitive health gains resulting from nursing care interventions in mobilizing the elderly after hip arthroplasty, expressed in Chart 2. The following discussion was structured according to the categories defined in this analysis process.

Client Satisfaction

"In the permanent search for excellence in professional exercise, the nurse pursues the highest levels of customer satisfaction" [23].

When users join rehabilitation exercises they demonstrate a higher degree of satisfaction, and a structured nursing care plan effectively improves the confidence and

Chart 2. Gains of nursing care intervention in mobilizing the elderly after hip arthroplasty

| Categories | Indicators |
|------------------------------|--|
| Client satisfaction | Greater degree of satisfaction [19, 20];Better adherence to rehabilitation exercises [20, 22] |
| Health promotion | - Improving the effect of health education [16] |
| Prevention of complications | Preventing various complications associated with poor mobilization [16]; Reducing complications [16, 18]; Lower incidence rate of deep vein thrombosis [22] |
| Wellness and self-care | Ease the pain [19]; Improve people's functional capacity [16, 17, 20, 21]; Greater independence in the mobility of the person [21]; Greater independence in bed mobilization [18]; Greater independence in transfers [18]; Greater independence in walking with or without assistance [18]; Improving people's quality of life [16, 21, 22]; Improve the patient's mood by promoting their mental health [16] |
| Functional recovery | Improve the recovery of the function of the hip joint [16–20, 22]; Enable earlier rehabilitation exercises [22]; More effective recovery and rehabilitation [20, 22] |
| Organization of nursing care | - Reduce hospital stays [18, 22] |

satisfaction of clients and their family members in the team, and consequently increases adherence to rehabilitation exercises [19, 22].

The fear of falling has a negative influence on the functional recovery of the elderly undergoing hip arthroplasty. Therefore, implementing strategies to reduce the fear of falling is a fundamental intervention to improve adherence to rehabilitation exercises in the elderly after hip arthroplasty. Fall prevention education is one of the strategies that the nurse should use in order to increase preventive behaviors in the fall and decrease the fear of falling, thus demonstrating the role of the nurse in achieving customer satisfaction [20].

Health Promotion

"In the permanent search for excellence in professional exercise, the nurse helps clients reach their maximum health potential" [23].

Elderly people and their relatives usually have limited awareness of rehabilitation care after discharge and its importance is usually not well emphasized. In recent decades, WeChat has been adopted as a nursing method to approach people after discharge and has been popularized and applied gradually. Through WeChat, even at a distance the nurse can develop health promotion actions in order to provide better rehabilitation of clients

undergoing hip arthroplasty. The nurse can send the person voice messages, videos and images, improving the effect of health education. We must keep in mind that the elderly have greater difficulties in capturing a large amount of information in good time, due to advanced age and sometimes associated with lack of memory. The WeChat is a useful and reliable tool for older people to obtain guidance and counseling in a timely and clear way [16].

Prevention of Complications

"In the permanent search for excellence in professional exercise, the nurse prevents complications for the health of clients" [23].

Several statements have advocated the importance of early rehabilitation in preventing complications. Usually 90% of complications associated with hip arthroplasty occur during the first days of postoperative and during hospitalization due to poor mobilization. These data highlight the value and necessity of early mobilization after surgery, as a way to prevent adverse complications [18].

In the study of Zhang and Xiao [22], they state that early rehabilitation after hip arthroplasty decreases the incidence rate of deep vein thrombosis. In their study, this complication was lower in the intervention group than in the control group (2.86% vs. 8.57%), and they found that there are several factors that contributed to the decrease in the incidence rate of deep vein thrombosis. First, the intervention group had a strict control in food intake before and after surgery. This strategy not only reduced insulin resistance after surgery, but also decreased the occurrence of nausea, vomiting, thirst and irritability, which allowed people to participate in early rehabilitation exercises; second, the intervention group reduced fluid intake after surgery, which helped them to leave bed early, reducing complications; and third, due to good preoperative education, people in the study group communicated with the health team more efficiently, which helped them to detect deep vein thrombosis earlier and deal with it pertinently.

The nursing care in the postoperative, in the long term, is an essential determinant in the effect of the rehabilitation of the person after the hip arthroplasty. Even after discharge, the nurse should help the person in his rehabilitation in order to recover more quickly. With the use of WeChat, even at a distance the nurse can implement various interventions so that the patient has a good rehabilitation thus avoiding various complications. Through WeChat, the nurse can inform the client of the importance of maintaining an adequate diet, supervise the taking of medication, help in the performance of rehabilitation exercises and prevent various complications associated with poor mobilization. Usually, if clients have questions or feel some discomfort while performing rehabilitation exercises, they can communicate with professionals in a timely manner, seeking solutions for immediate resolution of problems and preventing unfavorable factors that affect rehabilitation [16].

Wellness and Self-care

"The nurse maximizes the client's well-being and supplements/ complements the life activities on which the client is dependent" [23].

Most clients with hip arthroplasty experience negative emotions such as depression and anxiety, as well as several postoperative complications such as pain. The pain leaves people agitated and consequently secondary symptoms appear due to the psychological effects. The nurse plays an important role in reducing and controlling postoperative pain in order to provide comfort and well-being to the person. It is also important, that even before surgery, clients and their relatives receive pain education in order to be psychologically prepared for post-operative pain, considering that controlled pain has a positive influence on rehabilitation [19].

According to Ko et al. [20], functional decline is usually accompanied by loss of independence. The consequences of functional decline in hospitalized elderly include high morbidity, dependence, institutionalization and even mortality. Therefore, an early and individualized rehabilitation intervention during hospitalization is fundamental to decrease functional decline. To this end, the nurse should encourage the elderly person to undertake the rehabilitation exercises in order to promote their independence. The study by Li et al. [20], supports this idea, since the Barthel scale, used to evaluate the capacity to develop daily life activities, shows that an adequate mobilization technique increases the independence in the performance of daily life activities, with expression in the capacity to walk, position on the bed, up and down stairs.

This is corroborated in the study by Okamoto et al. [18], which states that clients who have had a more accelerated rehabilitation have shown greater independence in mobilizing in bed, in transfers and in walking with or without assistance.

Access to new technologies like WeChat has helped nurses improve their clients ability to live more independently and with quality of life. In the study by Luo et al. [16], the complete independence rate of patients in the intervention group was significantly higher than in the control group three months after discharge, and this finding supports WeChat's role in decreasing elderly dependency. According to the same study, clients who run the risk of adverse psychological and emotional effects may decrease adherence to long-term rehabilitation exercises after hip arthroplasty. Through WeChat the nurse can provide the necessary emotional support to the clients in order to improve their mood and consequently promote mental health and supervise the taking of medications in due time. Counseling, support, comfort, help, encouragement, and other measures by nurses help to alleviate patients' negative emotions, guiding them to have a more positive attitude and increase their confidence and courage to overcome pain. Thus, the result of this study indicates that nursing interventions via WeChat significantly improves the quality of life of clients after hip arthroplasty [16].

In order to improve the quality of life of the client, Zhang and Xiao [22] conducted a study to evaluate the effect of rapid surgery combined with nursing interventions in the rehabilitation of patients undergoing hip arthroplasty. The study showed that the quality of life of the 108 participants increased significantly, and in the intervention group there was a higher quality of life three weeks and three months after surgery.

Empowerment in education is based on theories of empowerment, which are aimed at strengthening or developing a person's abilities, not focusing solely on the multiple aspects linked to the disease. Thus Huang et al. [21], conducted a study to evaluate the effect of an educational nursing training program on elderly people with hip arthroplasty. This program encouraged elderly clients to explore their own needs, concerns and to seek and use resources to meet these needs, and during hospitalization, the individual needs of each participant were recognized and the necessary education was provided to establish self-care. At the end of the study, participants in both groups were found

to have improved significantly in daily life activities, demonstrated greater mobility and quality of life throughout the interventions, although participants in the educational intervention group showed significantly greater self-care skills and self-efficacy and a lower depression tendency compared with participants in the control group.

Functional Recovery

Hip arthroplasty has an almost immediate therapeutic effect, since the procedure can eliminate the original disease and restore normal hip function to a certain extent. The therapeutic effect of hip arthroplasty is not only related to the result of the surgery, but also to the rehabilitation process. After the surgery, it is of utmost importance that the nurse encourages the clients to perform rehabilitation exercises, with a correct mobilization technique, in order to improve the range of movements, at the level of flexion, abduction and abduction after the hip arthroplasty, thus evidencing the range of functional recovery [19].

According to Okamoto et al. [18], the success of recovery programs is essentially due to early mobilization, with repercussions on the client's functional recovery. Li et al. [17] refer that the nurse is responsible for ensuring care in mobilizing and performing muscle strength exercises of the client after hip arthroplasty, and these nursing cares assume an important role in the recovery of the function of the hip joint. It confirms this fact by mentioning that in the observation group the score of the Harris scale, used to evaluate the function of the limb, was higher than the control group, and six months after the surgery it reached a score of 95.

Nursing care in the rehabilitation of clients is fundamental, and pain control is essential for early adherence to mobilization exercises, and therefore enable more effective rehabilitation and recovery. The study reveals that the function and amplitude of the movements, were significantly larger in the intervention group, revealing that the nursing intervention is essential in the functional recovery [22].

The study by Ko et al. [20] demonstrates that an individualized nursing care plan after hip arthroplasty is essential for an effective recovery and rehabilitation, and for this, it is necessary to have pain control, muscular strength exercises, adequate mobilization, positioning and transference, and adequate deambulation technique, care in life activities after discharge. According to the study, the TUG scale score, used to evaluate the functional mobility capacity of the limb and balance, six weeks after surgery was less than 30 s in the experimental group, which indicates recovery in mobility, while in the control group it was more than 30 s. The improvement in score may have been a result of the early walking that clients were encouraged to perform after hip arthroplasty. Thus, Ko et al. [20], prove that functional mobility of the limb increases when early rehabilitation techniques are adhered to.

Lou et al. [16], evidence the recovery of the HJ, by stating that in the experimental group the Harris scale, used to evaluate limb function, was higher than in the control group six months after surgery.

Hospitalization

This category is one of the gains that is transversal to the combination of several factors.

One can consider the importance of a set of elements that are implicit in the organization of nursing care, in addition to other factors that are linked to the dynamics of the interdisciplinary team.

Increased hospital stays are often attributed to client factors such as increased BMI, comorbidities and age. Through recovery programs, institutions have been able to reduce the length of hospital stay, optimizing the person's nutritional status, education, post-operative pain and early rehabilitation. Thus, mobilization on the day of surgery significantly reduces the stay in hospital beyond 72 h compared to mobilization one day after surgery. The experimental group was ready for discharge 63.3 h after surgery, while the control group was ready for discharge 71.1 h [18].

According to Zhang and Xiao [22], rapid surgery combined with nursing interventions in the rehabilitation of clients undergoing hip arthroplasty, reduced the average length of hospital stay without increasing the rate of risks and complications. Criteria for clients to be discharged include: normal body temperature; absence of abnormal laboratory indicators; good healing of the surgical wound; absence of signs of infection; postoperative X-ray that confirms that the position of the prosthesis was satisfactory, that the replacement side of the hip joint was stable, did not present dislocation; ability to perform daily life activities.

6 Study Limitations

Although this integrative review of the literature integrates only experimental and quasi-experimental studies, the limitations of the study are related to the control of foreign variables in quasi-experimental studies. The non-inclusion in this research of data indexing bases of higher education institutions, namely regarding dissertations, is also one of the limitations in the methodological procedures on this object of study.

7 Contributions to Nursing

This synthesis of scientific production allowed to identify the gains of nursing care intervention in mobilizing the elderly person after hip arthroplasty and constituted an important contribution to the reflection on this problem and the relevance of nursing care, aiming at the implementation of professional intervention strategies for the safety of the person and compatible with care excellence.

In line with the studies included in this literature review, we propose an empirical study, of an experimental nature, to verify the effect of a mobilization program for elderly people undergoing hip arthroplasty on their functional capacity. We believe that an experimental approach, involving the triad of control, randomization and manipulation of the independent variable (mobilization program, according to a structured protocol) is a methodological quality assurance of a study, which allows to verify the effect of a program of intervention strategies in the mobilization of the elderly after hip arthroplasty in their performance in daily life activities.

8 Final Considerations

In the immediate and late postoperative period, the person submitted to hip arthroplasty needs several cares, of which the need in mobilization stands out.

The integrative literature review aimed to identify the gains of nursing interventions in mobilizing the elderly after hip arthroplasty, and, evidenced gains in customer satisfaction, health promotion, prevention of complications, functional recovery, well-being and self-care, hospital admission and health spending. These gains have demonstrated that an adequate nursing intervention in the mobilization/rehabilitation of the patient after hip arthroplasty is fundamental for their recovery.

Several authors have shown that interventions such as bed mobilization, teaching about bed positioning and transference, balance and gait training help the person to have a faster and more effective recovery. The nurse by implementing these interventions early contributes to the improvement of self-care, muscle strength, joint range, quality of life, walking ability and prevention of complications.

After discharge, it is essential to keep monitoring the care of the elderly person undergoing hip arthroplasty. The use of technologies, namely via WeChat, is essential to ensure the continuity of your rehabilitation process.

References

- Carvalho, A.S.: Preparação do regresso a casa. Dificuldades da família na continuidade de cuidados. Master's thesis on the Internet. Escola Superior de Enfermagem de Coimbra, Coimbra, Portugal (2013). https://repositorio.esenfc.pt/private/index.php?process=download&id= 24380&code=224
- World Health Organization: World report on ageing and health (2015). https://www.who.int/ageing/events/world-report-2015-launch/en/
- World Health Organization: Chronic diseases and health promotion (2020). https://www.who. int/chp/topics/rheumatic/en/
- Direção-Geral da Saúde: Artroplastia total da anca (2013). https://www.dgs.pt/directrizes-dadgs/normas-e-circulares-normativas/norma-n-0142013-de-23092013-png.aspx
- Reis, P.O.: Fatores que influenciam a capacidade funcional em indivíduos submetidos a Artroplastia Total da Anca. Master's thesis on the Internet. Escola superior de Enfermagem de Coimbra, Coimbra, Portugal (2016). https://repositorio.esenfc.pt/private/index.php?process= download&id=41933&code=630
- Fernandes, A.J.: A intervenção dos Enfermeiros de Reabilitação nos idosos com fratura proximal do fémur. Master's thesis on the Internet. Instituto Politécnico do Porto, Porto, Portugal (2016). https://recipp.ipp.pt/bitstream/10400.22/8776/1/Andrea_Fernandes_MGO_ 2015-2016_ramogestaodeunidadesdesaude.pdf
- Portugal, Ministério da Saúde: Decreto Lei n.º 161/96 de 4 de setembro. Diária da República, I Série-A (205), 2959–2962 (1996, Setembro 4) (1996). https://dre.pt/pesquisa/-/search/241 640/details/maximized
- 8. Daltro, M., Melo, K., Leitão, W.: Eficácia da mobilização passiva contínua no pós-operatório de pacientes submetidos à artroplastia total: revisão dea literatura (2009). https://interfisio.com.br/eficiencia-da-mobilizacao-passiva-continua-mpc-no-pos-operatoio-de-pacientes-sub metidos-a-artroplastia-total-de-joelho-atj-uma-revisao-literaria/

- Amaro, S.: O impacto da capacitação pré-operatória na pessoa submetida a artroplastia total da anca. Master's thesis on the Internet. Instituto Politécnico Viana do Castelo, Viana do Castelo, Portugal (2019). http://repositorio.ipvc.pt/bitstream/20.500.11960/2277/1/Sandra_ Amaro.pdf
- 10. Cunha, E.: Enfermagem em Ortopedia. Lidel Edições Técnicas Lda, Lousã (2008)
- Soares, M.J., Ferreira, R., Alcobia, A., Vieira, J.V., Fonseca, C.: Rehabilitation nursing in the elderly with mobility deficit due to fracture of the femur. In: García-Alonso, J., Fonseca, C. (eds.) Gerontechnology, IWoG 2019. Communications in Computer and Information Science, vol. 1185. Springer, Cham (2020). https://doi.org/10.1007/978-3-030-41494-8_29
- 12. Barros, E., Cambruzzi, G., Souza, J., Barroso, J., Silva, L.: Cuidados e Orientações ao paciente submetido a artroplastia do quadril. 1ª Ed. Versão digital, Florianópolis (2017). http://www.cefid.udesc.br/arquivos/id_submenu/2263/cuidados_e_orientacoes_ao_p aciente_submetido_a_artroplastia_de_quadril.pdf
- 13. Flamínio, J.: A pessoa submetida a artroplastia total do joelho: impacto dos cuidados de enfermagem de reabilitação e benefícios em saúde. Master's thesis on the Internet. Universidade de Évora, Évora, Portugal (2018). http://www.rdpc.uevora.pt/bitstream
- 14. Garção, A.: Recuperação global e marcha eficaz da pessoa idosa submetida a artroplastia da anca. Master's thesis on the Internet. Universidade de Évora, Évora, Portugal (2019). https://comum.rcaap.pt/bitstream/10400.26/29043/1/Relat%C3%B3rio%20F inal%20Ana%20Gar%C3%A7%C3%A3o.pdf
- Melnyk, B.M., Fineout-Overholt, E.: Evidence-Based Practice in Nursing & Healthcare. PA Lippincott Williams & Wilkins, Philadelphia (2005)
- Luo, J., Dong, X., Hu, J.: Effect of nursing intervention via a chatting tool on the rehabilitation of patients after total hip arthroplasty. J. Orthop. Surg. Res. 14(1), 417 (2019). https://doi.org/ 10.1186/s13018-019-1483-4
- Li, L., Ma, Z., Huang, Y., Xu, M., Sun, J., Yu, Y., Zhang, Z.: Effect of comprehensive nursing intervention on rehabilitation of patients after total hip arthroplasty. In: AIP Conference Proceedings, vol. 2079, p. 1 (2019). https://doi.org/10.1063/1.5092416
- Okamoto, T., Ridley, R.J., Edmondston, S.J., Visser, M., Headford, J., Yates, P.J.: Day of surgery mobilization reduces the length of stay after elective hip arthroplasty (2016). https:// doi.org/10.1016/j.arth.2016.03.066
- 19. Qi, Y., Hao, S., Zhang, J., Zhao, C., Lian, Y.: Effects of comprehensive nursing on the pain and joint functional recovery of patients with hip replacements. Biomed. Res. India **28**(12) (2017). https://www.biomedres.info/abstract/effects-of-comprehensive-nursing-on-the-pain-and-joint-functional-recovery-of-patients-with-hip-replacements-7721.html
- 20. Ko, Y., Lee, J., Oh, E., Choi, M., Kim, C., Sung, K., Baek, S.: Older adults with hip arthroplasty: an individualized transitional care program. Rehabil. Nurs. Off. J. Assoc. Rehabil. Nurses 44(4), E11 (2017). https://doi.org/10.1097/RNJ.000000000000234
- 21. Huang, T., Sung, C., Wang, W., Wang, B.: The effects of the empowerment education program in older adults with total hip replacement surgery. J. Adv. Nurs. **73**(8), 1848–1861 (2017). https://doi.org/10.1111/jan.13267
- Zhang, C., Xiao, J.: Application of fast-track surgery combined with a clinical nursing pathway in the rehabilitation of patients undergoing total hip arthroplasty. J. Int. Med. Res. 48(1), 300060519889718 (2019). https://doi.org/10.1177/0300060519889718
- Ordem dos Enfermeiros: Padrões de qualidade dos cuidados de Enfermagem: Enquadramento conceptual enunciados descritivos. Divulgar (2001). https://www.ordemenfermeiros. pt/media/8903/divulgar-padroes-de-qualidade-dos-cuidados.pdf



Women with Stress Urinary Incontinence: The Impact of a Rehabilitation Nursing Program on Quality of Life

Sara Mourão^{1(⊠)}, Rogério Ferreira², Susana Drago¹, César Fonseca³, and Sara Nobre⁴

Algarve University Hospital Center, Faro, Portugal
 Department of Health Faro, Polytechnic Institute of Beja, Faro, Portugal
 Nursing Department, University of Évora, Evora, Portugal
 Espírito Santo de Évora Hospital Evora, Evora, Portugal

Abstract. Objective The objective of this study is to evaluate the impact of Rehabilitation Nursing interventions on the quality of life of women with Stress Urinary Incontinence (SUI). Methodology: An Intervention Project was implemented at the Urogynecology Nursing Consultation of the Algarye University Hospital Center between October 2019 and January 2020, where three women completing the intervention program previously defined.. The King's Health Questionnaire (KHQ) was used as an instrument for pre- and post-implementation evaluation of the previously established conservative treatment, based on pelvic floor muscle training (PFMT). Results: From the implementation of the rehabilitation nursing program to women with SUI, who have fully completed the proposed program, the results show overall gains in women's quality of life, noting a decrease in the KHQ score in all dimensions. Conclusion: There is evidence of an improvement in the quality of life of women who have participated in the rehabilitation nursing program, which involves a pre-established program based on conservative treatment, based on the PFMT. It is suggested the development of more intervention projects focused on this problem, to certify the improvement of the quality of life, in larger samples. As a way of responding to this problem the largest number of women is crucial to invest in online programs. Self-management of SUI through distance learning is decisive with evidence of clinically relevant improvements, in a close partnership between rehabilitation nursing and new technologies.

Keywords: Stress urinary incontinence \cdot Quality of life \cdot Conservative treatment \cdot Rehabilitation nursing \cdot Woman

1 Introduction

Urinary incontinence (UI) is defined by the International Continence Society (ICS) as an involuntary loss of urine [1], denoting itself to be a problem all over the world, with high costs as well as at the level of the health systems [16, 22, 35]. It is a frequent disease in the adult female, and we can see an increase in prevalence into old age population.

The association between age and female UI is clearly important for planning healthcare resource allocation [2]. SUI presents a greater expression to the detriment of other subtypes, being diagnosed in about 50–70% of cases [42]. SUI is defined as an involuntary loss of urine in the face of an effort (coughing, sneezing, laughing and physical activity), which causes an increase in intra-abdominal pressure, where the contraction of the bladder and urethral sphincter is non-existent [2, 4, 20].

UI is responsible for important comorbidities, with physical, social, psychological and economic repercussions in the most varied contexts of women's lives, translating into depression, anxiety, work difficulties and social isolation, sexual dysfunction, perineal infections, sleep disorders and falls [40]. Thus, besides being a common problem, it consists of a well-documented problem, with impact in daily life [2, 4, 42], so its evaluation becomes crucial. Quality of life can be defined as a very broad concept that encompasses the individual's perception, always based on his/her physical, psychological, relational health as well as his/her system of values and beliefs, objectives and expectations [45].

As part of an appropriate clinical response to a woman with incontinence, starting with a collection of information through a detailed and systematized clinical history is fundamental and consensual by the various expert societies [16, 34, 35, 42].

A complete history should include, in a first stage, a history of surgical, obstetric and gynecological antecedents, as well as the usual therapy. Then, a detailed urological history with information on the type of incontinence, its time and severity, signs, and symptoms, is basic for a diagnosis and implementation of a treatment in accordance [34, 42]. After the detailed clinical history, the physical examination also presents a strong degree of recommendation, as an essential aspect to be contemplated in the evaluation of women with UI. The physical examination includes abdominal examination and pelvic examination [4, 16, 34]. The objective examination of the perineum allows the identification and/or exclusion of factors that may contribute to the UI and negatively interfere with the success of treatment [34]. It is also recommended, as part of the physical examination, the evaluation of post-void residual urine volume, cough test (stress test) and urethral mobility [16, 28, 40].

It is consensual in some guidelines, as part of the initial evaluation, the indication to perform a summary analysis of urine, which will allow to identify/exclude hematuria, proteinuria, glucosuria, pyuria and bacteriuria. Thus, this analysis is the first exam to be requested from a woman with urinary symptoms, with a strong degree of recommendation [16, 34, 35].

In addition to the aspects mentioned above, as a way to obtain a more objective evaluation of women's complaints, it is elementary to institute the application of a voiding diary and pad-testing. The voiding diary has the purpose of self-registration of symptoms during a period, to determine the frequency of urination, the times of urination and to verify and/or quantify the number of losses. Requesting the completion of a voiding diary allows a standardized evaluation and can be instituted that of three or seven days. In turn, the pad-testing is a useful tool since it allows a complementary evaluation with the demonstration of involuntary urine loss when it cannot be objectified in the initial physical examination [16]. In this test, the woman is asked to perform a set of standardized exercises, according to a performance protocol, over a period of one hour, where she has placed a disposable pad, previously weighed, which is then weighed

again at the end of that hour. Insensitive losses of about 1gram/hour are considered [16, 40]. Pad-testing, besides being valuable diagnostic tools, allowing an evaluation of the bladder function of the woman, are also a therapeutic asset that allows a monitoring of the impact of the implemented treatment [23, 40].

Once the SUI is diagnosed, through a detailed assessment, a therapeutic approach is implemented as early as possible. Conservative treatment, in a consensual manner, is recommended as the approach of choice in UI [35, 42]. As a conservative treatment it should encompass any intervention that does not include a surgical or pharmacological approach and, in general, focus on two aspects, lifestyle adaptations and pelvic floor muscle rehabilitation [27, 31, 37]. Thus, based on the risk factors associated with the problem of SUI, aspects of lifestyle are defined which, with their adaptation, may bring benefits in the resolution / improvement of incontinence [40]. The following aspects of lifestyle are identified as important modifiable factors according to scientific evidence: obesity/weight loss, exercise, caffeine reduction, tobacco, constipation and fluid intake [16, 25, 40]. Obesity, as a risk factor identified in many epidemiological studies, is one of the most relevant aspects since the high body mass index (BMI) is predictive of an increase in the prevalence of SUI [36], so the weight loss presents a strong recommendation for its correction [16, 25, 36, 40]. Regular moderate physical activity can optimize the strengthening of the pelvic floor muscles, so it can decrease the risk of developing SUI, hence the recommendation for its achievement [16, 35, 40]. The available evidence cannot ensure that a decrease in caffeine intake improves UI, however it seems to improve the urgency and frequency of urination, so indicating a reduction in caffeine intake for women with UI was a strong recommendation. As a public health measure, smoking cessation is increasingly internalized and widespread, which has shown benefits in improving the frequency and urgency of women with UI. Thus, providing smoking cessation strategies for users diagnosed with UI who smoke presents a strong recommendation [16, 34, 40]. There is a strong association between the presence of constipation and UI [8], so treating constipation, according to good medical practices to regulate intestinal transit, is strongly recommended as a conservative treatment [16, 34, 40]. As a way to improve the symptomatology of incontinence, it is frequent that women minimize the intake of liquids, however, it is necessary to take into account the daily hydric needs to maintain an adequate hydration. The available scientific evidence is not consistent regarding the effectiveness of water restriction, so the recommendation to evaluate the amount and type of fluid ingested is weak [16, 40]. In many cases, the approach to adaptation of lifestyles is multifactorial, since the presence of more than one aspect to be improved may be present.

Pelvic floor muscle training is the approach of choice for conservative treatment of UI, and is recommended for women of all ages, with the diagnosis of UI, regardless of subtype, since this muscle is crucial throughout the mechanism of continence [13, 40]. The institution of PFMT in SUI has as main objective to compensate anatomical deficits, through the increase of strength, endurance, resistance and/or relaxation of the entire muscle structure, in order to improve urethral stability, as well as to favor the adequate support of the pelvic organs [5, 7]. Its effectiveness is studied and shows an improvement, or even recovery, of the continence, as well as of the quality of life [15, 16, 26, 34, 39]. The main disadvantage of PFMT is the ability of women to maintain

an exercise program, absent of supervision [33]. The following are indicative of a poor prognosis for the efficacy of PFMT in SUI: severe SUI, presence of pelvic organ prolapse (with more than two degrees), unsuccessful anterior pelvic floor rehabilitation, second prolonged labor, BMI greater than 30, psychological instability and poor physical health [21].

Prior to the implementation of any PFMT plan, it is essential to validate the integrity of pelvic floor muscle contraction through digital evaluation. This evaluation should contemplate, on the one hand, the inspection of the external genitalia, as well as the palpation of the vaginal introitus as a way to validate the capacity of contraction of the musculature bilaterally [4, 31, 34, 35]. The first step in reeducating the pelvic floor muscles is to become aware of them, which requires concentration. Then, after emptying the bladder, the reeducation of the pelvic floor muscles begins, contracting the perivaginal muscles and the anal sphincter, as if there were an attempt to control the motion or defecation and where the contraction of abdominal muscles, buttocks and the inner face of the thighs, in order to prevent ineffective contraction [37].

The training proposal presented in the Urogynecology Consensus consists in the realization of an active pelvic floor muscle contraction protocol, three times a day, 8–12 sustained contractions, up to 10 s, followed by a complete relaxation, during the same time [26, 37, 40].

According to a strong recommendation of the EUA (2018) [16], PFMT programs should be implemented with the greatest possible intensity. However, it is essential to establish an individualized and adapted plan in order to respect the individuality of each woman. Based on the evaluation, the contraction time to be performed during the exercises is determined, always keeping in mind the need for an effective muscular contraction [37].

Once the mechanism of contraction has been well grasped, training to contract the pelvic floor muscles begins during or just before the effort that usually results in involuntary urine loss [19]. Self-control of urinary continence requires cognitive potential and motivation to maintain training [10].

As an adjunct to the PFMT, the vaginal cones are presented. The vaginal cones increase the proprioceptive capacity to the intended pelvic contraction, which enhances the strengthening of the pelvic floor muscles [37, 40].

Faced with the diagnosis of SUI, rehabilitation nursing designs, monitors and implements a program of motor functional re-education of the pelvic floor muscles, with the objective of recovering the functionality lost in the process of dysfunction, and obtaining its maximum independence [4]. Thus, it trains women through a continence education program, covering prevention, modifiable risk factors and conservative treatment options [9].

In view of the above and assuming the importance of rehabilitation nursing care in adapting the lifestyle and rehabilitation of pelvic floor muscles of women with SUI, we defined as a central objective for this study:

 Assess the impact of Rehabilitation Nursing interventions on the quality of life of women with SUI.

2 Methodology

2.1 Type of Study

In this pilot study, it was opted for an approach of descriptive and transversal nature, which is motivated by the necessity of obtaining information in the scope of the phenomenon in study and to contribute to the development of the knowledge about the object and specialized intervention of nursing. This strategic decision allowed for the application of an evaluation tool, which aims to identify the impact that rehabilitations nursing interventions have on the person, with a specific profile and context [14, 18].

2.2 Participants

The eligibility criteria for participation in the study imply that the woman presents a diagnosis of SUI, the ability to communicate verbally and in writing, with admission to the consultation by the first half of October. Nine women entered the consultation, six of whom were excluded at the outset because the baseline diagnosis was mixed urinary incontinence (4 women) and urgency urinary incontinence (2 women). According to preestablished time and eligibility criteria, a convenience sample was used which included three women.

2.3 Data Collection Tools and Techniques

Based on the research problem and the type of study, the data collection methods used were: Interview, observation, voiding diary, pad-testing and Quality of Life Ouestionnaire.

Once the sample has been identified and the data collection methods have been selected, the two premises for starting the data collection itself are brought together.

After an advanced research, KHQ is chosen because it allows quantifying the results of the implemented program and, on the other hand, reliably obtaining a woman's perception about her quality of life. The KHQ, according to scientific evidence, consists of an adequate and relevant questionnaire for the evaluation of the quality of life in people with urinary incontinence with viability, reliability and sensitivity achieved in several studies, as well as it is validated for the Portuguese population. The Portuguese version of KHQ shows psychometric properties and validity, with recommendation to its application [16, 40]. The questionnaire has three parts. The first evaluates the woman's self-perception of her health condition and the second evaluates the presence and severity of symptoms. However, in the pursuit of the object of the study - to evaluate the impact of stress urinary incontinence on women's quality of life - the application of Part 3 is limited, which is composed of nineteen items, distributed by 3 dimensions: Personal and Daily Life Limitations - 8 questions; Emotions and Social Relations - 8 questions; Urinary Symptomatology - 3 questions. The KHQ translates into a score ranging from 0–100, with zero being the best possible result and one hundred the worst [44].

2.4 Study Context

The woman enters the Urogynecology Nursing Consultation by referral of the Specialty Medical Consultation.

The Rehabilitation Nursing Program, in a systematic way, includes: Data collection; Physical examination; Implementation of diagnostic/evaluation tools, such as: voiding diary, pad-test, Questionnaire; Lifestyle Adaptations; and PFMT. The implementation of the pad-test and voiding diary (3 days) proceeds. Afterwards, health education sessions are planned regarding: Healthy Lifestyle and Self-Control: Urinary Continence. When the patient presents urinary complaints, a rapid urine test is performed and, if there are any changes, the user is referred to the emergency service.

After the first consultation, the following are defined, which will be scheduled with a fifteen-day break, which is readjusted according to the woman's needs. In addition, weekly, telephone contacts are established, and the electronic address of the consultation is made available as a way to maintain a direct line of contact with the user, for the clarification of questions or sharing of experiences, also allowing the maintenance of adherence to the protocol requested. A first consultation will last about 45 min and the subsequent 30 min. The application of the project in practice will last 15 weeks.

Initially three evaluations were estimated: Pad-testing, voiding diary and application of the quality of life questionnaire. The first moment of evaluation is in the first consultation, the second will be in the 7th/8th week of the program and the third after 15 weeks. This is because, if the exercise plan is maintained continuously, the benefits appear after the 4–6 weeks of implementation of the program and at the end of the three months it is already possible to aim for its effectiveness [37].

As part of the evaluations, self-filling of the KHQ questionnaire is requested, which is identified with the user's file number and is filed, in his/her clinical file. The pad-testing is implemented, which is evaluated and the result recorded. In addition, the woman is given a registration sheet of the voiding diary, with guidance on the fields to be filled in, and in the subsequent consultation the woman is accompanied by it, which is evaluated, and the information collected is recorded in the available information system. In the subsequent consultations, the maintenance of the initiated teachings is carried out, and the capacity of contraction of the pelvic floor musculature is re-evaluated, with the objective of the necessity or not of readjustments in the objectives.

In short, the program lasts 15 weeks, after which the woman is reassessed by the nursing team, after a final application of all the instruments. In the face of a positive evolution, she is redirected to the medical consultation.

2.5 Ethical Principles

Before this study was carried out, a request was made to the ethics committee of a higher education institution and to the ethics committee of the University Hospital Centre of the Algarve. It was approved by both committees.

The participants, after having been duly informed and having been assured confidentiality and anonymity, were asked for a signed declaration of informed consent, previously approved by the ethics commission.

3 Results

After the time foreseen for the accomplishment of this study, it was confirmed the complete implementation of the rehabilitation nursing program to the selected sample with the following ages in years, M1 = 38 years, M2 = 48 years; and M3 = 54, respectively. All are of Caucasian race. M1 and M2 are married and M3 are single. M1 is licensed and M2 and M3 have equivalent 12th grade courses.

The rehabilitation nursing programs lasted 16, 15 and 15 weeks, respectively.

All women were pregnant and had at least one eutocic partum.

M1 and M3 show urine loss when sneezing or coughing and M2, also on effort. The cough stress test is positive for M1 and M2. Urethral hypermobility is found at M1 and M2. There is no evidence of post-void residual urine volume present.

At the time of implementation of the project, they deny being in menopause, smoking, consuming caffeine, having constipation, practicing physical activity, or having undergone previous surgery for hysterectomy.

With the exception of M1, with normal weight, M2 and M3 are with high BMI, with excess weight.

From the clinical history performed through the interview and direct observation, as well as from the consultation of the records, the characterization of the participants is presented, as shown in the table (Table 1).

| | M1 | M2 | M3 | |
|--|-----------------------------------|--|---|--|
| Program start | 01/10/2019 | 08/10/2019 | 08/10/2019 | |
| Program end | 14/01/2020 | 14/01/2020 | 14/01/2020 | |
| Personal objective | Stop having losses | Stop using pads | Decrease the number of toilet visits (goes from 1H/1H) | |
| Race | Caucasian | Caucasian | Caucasian | |
| Age | 38 | 48 | 54 | |
| Marital status | Married | Married | Single | |
| Level of education | Teaching degree | 12th year | 12th year | |
| Obstetric history | 2 pregnancies 2 Eutocic births | 3 pregnancies 3 Eutocic births | 2 pregnancies 1 Eutocic birth | |
| History of the current disease Urinary loss when sneezing and coughing | | Loss of urination when coughing, sneezing and straining | Urinary loss when sneezing and coughing | |
| Body Mass Index (BMI) [12] | 22 – Normal weight | 26 – Excess weight | 28,48 – Excess weight | |

Table 1. Demographic and clinical characterization of participants

(continued)

| | M1 | M2 | M3 |
|---|-------------------------|--------------------------------|--------------------|
| Stress cough test | Positive | Positive | Negative |
| Post-voiding residual urine volume | Absent | Absent | Absent |
| Urethral hypermobility | Present | Present | Absent |
| Reflex bulb-cavernous | Without alteration | Without alteration | Without alteration |
| Capacity of pelvic floor muscle contraction | Present | Present | Present |
| Use of sanitary towels | Denies | Yes (2/day) - keeps at the end | Denies |
| Menopause | Denies | Denies | Denies |
| Hysterectomy | terectomy Denies | | Denies |
| Presence of POP | Yes | No | No |
| Constipation | Denies | Denies | Denies |
| Smoking | Denies | Denies | Denies |
| Consumes caffeine | Denies | Denies | Denies |
| Practice physical activity | hysical activity Denies | | Denies |
| Urine summary analysis | Without alteration | Without alteration | Without alteration |
| Urodynamic/Imagiological study | Did not do it | Did not do it | Did not do it |

Table 1. (continued)

Regarding the results of the exercises/instruments applied, before the application of the PFMT and after 15 weeks, are presented in Table 2.

It was found impossible to reassess the three instruments, namely KHQ, pad-testing and voiding diary, at 7/8 weeks as initially planned, since, due to the need to adjust the dates of consultations, considering the end of the calendar year, with the festive periods, the last assessment would be almost overlapping. It is chosen to carry out this evaluation in two moments, before and after the implementation of the rehabilitation nursing program.

M1 and M3 were shown to be receptive to the use of vaginal cones, with benefit. M2 was the user with the least increment in pelvic floor contraction time, and the only one refusing the use of strength training with vaginal cones.

M1 and M3 did not present any change in the initial and final pad-test, because there were no changes in the weighing.

In M3 no involuntary urine losses were identified, in both voiding diaries. On the other hand, M1 and M2, reduced the number of involuntary losses per day, compared to the first evaluation.

| Exercises/Instruments applied | M1 | M2 | M3 | |
|--|-----------|------------------------|-----|------------------------|
| Padtesting - Amount of loss (g) | Start/End | 0/0 | 8/6 | 0/0 |
| Voiding diary (Number of losses per day) | Start/End | 3/2 | 7/2 | 0/0 |
| PFMT - muscular contraction time (seconds) | Start/End | 4/6 | 5/6 | 3/10 |
| Use of vaginal cones | | Yes (since 19/11/2019) | - | Yes (since 08/11/2019) |
| Time use of vaginal cones | Start/End | 0/1 min | - | 1 min/1 0min |

Table 2. Applied exercises/instruments.

Regarding the application of the questionnaire, an instrument of evaluation of choice, the results presented in the table - Evaluation of the KHQ are verified. A decrease from the first evaluation to the second is shown in the global score of the KHQ scale and specifically in the domains related to personal and daily life limitations, emotions and social relations and linked to urinary symptomatology (Table 3).

Escala KHQ M1M2. M3 Domain 1 - Personal and daily life limitations Start/End 58/29 46/21 26/4 **Domain 2 -** Emotions and social relations Start/End 88/58 54/38 81/53 40/4 **Domain 3 -** Uurinary symptomatology Start/End 29/29 56/44 Start/End 52/34 49/20 Global Score KHO 58/39

Table 3. KHQ assessment.

4 Discussion

Nine women entered the consultation, three of whom met the eligibility criteria for participation in the study.

All users are able to set personal goals. The M1 participant, had as a goal "to stop having losses". With the evaluation of the diary, it was found that in the first evaluation she had an average of three losses per day, and in the last evaluation, two losses per day.

The participant M2, defined as an objective "Stop using dressings". At the end of the program, she maintains the use of dressings. The losses decreased from 7 to 2, in the evaluation of voiding diary.

Finally, M3 at the beginning of the program verbalized that its goal was to reduce the number of toilet visits, which was achieved, from 14 visits to 8.

The UI progresses with age [17, 29], as is confirmed with the participants. None is in the menopause period.

The presence of excess weight increases the risk of women developing UI [11, 24, 41] and two of the participants are overweight. There is also evidence that the prevalence of SUI increases proportionally with an increase in BMI [36], and it is found that M2 and M3 have high BMI. Both participants were referred for the nutrition consultation, but both are still waiting to be called due to the resolution of waiting lists, at the end date of the internship.

Women undergoing vaginal delivery are at greater risk of developing a specific subtype of incontinence - SUI [30, 38] and all participants have at least 1 euthoccal birth, M1 has 2, M2 has 3 and M3 has 1.

All participants are Caucasian, as reported by the scientific community (women of caucasian race have a higher prevalence of UI, and in particular SUI, at the expense of other ethnic groups [43]).

A positive cough stress test and urethral hypermobility are two predictive aspects of SUI [32, 40] and M1 and M2 show losses associated with coughing effort and urethra displacement greater than 30° in the evaluation.

All the women were able to carry out the PFMT, in a supervised manner in the consultation and, following their testimony, kept at home.

In the three women there was an increase in the capacity of contraction of the pelvic floor muscles, with improved continence capacity, and improved urinary symptoms. In the M2 participant, the only one with documented change in the pad-test, the amount of urine lost from the first to the second evaluation decreased from 8 to 6g. In voiding diary, M3 never had losses, but M1 and M2 reduced from 3 to 2 and from 7 to 2 daily losses respectively. The PFMTs are studied and the scientific community argues that they promote an improvement, which concerns the urinary symptoms and the number of urinary losses [15].

In order to potentiate the effects of PFMT, two women started treatment with the use of vaginal cones, M1 and M3, with an increase in the capacity to remain in the vagina, inferring an optimization of the strength of the pelvic floor muscles, as is evident in the literature [4, 23].

The M2 participant, never showed openness to try the cones, although the benefits were made explicit, as well as the positive results with other women.

Increasingly, quality of life is used as a tool to evaluate the effectiveness of a treatment. Taking into account the pejorative impact UI has on it, using it for this purpose is crucial [22]. In all participants, the total score of the KHQ questionnaire decreased, M1 went from a score of 58 to 39, M2 from 52 to 34 and M3 from 49 to 20. Since the impact on the quality of life is lower, the higher the zero approach, there is an improvement. The decrease in domain 1 - Personal and Daily Life Limitations - in increasing order, is verified in M2, M3 and finally in M1. In domain 2 - Emotions and Social Relations, in the same order of presentation, happens in M2, followed by M3 and the biggest decrease, in M1. Finally, in Domain 3 - Urinary Symptomatology, from the smallest to the greatest difference, we have M1 - M2 - M3.

With the implementation of this intervention project, it was found that a rehabilitation nursing program has an impact on the quality of life of women with SUI. In general, urinary symptoms and women's perception of quality of life have improved. These results are in line with the results of other published studies, which show that

conservative treatment, with the implementation of PFMT, promotes an improvement in urinary symptoms and the number of urinary losses, as well as showing an increase in women's quality of life [15, 16, 26, 34, 39].

Despite the importance of the results obtained with the implementation of this study, it is suggested to carry out more investigations with larger samples.

SUI remains a public health issue with important impact in women's quality of life, therefore equitable access to conservative treatment with rehabilitation nurse is essential. In order to reach the largest number of women the online programs are a crucial aspect. Sel-management of SUI through distance learning are determinat with clinically relevant improvements in women's, whereby are defined like an effective service, combining rehabilitation nursing with new technologies [3, 6].

5 Conclusion

UI consists of a health problem, multicausal, with high prevalence in women. Not being a life-threatening situation, it has severe and negative implications in several health areas, with impact on quality of life. The operationalization of this project proved that the implementation of specialized nursing care for women with SUI, point to an evident increase in quality of life, with the implementation of a global conservative treatment. More specifically, these women showed gains in terms of personal limitations and daily life, in the management of their emotions and personal relationships and, in urinary symptoms.

It is assumed that the consistency of the results obtained is limited, given the small number of people who participated in this study, compatible with conducting a pilot study. We suggest more studies of this nature, within a broader time limit and to identify the gains from the implementation of rehabilitation nursing programs in the quality of life of women with SUI. We recommend that studies of an experimental nature be carried out to verify the effect of a functional motor re-education program for women with SUI. An experimental approach, involving the triad of control, randomization and manipulation of the independent variable (motor functional re-education program, according to a structured protocol) are a methodological quality assurance of a study, which allows to verify the effect of a program of intervention strategies in the quality of life of women with this problem, in a global perspective and in more specific dimensions.

References

- Abrams, P., Cardozo, L., Fall, M., Griffithsd, D., Rosier, P., Ulmsten, U., Wein, A.: The standardization of terminology of lower urinary tract function: report from standardisation subcommittee of the international continence society. Neurourol. Urodyn. 21, 167–178 (2002). https://doi.org/10.1002/nau10052
- Abrams, P., Cardozo, L., Khoury, S., Wein, A.: Incontinence. In: Em I. C. Society, & I. C. Diseases (ed.), 6th International Consultation on Incontinence (2017). file:///C:/Users/Usuario/Downloads/Incontinence_6th_Edition_2017_eBook_v2.pdf
- Barbato, K., Wiebe, J., Cline, T., Hellier, S.: Web-based treatment for women with stress urinary incontinence. Urol. Nurs. 34(5), 252–257 (2014). https://doi.org/10.7257/1053-816X. 2014.34.5.252

- Bo, K., Frawley, H., Haylen, B., Abramov, Y., Almeida, F., Berghmans, B., Wells, A.: International Urogynecological Association (IUGA)/International Continence Society (ICS) joint report on the terminology for the conservative and nonpharmacological management of female pelvic floor dysfunction. Neurourol. Urodyn. 24, 1-24. (2016). https://doi.org/10.1002/nau. 23107
- Bo, K.: Pelvic floor muscle training is effective in treatment of female stress urinary incontinence, but how does it work? Int. Urogynecol. J. 15(2), 76–84 (2004). https://doi.org/10.1007/s00192-004-1125-0
- Bokne, K., Sjöström, M., Samuelsson, E.: Self-mangement of stress urinary incontinence: effectiveness of two treatment programmes focused on pelvic floor muscle training, one booklet an one internet-based. Scand. J. Prim. Health Care 37(3), 380–387 (2019). https:// doi.org/10.1080/02813432.2019.1640921
- Borello-France, D., Burgio, K., Goode, P., Ye, W., Weidner, A., Lukacz, E., Spino, C.: Adherence to behavioral interventions for stress incontinence: rates, barriers, and predictors. Am. Phys. Ther. Assoc. 93(6), 757–773 (2013). https://doi.org/10.2522/ptj.20120072
- Byles, J., Millar, C., Sibbritt, D., Shiarelli, P.: Living with urinary incontinence: a longitudinal study of older women. Age Ageing 38(3), 333–338 (2009). https://doi.org/10.1093/ageing/ afp013
- Cera, J., Twiss, J., Struwe, L.: Implementing a nurse practitioner-led delivery model for continence care within community fitness facilities. Urol. Nurs. 39(1), 17–27 (2019). https:// doi.org/10.7257/1053816X.2019.39.1.17
- Cera, J., Twiss, J.: Focused integrative review of current continence care and prevention strategies: expanding the role of the nurse practitioner. Urol. Nurs. 38(4), 169–176 (2018). https://doi.org/10.7257/1053816X.2018.38.4.169
- Chen, C., Gatmaitan, P., Koepp, S., Barber, M., Chand, B., Schauer, P., Brethauer, S.: Obesity is associated with increased prevalence and severity of pelvic floor disorders in women considering bariatric surgery. Am. Soc. Bariatr. Surg. 5, 411–415 (2008). https://doi.org/10.1016/j.soard.2008.10.006
- Direção Geral de Saúde. Obesidade: Otimização da Abordagem Terapêutica no Serviço Nacional de Saúde (2017). https://www.alimentacaosaudavel.dgs.pt/activeapp/wpcontent/ files_mf/1513848603Obesidade_otimizacaodaabordaemterapeuticanoservi%C3%A7onac ionaldesaude.pdf
- 13. Donahoe-Fillmore, B., Chorny, W., Brahler, C., Ingley, A., Kenndy, J., Osterfeld, V.: A comparison of two pelvic floor muscle training programs in females with stress urinary incontinence: a pilot study. J. Appl. Res. 11(2), 73-83. (2011). https://jrnlappliedresearch.com/articles/Vol11Iss2/Donahoe-Filmore.pdf
- Duhamel, F., Fortin, M.: Os Estudos do tipo descritivo. In: Fortin, M. (ed.) O Processo de Investigação – da concepção à realização, 5a, Edição, pp. 161–172. Lusociência, Loures (2009)
- Dumoulin, C., Cacciari, L., Hay-Smith, E.: Pelvic floor muscle training versus no treatment, or inactive control treatments, for urinary incontinence in women. Cochrane Database Syst. Rev. (2018). https://doi.org/10.1002/14651858.CD005654.pub4
- Burkhard, J., Bosch, F., Cruz, G., Lemack, A., Nambiar, N., Thiruchelvam, N., Tubaro, A., (eds.): European Association Urology. EAU Guidelines on Urinary Incontinence in Adults. Obtido de European Association of Urology (2018). https://uroweb.org/wp-content/uploads/ EAU-Guidelines-on-Urinary-Incontinence-2018-large-text.pdf
- 17. Ebbesen, M., Hunskaar, S., Rortveit, G., Hannestad, Y.: Prevalence, incidence and remission of urinary incontinence in women: longitudinal data from the Norwegian HUNT study (EPINCONT). Bio Med. Cent. Urol. 13, 13–27 (2013)
- 18. Fortin, M.: O Processo de Investigação- da concepção à realização, 5a, Edição Lusociência, Loures (2009)

- Golmakani, N., Khadem, N., Arabipoor, A., Kerigh, B., Esmaily, H.: Behavioral intervention program versus vaginal cones on stress urinary incontinence and related quality of life: a randomized clinical trial. Oman Med. J. 29(1), 32–38 (2014). https://doi.org/10.5001/omj. 2014.08
- Haylen, B., Ridder, D., Freeman, R., Swift, S., Berghmans, B., Lee, J., Schaer, G.: An International Urogynecological Association (IUGA)/International Continence Society (ICS) joint report on the terminology for female pelvic floor dysfunction. Neurourol. Urodyn. 29, 4–20 (2010). https://doi.org/10.1002/nau.20798
- 21. Hendriks, E., Kessels, A., Vet, H., Bernards, A., Bie, R., (março de, : Prognostic indicators of poor short term outcome of physiotherapy intervention in women with stress urinary incontinence. Neurol. Urodyn. **29**(3), 336–343 (2010). https://doi.org/10.1002/nau.20752
- Hillary, C., Slovak, M., McCarthy, A., Hashim, H., Chapple, C.: Recent developments in technology for the assessment and management of incontinence. Med. Eng. Technol. 39(7), 434–440 (2015). https://doi.org/10.3109/03091902.2015.1088088
- Hoffman, B., Schorge, J., Schaffer, J., Halvorson, L., Brads, K., Cunningham, F.: Williams Ginecología, 2ª edição ed. In: Ruiz, A., Martínez, M., Pinto, J., Albarrán, A., (Trads.). McGraw-Hill. México (2014)
- Hunskaar, S.: A systematic review of overweight and obesity as risk factors and targets for clinical intervention for urinary incontinence in women. Neurourol. Urodyn. 27(8), 749–757 (2008). https://doi.org/10.1002/nau.20635
- 25. Abrams, P., Cardozo, L., Khoury, S., Wein, A., (eds.): International Continence Society. Incontinence, 6th edn. 2017, vol. 1, Tokyo (2017). file:///C:/Us-ers/Usuario/Downloads/Incontinence 6th Edition 2017_eBook_v2.pdf
- International Uroyginecology Association. Incontinência Urinária de Esforço. Um Guia para as Mulheres (2011). Obtido de https://www.yourpelvicfloor.org/media/stress-urinary-incont inence-portuguese.pdf
- 27. Kashanian, M., Ali, S., Nazemi, M., Bahasadri, S.: Evaluation of the effect of pelvic floor muscle training (PFMT or Kegel exercise) and assisted pelvic floor muscle training (APFMT) by a resistance device (Kegelmaster device) on the urinary incontinence in women "comparison between them: a randomized tri." Eur. J. Obstet. Gynecol. Reprod. Biol. 159(1), 218–223 (2011). https://doi.org/10.1016/j.ejogrb.2011.06.037
- Knarr, J., Musil, C., Warner, C.K., Long, J.: Female stress urinary incontinence: Na evidence-based, case study approach. Urol. Nurs. 34(3), 143–151 (2014). https://doi.org/10.7257/1053-816X.2014.34.3.143
- Legendre, G., Ringa, V., Panjo, H., Zins, M., Fritel, X.: Incidence and remission of urinary incontinence at midlife: a cohort study. Int. J. Obstet. Gynaecol. 122, 816–823 (2014). https:// doi.org/10.1111/1471-0528.12990
- Lukacz, E., Lawrence, J., Contreras, R., Nager, C., Luber, K.: Parity, mode of delivery, and pelvic floor disorders. Obstet. Gynecol. 107, 1253–1260 (2006). https://doi.org/10.1097/01. AOG.0000218096.54169.34
- 31. Lukacz, E., Santiago-Lastra, Y., Albo, M., Brubaker, L.: Urinary incontinence in women: a review. JAMA 318(6), 1592–1604 (2017). https://doi.org/10.1001/jama.2017.12137
- 32. Mascarenhas, T.: Manual de Ginecologia. In: Oliveira, C.F. (ed.) Disfunções do pavimento pélvico, pp. 97–140. Permanyer, Lisboa (2011)
- McIntosh, L., Andersen, E., Reekie, M.: Conservative treatment of stress urinary incontinence in women: a 10-year (2004–2013) scoping review of the literature. Urol. Nurs. 35(4), 179–186 (2015). https://doi.org/10.7257/1053-816X.2015.35.4.179
- 34. Nambiar, A., Bosch, R., Cruz, F., Lemack, G., Thiruchelvam, N., Tubaro, A., Burkhard, F.: EAU guidelines on assessment and nonsurgical management of urinary incontinence. Eur. Urol. (2018). https://doi.org/10.1016/j.eururo.2017.12.031

- 35. National Institute for Health and Care Excellence. Urinary incontinence and pelvic organ prolapse in women: management. NICE Guideline, 2 de Abril de 2020. https://www.nice.org.uk/guidance/ng123/resources/urinary-incontinence-and-pelvicorgan-prolapse-in-womenmanagement-pdf-66141657205189
- Nygaard, I., Barber, M., Burgio, K., Kenton, K., Meikle, S., Schaffer, J., Network, P.F.: Prevalence of Symptomatic Pelvic Floor Disorders in US Women. National Institutes of health, pp. 1311–1316. (2008). https://doi.org/10.1001/jama.300.11.1311
- 37. Pires, M.: Eliminação e continência vesical. Em S. Hoeman, Enfermagem de Reabilitação Aplicação e processo, 4a. Lusociência, Loures (2011)
- 38. Rortveit, G., Hannestad, Y., Daltveit, A., HunsKaar, S., (dezembro de, : Age- and type-dependent effects of parity on urinary incontinence: the Norwegian EPINCONT study. Obstet. Gynecol. **348**, 1004–1010 (2001). https://doi.org/10.1016/S0029-7844(01)01566-6
- 39. Shamliyan, T., Wyman, J., Kane, R.: Nonsurgical Treatments for Urinary Incontinence in Adult Women: Diagnosis and Comparative Effectiveness, abril de 2012. (A. f. Qual-ity, Ed.) https://www.ncbi.nlm.nih.gov/books/NBK92960/pdf/Bookshelf_NBK92960.pdf
- Sociedade Portuguesa de Ginecologia [SPG]. Consenso Nacional sobre Uroginecologia. Lisboa (2018). Obtido de https://www.spginecologia.pt/uploads/livro-consensos-sobre-urogin ecologia.pdf
- Subak, L., Richter, H., Hunskaar, S.: Obesity and urinary incontinence: epidemiology and clinical research update. J. Urol. 182, S2–S7 (2009). https://doi.org/10.1016/j.juro.2009. 08.071
- 42. Syan, R., Bucker, B.: Guideline of guidelines: urinary incontinence. BJU Int. 117, (2016). https://doi.org/10.1111/bju.13187
- 43. Townsend, M., Curhan, G., Resnick, N., Grodstein, F.: The incidence of urinary incontinence across Asian, black, and white women in the United States. Am. J. Obstet. Gynecol. **378**, 378-e1 (2010). https://doi.org/10.1016/j.ajog.2009.11.021
- 44. Viana, R., Viana, S., Neto, F., Mascarenhas, T.: Adaptation and validation of the King's health questionnaire in Portuguese women with urinary incontinence. Int. Urogynecol. Assoc. **26**, 1027–1033 (2015). https://doi.org/10.1007/s00192-015-2628-6
- 45. Worl health Organisation. Programme on Mental Health Whoqol User Manual, março de 2012. https://apps.who.int/iris/bitstream/handle/10665/77932/WHO_HIS_HSI_Rev.2012.03_eng.pdf?sequence=1&isAlloed=y&ua=1



Promotion of Functional Independence in the Deficit of Self-care in the Elderly Person with Stroke in Home Context and Technology

Anabela Silva¹(⋈), Susana Silva¹, César Fonseca², José Garcia-Alonso³, Manuel Lopes², Inês Cardoso², and Lara Guedes de Pinho²

 Portalegre School of Health, Portalegre, Portugal
 Comprehensive Health Research Center, University of Évora, POCTEP 0499_4IE_PLUS_4_E, Évora, Portugal
 University of Extremadura, POCTEP 0499_4IE_PLUS_4_E, Cáceres, Spain

Abstract. Stroke continues to be one of the main causes of functional disability, in which the Rehabilitation Nursing Specialist (RNS) has an active intervention in promoting motor, sensory and self-care functional re-education for the recovery of autonomy in Activities of Daily Living (ADL), decreasing the impact of disabilities. Objective: Acquire RNS skills, through an intervention plan for elderly people with neurological disease with self-care deficit and demonstrate health gains. Methodology: Training of functional activities in people with neurological disease, with intervention based on the Yin Case Studies (2018), Orem's Self Care Nursing Deficit Theory (SNDT), Lopes Medium Range Theory (2006), through the ENCS instruments and Barthel Index. Results: Verified health gains in terms of functionality with decreased self-care deficit. Conclusions: Acquisition of RNS skills through the planning of interventions, based on functionality, promotion of education, definition of objectives, providing one with capabilities and tools to maximize its functionality.

Keywords: Rehabilitation nursing · Intervention · Self-care · Elderly · Stroke

1 Introduction

The stroke is characterized by the suspension or obstruction of the blood flow that stops or damages a certain area of the brain, manifested by focal or global disorders of brain function, whose symptoms have a duration of more than 24 h [1]. It occurs when the blood vessel is blocked by a clot or by ruptures, making blood and oxygen circulation to a certain part of the brain impossible, although 80% of these can be prevented. It can be caused by a clot that obstructs blood flow to the brain (ischemic stroke) or by a blood vessel that ruptures and prevents blood flow to the brain (bleeding stroke), a transient ischemic stroke (TIA) can also occur caused by a temporary clot [2].

Every year, 17 million people suffer a stroke, of these, 6 million die and another 5 million have permanent disability, being considered the second leading cause of death and the third for disability, however, at least half of the strokes are potentially preventable, acting previously in awareness and prevention appropriate, being also a fundamental objective in preventing dementia, this a possible consequence of the disease [2]. There is evidence that stroke can be prevented, treatable and controlled by reducing its effects and long-term consequences, in joint collaboration with health ministries, government agencies, research and health professionals [3]. The same authors name hypertension, tobacco, obesity, lack of exercise, diabetes and auricular fibrillation as risk factors.

In Portugal the mortality caused by cerebrovascular diseases has been showing a reduction over the years, in the year 2,000 there are 20,995 deaths compared to 2016 in which there were 11,738 deaths caused by this disease [4].

The mortality rate from cerebrovascular diseases in 2017 registered 109.4 deaths per 100,000 inhabitants, a lower number of 31.7 deaths compared to 2007 (141.1) [5]. In sum, there were a total of 11,270 deaths, representing 10.2% of the mortality in 2017, reaching the highest number of women, with a ratio of 77.2 male deaths per 100 females, with an average age of 83.8 years and in men of 80.0 years. Also according to INE (2019), deaths were 93.4% of people aged 65 and over and 82.9% of people aged 75 and over, reaching an average number of potential years of life lost of 10.1.

The essence of the practice of Rehabilitation Nursing (RN) is applicable in all levels of intervention, fundamental to provide quality care, with the aim of achieving maximum functionality and thus improving the quality of life [6]. In a scenario of RNS intervention in the community, where the study took place, the nurse must optimize the resources of the person, family and community to maintain or promote their participation and integration in life in society [7].

With this work, we intend to acquire RNS skills through the intervention of people with neurological diseases, due to the wide scope in this area, we chose to provide RN care to the person with a stroke through a home intervention program. The design of intervention plans that promote adaptive skills for self-control and self-care of the person in the processes of health/disease and/or disability evolution, are based on Orem's theory of self-care [8].

This perspective is part of the National Program for Brain and Cardiovascular Diseases (NPBCVD), which states the need to promote a planned and organized action throughout the health system, avoiding not only brain-cardiovascular diseases, but also reducing the disabilities caused by them, prolonging life [9].

Therefore RNS should centralize its care in the prevention of complications and in training for the return of active life, beginning its intervention with a rigorous initial evaluation, which allows the definition of diagnoses and an objective intervention plan [10], oriented also towards demonstrating sensitive results to nursing care [8]. These problems can be detected early, through a complete and holistic assessment, identifying strengths and compensatory strategies that can allow the person to maximize independence and reintegrate into ADL [11].

2 Methodology

In this work, we proceeded to the realization of 2 case studies, the methodology used is based on the Case Studies of [12], used in the search for the knowledge of a certain complex social phenomenon, which allows to focus in depth the holistic perspective of reality, studying life cycles or behavior of small groups [12]. It is also a detailed and complete analysis of a certain phenomenon related to the elderly person and family [13]. It is complemented by the Medium Range Theory [14], supported by two concepts, the diagnostic evaluation and the therapeutic intervention, formed by strategies that are organized and developed in a process of mutual influence and interaction, such as the interview to the person and family and data collection [14].

The main instrument used for data collection is the Elderly Nursing Core Set [15] because it contains indicators related to nursing care that allow to evaluate the needs in the different moments of care in which the person is [16], based on the ICF that evaluates the disability of the person or population according to the context of health [17]. Including the Barthel Index as one of the most used tools in studies and practice, because it evaluates the functional capacity during the execution of ADLs [18], defining the level of independence of the person in these same activities.

The choice of case studies was related to a period of clinical training dedicated to the person with neurological disease, in which 2 people (C1, C2) were included with a diagnosis of ischemic stroke, manifesting motor and functional alterations and deficit in self-care, but with potential to recover its functionality, in a home context and technology. However, to hide and protect their identity, intimacy and confidentiality [19], they are identified with letters and numbers and their demographic characterization is shown in Table 1.

| Case studies | C1 | C2 |
|--------------------|----------------------------|---|
| Age | 67 | 84 |
| Gender | Male | Female |
| Nationality | Portuguese | Portuguese |
| Marital status | Living in a de facto union | Married |
| Family Attaché | Companion/caregiver | Husband and grandson/caregivers |
| Level of education | Ninth year of schooling | Didn't go to school, but can read and write |
| Profession | Office worker | Retired |

Table 1. Sociodemographic characterization of study participants.

Table 1 shows people in different phases within their life cycles. Then, strategies were developed that initiated the diagnostic evaluation process, with the displacement to the home context to perform the initial evaluation to the person and family/caregivers, through interview, observation, evaluation of the person/family's knowledge about their clinical situation, disabilities, motivations, potentialities, personal goals for recovery and rehabilitation, and also the housing context and architectural barriers, corresponding to

the first moment of evaluation. The relationship begins with the intention of planning the RNSintervention together with the person/family/career, promoting greater involvement in recovery and adaptation to the new situation, and can arrive at the results of the RN care that validate their efficacy and quality [20], after the second moment, defined at the end of the therapeutic intervention, which in the C1 study lasted 3 weeks and in the C2 study, 6 weeks.

3 Intervention Plan

The RN should concentrate its practice around the prevention of complications and centralize its interventions for the empowerment of the return to active life [21], oriented to results sensitive to care [8, 22]. RNS should optimize the resources of the person, family and community, to maintain or promote their participation and integration in life in society [7], providing information about the importance and objectives of an RN plan [23], involving the family/career in the planning and rehabilitation process, these elements being important for decision making [11, 24].

The plan presented in Table 2 was directed to the functional limitations and comorbidities [25] of participants in this study within the community context [26].

Of note is the responsibility of RNS in promoting safe environments, di-minution of environmental risk factors, related to functional change [8]. With this, attention was paid to its personal goals, health project [8], personal history, psychological complexity [27], the safety of the person [28], at all times of implementation of the planned interventions, regarding pain, tiredness, intensity and rhythm of the exercises as architectural barriers, planning rest periods for the person, managing to carry out the activities [6].

 Table 2. Motor Functional Rehabilitation Intervention Plan for the person affected with stroke.

| Indicators of results | Objectives | Interventions | Expected results |
|---------------------------|--|--|--|
| Knowledge about people | - To know the expectations of the person, taking into account their personal goals and health project [8] - Evaluate functional capacity to obtain necessary information and be able to plan interventions [6] | - Provide a calm and welcoming environment [29] - To evaluate the person through the subjective and objective examination [30], to collect pertinent information [8] in the observation and interview - Use scales and measurement instruments [8], such as the ENCS [15], Barthel Index [31], to verify physical and motor capacity [32] - Prepare registration documents, field notes [14] and SClinico record | Selection of a program adapted to the needs of each person [32, 33] The person must feel, encouraged and accompanied [34], from the beginning to the end of the program |

(continued)

 Table 2. (continued)

| Indicators of results | Objectives | Interventions | Expected results |
|-----------------------------------|--|--|--|
| Improvement of cognitive function | - To evaluate the emotional domain in the context of cognitive difficulties in a person after a stroke [35] | - To evaluate cognitive deficits with valid, reliable and responsive tools and establish an intervention program, taking into account psychological complexity and personal history [27] - To evaluate memory and other relevant areas of cognitive function, to use interventions concentrated on functional tasks, to increase awareness of memory deficit with associations (for example with visualization) [35] - To provide a structured, calm environment, away from sources of stress and inappropriate behavior [36] - Use combined cognitive dual task, such as postural control and walking simultaneously, to stimulate concentration and cognitive function [10, 37] - To support and educate people and their caregivers regarding emotional changes, as well as recognize the psychological needs [35] | Identify the existence of physical limitations, anxiety, fatigue that makes it impossible for the person to collaborate in the exercise [27] To support and educate people and their caregivers regarding emotional changes, as well as recognize the psychological needs [35] |
| Training for Self-Care | - Encourage the spontaneous function of the trunk muscles, re-educate the postural reflex, stimulate sensitivity, reintegrate the body scheme and facilitate self-care [1] | Cross facilitation, approaching the person from the affected (left) side [1], encouraging use of the neglected side, facilitating access to personal objects Train the use of the upper limbs bilaterally, reduce motor commitment and improve function [37] Positioning in lateral decubitus (affected side) establish weight support and body alignment, Bobath neuro-development approach [6] Anti-spastic positions, favor body alignment1, control pain and teach caregivers about the prevention of shoulder pain by spasticity of the upper limb [38] Start with passive mobilization and slow movements, associate proprioceptive stimulation, interact with the person during the exercises to observe the movements [1], stimulate neuroplasticity to recover lost functions [39] Perform passive and self-assisted exercises, light stretches maintained for a longer period of time [40] To enhance respiratory control through the dissociation of breathing times and diaphragmatic breathing, relaxation techniques and rest positions [41] | - Improve balance, reacquisition of skills, quality of life and mobility [26] - Raise awareness of the affected hand as an integral part of the body, in an anti-spastic pattern [1] - To counteract posture changes in sitting and standing, to improve bilateral weight support [6] - To provide comfort, to prevent musculoskeletal alterations, to modify the visual field, to constitute a body scheme [1] - To reduce the insidious installation of spasticity [1], preventing contractures [40] |

(continued)

 Table 2. (continued)

| Indicators of results | Objectives | Interventions | Expected results |
|---|---|--|---|
| Increase in physical capacity and muscle strength | - Encourage the person to perform physical activity after stroke [38] - Increase strength and muscle resistance [26] | To promote specific mobilization of soft tissues, through the correct realignment, to re-learn active movements, to integrate them in the realization of functional activities, to reach patterns of normal movement [39] Increase of repetitions of body weight activities (push-up), progressive resistance exercises [38] Duration of 20 min each session, with a period of 3 to 5 min with low intensity exercises [11], 1-3 series of 10 to 15 repetitions of 8 to 10 exercises involving the main muscle groups [26] To teach caregivers about the importance of establishing goals for the continuity of the person's participation in exercise and physical activity [26] Perform exercises with a high level of safety [26] | Price-ec implementation of therapeutic exercises of articular mobilization for the prevention of complications associated with immobility and prolonged re-suspension in the bed, such as the reduction of articular amplitude [42] Progressively increase strength [38]; Improve exercise tolerance (functional capacity) [26], because the physical capacity more associated with autonomy is muscle strength [43] |
| Improvement of the functional state in body balance | - Re-educate the postural reflex mechanism [1]; - Encouraging self-care through early lifting [44] - Promoting independence in mobility [1] | Perform activities and therapeutic exercises: bridge; roll and lift [45] in bed, alternate position to relieve pressure zones, make the bridge [6], load on the elbow and self-mobilizations [1], mobilize soft tissues with active-resisted exercises, proprioceptive training, load introduction and directed activity [39] Training sitting balance and balance of [45] to maintain orthostatic position [37] Lift to chair or armchair, should start after stable clinical situation, with safe transfer technique, the person should be dressed and with closed and non-slip footwear, preventing the risk of falling [44], the chair should be placed at an angle with the bed, on the affected side of the person (Bobath neurodevelopment) [6] Maintain a correct and comfortable posture on the chair, with the upper limb in an anti-spastic position [1] Before starting the process the person and family should realize the benefits of walking, such as possible obstacles and rest points [30] Use support devices, adapted to the clinical state, age, degree of dependence and collaboration of the person, instruct and train the procedure, follow and monitor the technique, ensure safety and prevent incidents (walking) [44] | Generate the restart of muscle contraction and active movement [39] Body awareness with correct posture and maintenance of balance [37], preventing and correcting postural defects [46] To strengthen the physical and psychosocial domains through exercise and physical activity, preventing relational complications with inactivity, in order to recover voluntary movement and ADL [26] Training to walk [30] To diminish or attenuate the impact of the functional deficit, providing support and stability for the balance, promoting strength, improving flexibility and motor dominance, improving sensory capacity [6] |

| Indicators of results | Objectives | Interventions | Expected results |
|-----------------------|---|---|--|
| Therapeutic adherence | - Establish effective strategies to facilitate long-term adherence to regular physical exercise [26] | Planning and defining strategies with the person/family for self-care, including ability to recognize safety issues at home, therapeutic adherence, medication and exercise program [6], the exercises should be repeated in a sequence of 10, repeated 2 to 3 times a day [1] Teach the person and caregivers to use support products such as bath accessories, sponges, dress handles [35] | - Improve the level of security and independence in ADL [26] |
| Evaluation | - Quantify [30], and monitor health gains, produce sensitive indicators aiming at continuous improvement of health quality | Evaluate results at the beginning and end of the program [30] | Confer significant gains in health [47], mobility and self-confidence [48], self-care and self-management [49] |

Table 2. (continued)

4 Results and Discussion and Conclusions

4.1 Discussion of Results

The data was analyzed according to the method of [12], which consists of examining, categorizing and classifying, combining evidence and the results of cross cases, shown in Table 3.

In this analysis of the data in Table 3, a balance is found between the 2 case studies regarding gains at the level of the functionality parameter, although overall gains in this area of about 12.12% were observed.

The C1 case study distinguished itself with a gain of 27.00% in terms of self-care, compared to C2 which acquired a value of 16.00%, both totaling a final gain of 21.50%.

In learning and memory functions, both achieved final gains of 6.50%. In terms of communication, they stand out in total with 17.50%, but C2 showed a higher evolution with 25.00%. There is also a 3% overall gain in the relationship with caregivers, in which C2 kept 33% in both evaluations.

Regarding the Barthel Index, a score of 27.5 in gains was reached after intervention, emphasizing, however, that C1 maintained severe dependence and C2 evolved from severe to moderate dependence.

| Cases | Evaluation | Global Functionality Score | Self-care | Learning and memory functions | Communication | Relationship with friends and Caregivers | Barthel Index |
|---------------|------------|----------------------------------|-----------|--|---------------|---|------------------|
| C1 | Initial | 43.25% | 92.00% | 18.00% | 30.00% | 33.00% | 20 |
| | Final | 31.00% | 65.00% | 12.00% | 20.00% | 27.00% | 40 |
| | Gains | 12.25% | 27.00% | 6.00% | 10.00% | 6.00% | 20 |
| C2 | Initial | 42.00% | 68.00% | 22.00% | 45.00% | 33.00% | 20 |
| | Final | 30.00% | 52.00% | 15.00% | 20.00% | 33.00% | 55 |
| | Gains | 12.00% | 16.00% | 7.00% | 25.00% | 0.00% | 35 |
| Average score | gain per | 12.12% | 21.50% | 6.50% | 17.50% | 3.00% | 27.5 |

Table 3. Evaluation of gains according to the ENCS scale.

Cognitive functional gains were also observed, with the performance of teachings and exercises with the presence of families for their involvement in care [24], ensuring the absorption of knowledge in order to facilitate the continuity of care, given also the existence of a high deficit in self-care, as well as teachings regarding emotional changes [35].

The case study C1, maintained difficulty in performing therapeutic activities in the bed, registering improvement in the level of the bearing to the unaffected side, and in the self-mobilizations, with ataxia of movement less exacerbated when stimulation in passive mobilizations, as well as, slight improvement of the articular amplitude [42].

Pain has improved in both cases and should be controlled, but it is necessary to teach caregivers about ways to prevent shoulder pain caused by spasticity of the upper limb [38].

Case study C1 tolerates static seated equilibrium, although the remaining equilibrium is compromised. The C2 case study progressively increased strength by increasing repetitions of body weight activities (push-up) [38] through a parallel bar. It also presents static and dynamic sitting equilibrium and static orthostatic balance, maintaining changes in dynamic orthostatic balance, tolerating walking with a walker about 20 m with supervision.

Although the C1 case study presented dependence in all the ADLs, it obtained improvement in the vesical and intestinal pattern, requesting urinal and with improvement of the constipation, being removed the use of diaper, also managing to collaborate in the dressing and undressing. The case study C2, presents sphincter control, manages to collaborate in the dressing and undressing, feeds by the own hand, but without using a knife.

Being the nursing intervention understood as a complex action in a whole [14], after elaborating, carrying out and analyzing the plans and programs in RN [8], it is verified improvement of the functionality in these 2 case studies.

4.2 Implications and Conclusion

Immobility and functional limitation [15] lead to several challenges and consequences that manifest themselves in the functions and structure of the body, participation activities and environmental factors. They are factors which influence the capacity for self-care, however, a modifiable factor if RNS acts early, with structured and individualized programs.

A rehabilitation program, helps adaptation to a new condition and improvement of quality of life [50], which reinforces the care of RN, as an area specialized in maintenance, promoting comfort and quality throughout the life cycle, preventing complications and disabilities caused by disease or accident, at various levels, based on decision making for the design of intervention plans in various areas including motor training and self-care [7]. Since the gains in RN are always the gains of the person, the goals of RNS are the goals of the person, this is the contribution of this specialty.

References

- Menoita, E., Sousa, L., Pão-Alvo, I., Vieira, M.: Reabilitar a pessoa idosa com AVC: Contributos para um envelhecer resiliente. Lusociencia, Loures (2012)
- American Stroke Association (ASA): About Stroke. American Heart Association, Inc., Dallas (2019). https://www.stroke.org/en/about-stroke
- 3. Norrving, B., Barrick, J., Davalos, A., Dichgans, M., Cordonnier, C., Guekht, A., Kutluk, K., Mikulik, R., Wardlaw, J., Richard, E., Nabavi, D., Molina, C., Bath, P.M., Stibrant, K., Sunnerhagen, R.A., Drummond, A., Planas, A., Caso, V.: Guideline action plan for stroke in Europe 2018–2030. Eur. Stroke J. 0(0), 1–28 (2018). https://actionplan.eso-stroke.org/
- Organization for Economic Co-operation and Development (OCDE): Health Satus-Key indicators. Organization for Economic Co-operation and Development. https://stats.oecd.org/ Index.aspx?DatasetCode=HEALTH_STAT
- 5. Instituto Nacional de Estatística (INE): Causas de morte. A mortalidade por tumores malignos da traqueia, brônquios e pulmão regista valores significativos a partir dos 45 anos. Instituto Nacional de Estatística: destaque informação à comunicação social (2017). https://www.ine.pt/xportal/xmain?xpid=INE&xpgid=ine_destaques&DESTAQUES dest_boui=345373282&DESTAQUESmodo=2&xlang=pt
- Hoeman, S.: Enfermagem de Reabilitação: Prevenção, Intervenção e Resultados Esperados. 4.ª ed. Lusodidacta, Loures (2011)
- 7. Ordem dos Enfermeiros: Assembleia do colégio da especialidade de Enfermagem de Reabilitação: Padrões de Qualidade Especializados em Enfermagem de Reabilitação. Colégio da Especialidade de Enfermagem de Reabilitação. Colégio da Especialidade de Enfermagem de Reabilitação, Lisboa (2018). https://www.ordemenfermeiros.pt/media/8141/ponto-4_regu lamento-dos-padr%C3%B5es-qualidade-ceer.pdf
- Regulamento nº 392/2019 de 3 de maio: Regulamento das competências específicas do enfermeiro especialista em Enfermagem de Reabilitação. Diário da República, 2ª série, n.º 85, 13565–13568 (2019). https://dre.pt/web/guest/pesquisa/-/search/122216893/details/ normal?l=1
- Direção Geral da Saúde [DGS]. Programa Nacional para as Doenças Cérebro-Cardiovasculares. Lisboa: Direção Geral de Saúde (2019). https://www.sns.gov.pt/instit ucional/programas-de-saude-prioritarios/programa-nacional-para-as-doencas-cerebro-car diovasculares/

- Vieira, C., Sousa, L., Braga, R.: Reabilitar a pessoa com Acidente Vascular Cerebral. In Marques-Vieira e Sousa. 1ª edição. Cuidados de Enfermagem de Reabilitação à Pessoa ao longo da vida, pp. 465–474. Lusodidacta, Loures (2016)
- 11. Winstein, C., Stein, J., Arena, R., Bates, B., Cherney, L., Cramer, S., Deruyter, F., Eng, J., Fisher, B., Harvey, R., Lang, C., MacKay-Lyons, M., Ottenbacher, K., Pugh, S., Reeves, M., Richards, L., Stiers, W., Zorowitz, R., American Heart Association Stroke Council, Council on Cardiovascular and Stroke Nursing, Council on Clinical Cardiology, and Council on Quality of Care and Outcomes Research: Guidelines for adult stroke rehabilitation and recovery: a guideline for healthcare professionals from the American heart association/American stroke association. Stroke 47(6) (2016). https://doi.org/10.1161/STR.000000000000000098
- 12. Yin, R.: Case Study Research and applications: Design and Methods, 6th edn. Sage Publications, Inc., Los Angels (2018)
- 13. Fortin, M.: Fundamentos e etapas de processo de investigação. Lusodidata, Loures (2009)
- Lopes, M.: A relação Enfermeiro-Doente como intervenção terapêutica. Formasau, Coimbra (2006)
- 15. Lopes, M., Fonseca, C.: Elderly core set: short form-manual & instrumento. Universidade de Évora, Évora, Portugal (2018)
- Lopes, M., Fonseca, C.: The construction of the elderly nursing core set. J. Aging Inov. 2(1), 121–131 (2013). http://journalofagingandinnovation.org/pt/volume2-edicao1-jan eiro2013/elderly-nursing-core-set/
- 17. Reis, F., Pereira, C., Escoval, A., Reis, F.: Contributo para a classificação da funcionalidade dos utentes da Rede Nacional de Cuidados Continuados Integrados segundo a Classificação Internacional de Funcionalidade. Revista Portuguesa de Saúde Pública 33(1), 84–97 (2015). https://run.unl.pt/bitstream/10362/20411/1/v33n1a09%20%20Contributo%20para% 20a%20classificacao%20da%20funcionalidade.pdf
- Araújo, F., Ribeiro, J., Oliveira, A., Pinto, C.: Validação do Índice de Barthel numa amostra de idosos não institucionalizados. Revista Portuguesa de Saúde Pública 2(25), 59–66 (2007). https://repositorio-aberto.up.pt/bitstream/10216/15740/2/84575.pdf
- Nunes, L.: Considerações éticas a atender nos trabalhos de investigação académica de enfermagem. Departamento de Enfermagem ESSIIP, Setúbal, Portugal (2013)
- Donabedian, A.: Evaluating the quality of medical care. Milbank Q. 4(83), 691–729 (2005). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2690293/
- 21. Braga, A., Silva, E.: Peplau X Orem: interação e autocuidado como estratégia da assistência de enfermagem. Revista pró-universus **08**(1), 08–11 (2017). https://editora.universidadedev assouras.edu.br/index.php/RPU/article/view/690
- Fonseca, C., Lopes, M., Mendes, D., Parreira, P., Mónico, L., Marques, C.: Psychometric properties of the elderly nursing core set. In: García-Alonso, J., Fonseca, C. (eds.) Gerontechnology. Communications in Computer and Information Science, pp. 143–153. Springer, Cham (2019). https://doi.org/10.1007/978-3-030-16028-9_13
- 23. Sousa, L. e Carvalho, M. L.: Pessoa com osteoartrose na anca e joelho em contexto de internamento e ortopedia. In: Marques-Vieira e Sousa. 1ª edição. Cuidados de Enfermagem de Reabilitação à Pessoa ao longo da vida, pp. 405–420. Lusodidacta, Loures (2016b)
- Cosgrove, D., Macmahon, J., Bourbeau, J., Bradley, J., O'Neill, B.: Facilitating education in pulmonary rehabilitation using the living well with COPD programme for pulmonary rehabilitation: a process evaluation. BMC Pulm. Med. 13(50), 10 (2013). https://doi.org/10. 1186/1471-2466-13-50
- Luk, E., Hutchinson, A., Tacey, M., Irving, L., Khan, F.: COPD: health care utilisation patterns with different disease management interventions. Lung 195(4), 455–461 (2017). https://doi.org/10.1007/s00408-017-0010-9

- 26. Billinger, S., Arena, R., Bernhardt, J., Eng, J., Franklin, B., Johnson, C., MacKay-Lyons, M., Macko, R., Mead, G., Roth, E., Shaughnessy, M., Tang, A., American Heart Association Stroke Council, Council on Cardiovascular and Stroke Nursing, Council on Lifestyle and Cardiometabolic Health, Council on Epidemiology and Prevention e Council on Clinical Cardiology: Physical activity and exercise recommendations for stroke survivors: a statement for healthcare professionals from the American heart association/American stroke association. Stroke 45(8), 2532–2553 (2014). https://doi.org/10.1161/STR.00000000000000022
- 27. National Institute for Health and Care Excellence (NICE). Clinical Guideline: Stroke rehabilitation in adults. NICE Pathway (2013). https://www.nice.org.uk/search?q=Stroke+rehabilitation+in+adults
- 28. Fragata, J.: Segurança dos doentes: uma abordagem prática. 1ª Edição. Lidel, Lisboa (2011)
- Cordeiro, M., Menoita, E.: Manual de boas práticas na reabilitação respiratória, 1ª edição. Lusociencia, Loures (2012)
- Marques, A., Figueiredo, D., Jácome, C., Cruz, J.: Doença Pulmonar Obstrutiva Crónica (DPOC). E agora?: Orientações para um programa de reabilitação respiratória. 1ª edição. Lusodidata, Loures (2016)
- Mahoney, F., Barthel, D.W.: Functional evaluation: the Barthel index: a simple index of independence useful in scoring improvement in the rehabilitation of the chronically ill. Maryland State Med. J. 14, 56–61 (1965). https://www.semanticscholar.org/paper/Functional-evaluation%3A-The-Barthel-Index%3A-A-simple-Mahoney-Barthel/c71fe40c867d7e7046e2b655cf70e12eedaac8b3
- Accioly, M., Patrizzi, L., Pinheiro, P., Bertoncello, D., Walsh, I.: Exercícios físicos, mobilidade funcional, equilíbrio, capacidade funcional e quedas em idosos. ConScientiae Saúde 15(3), 378–384 (2016). https://doi.org/10.5585/ConsSaude.v15n3.6338
- 33. Lee, E., Kim, M.: Meta-analysis of the effect of a pulmonary rehabilitation program on respiratory muscle strength in patients with chronic obstructive pulmonary disease. Asian Nurs. Res. **13**, 1–10 (2019). https://doi.org/10.1016/j.anr.2018.11.005
- 34. Khoshkesht, S., Zakerimoghadam, M., Ghiyasvandian, S., Kazemnejad, A., Hashemian, M.: The effect of home-based pulmonary rehabilitation on self-efficacy in chronic obstructive pulmonary disease patients. J. Pakistan Med. Assoc. 10(65), 1041–1046 (2015). https://search.ebscohost.com/login.aspx?direct=true&db=mdc&AN=26440829&lang=pt-pt&site=ehost-live
- 35. National Institute for Health and Care Excellence (NICE): Stroke rehabilitation: therapy. NICE Pathway (2020). https://pathways.nice.org.uk/pathways/stroke#path=view%3A/pathways/stroke/stroke-rehabilitation-therapy.xml&content=view-index
- 36. Varanda, E., Rodrigues, C.: Reeducação cognitiva em Enfermagem de Reabilitação: recuperar o bailado da mente. In Marques-Vieira e Sousa. 1ª edição. Cuidados de Enfermagem de Reabilitação à Pessoa ao longo da vida, pp. 215–225. Lusodidacta, Loures (2016)
- 37. Vieira, C., e Caldas, A.: A relevância do Andar: reabilitar a pessoa com andar comprometido. In: Vieira e Sousa. 1ª edição. Cuidados de enfermagem de reabilitação à pessoa ao longo da vida, pp. 547–557. Lusodidacta, Loures (2016)
- 38. National Institute for Health and Care Excellence (NICE). Managing movement diffificulties after a stroke. NICE Pathway (2020). https://pathways.nice.org.uk/pathways/stroke#path=view%3A/pathways/stroke/managing-movement-difficulties-after-a-stroke.xml&content=view-index
- Toubarro, F.: Função Sensoriomotora. In Marques-Vieira e Sousa. 1ª edição. Cuidados de Enfermagem de Reabilitação à Pessoa ao longo da vida, pp. 159–166. Lusodidacta, Loures (2016)
- 40. Henriques, F., Fumincelli, L.: A pessoa com lesão medular. In: Vieira e Sousa. 1ª edição. Cuidados de enfermagem de reabilitação à pessoa ao longo da vida, pp. 433–450. Lusodidacta, Loures (2016)

- 41. Cerqueira, A., Grilo, E.: Prevenção das consequências da imobilidade na pessoa em situação crítica. Revista Portuguesa de Enfermagem de Reabilitação 78–89 (2019). https://doi.org/10.33194/rper.2019.v2.n1.10.4574
- 42. Vieira, J., Ferreira, R.: Mobilização precoce da pessoa submetida a ventilação mecânica invasiva. Revista Ibero-Americana De Saúde E Envelhecimento **4**(2), 1388–1399 (2018). https://doi.org/10.24902/r.riase.2018.4(2).1388
- 43. Preto, L., Gomes, J., Novo, A., Mendes, M., Granero-Molina, J.: Efeitos de um Programa de Enfermagem de Reabilitação na Aptidão Funcional de Idosos Institucionalizados. Revista de Enfermagem Referência 4(8), 55–63 (2016). https://doi.org/10.12707/RIV15019
- 44. Ordem dos Enfermeiros: Guia orientador de boas práticas: Cuidados à pessoa com alterações de mobilidade, posicionamentos, transferências e treino de deambulação. Série 1, nº 7. Ordem dos Enfermeiros, Edição (2013). https://www.ordemenfermeiros.pt/arquivo/publicacoes/Doc uments/GOBP_Mobilidade_VF_site.pdf
- 45. Coelho, C., Barros, H., e Sousa, L.: Reeducação da Função Sensoriomotora. In: Marques-Vieira e Sousa. 1ª edição. Cuidados de Enfermagem de Reabilitação à Pessoa ao longo da vida, pp. 227–251. Lusodidacta, Loures (2016)
- Branco, P., Barata, S., Barbosa, J., Cantista, M., Lima, A., Maia, J.: Temas de Reabilitação
 Reabilitação Respiratórias. Medesign, Porto (2012). https://repositorio.chlc.min-saude.pt/ handle/10400.17/765
- Murphy, L., Harrington, P., Taylor, S., Teljeur C., Smith, S., Pinnock, H., Ryan, M.: Clinical-effectiveness of self-management interventions in chronic obstructive pulmonary disease: an overview of reviews. Chron. Respir. Dis. 14(3), 276–288 (2017). https://doi.org/10.1177/147 9972316687208
- Correia, C., Barbosa, L. Rebelo, L., Alves, M., Pinho, N., Magalhães, B.: O treino propriocetivo e de equilíbrio postural no idoso para a prevenção de quedas: scoping review. Revista Portuguesa de Enfermagem de Reabilitação, 66–77 (2019). https://doi.org/10.33194/rper.2019.v2.n1.09.4573
- 49. Nabais, A., Sá, M.: Intervenção do Enfermeiro na Promoção do Autocuidado na Pessoa com DPOC: uma Revisão Sistemática da Literatura. Investigação Qualitativa em Saúde: Atas 7º Congresso Ibero-americano em investigação qualitativa, 2, pp. 131–139 (2018). https://pro ceedings.ciaiq.org/index.php/ciaiq2018/article/view/1772/1725
- Ettinger, L., Soares, M., Vaez, A., Araújo, D., Pinheiro, F., Sousa, D.: Qualidade de vida das vítimas de trauma raquimedular atendidas em centros de reabilitação de aracaju. Interfaces Científicas. Saúde e Ambiente 5(2), 53–62 (2017). https://doi.org/10.17564/2316-3798.201 7v5n2p53-62



Rehabilitation Nursing and Elderly People with Neurological Alterations - Home Context Technology

Andreia Duarte^{1,2(⊠)}, César Fonseca³, Juliano Branco⁴, José Garcia-Alonso⁵, Lara Guedes de Pinho³, and Inês Cardoso³,

- ¹ Nurse at UCCI Manuel Fanha Vieira, Entroncamento, Portugal
- ² Superior School of Health of Portalegre, Portalegre, Portugal
- Omprehensive Health Research Center, University of Évora, POCTEP 0499 4IE PLUS 4 E, Évora, Portugal
- ⁴ Nurse Specialists in Rehabilitation, Nursing, Nurse at UCC Chamusca-Golegã, Chamusca, Portugal

Abstract. The main objective of this systematic literature review is to understand the gains that the Nurse Specialist in Rehabilitation Nursing interventions develop to the user with neurological changes in home context technology. A systematic review of the literature was conducted, where 110 articles were reviewed.

Results and conclusions: that the rehabilitation process to be effective must have as its basic point the motivation, the knowledge of the difficulties that the user has in his/her home for the realization of his/her ADL. The interventions to be developed must cover all these components, so that elderly people can achieve the maximum functional capacity.

Implication in professional practice: there is a need to publish new studies on this topic.

Keywords: Nursing \cdot Rehabilitation \cdot Self-care \cdot Neurological disorder \cdot Education \cdot Blood pressure \cdot Stroke \cdot Neurology \cdot Cerebrovascular disorders and cardiovascular diseases

1 Introduction

The role of the Rehabilitation Nursing Specialist (RNS) exerts a preponderant action on the quality of life of the user through the action of his interventions. Thus the need arose for this systematic review of the literature to give greater visibility to the action RNS has in the community with neurological changes. Thus RNS in the home context technology plays an important role in the rehabilitation of these users, since it always adapts to the reality that the user encounters every day in his or her home, having a personalized intervention. Thus the relevance of adapting Orem's model of self-care emerges, which is composed of three subcategories: the theory of self-care, the theory of self-care deficit and the theory of the nursing system. For this theory one of the

⁵ University of Extremadura, POCTEP 0499_4IE_PLUS_4_E, Cáceres, Spain

objectives of nursing is to assist the user in their self-care needs and allow the return of the user to self-care (Hoeman 2011). The nurse is the responsible health professional in the practice of teaching aimed at self-care, with the objective of training the person to take care of him/herself (Braga and Silva 2017). Thus, the gains of the nursing care of rehabilitation are demonstrated, translating in the decrease of the degree of dependence of the user. In this sense, the need arises for the realization of this systematic review of the literature with the aim of identifying the nursing care of rehabilitation in a home context technology. It was then elaborated the guiding question of this revision "Which the cares of rehabilitation nursing, to the patient with neurological alterations in home context technology?", following the PICO methodology. A problem was formulated from a starting question, based on the PICO structure, defined by an acronym, which corresponds to (P - Population) user or problem, (I - Intervention) Intervention, (C) - Comparison and (O - Outcomes).

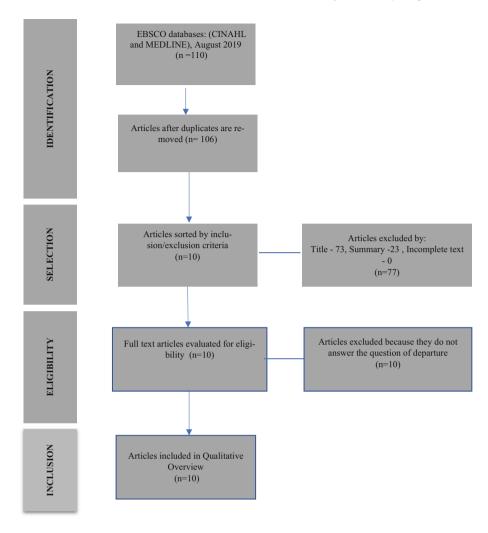
| [P] POPULATION | ADULT PEOPLE WITH NEUROLOGICAL ALTERATIONS |
|------------------|--|
| [I] INTERVENTION | REHABILITATION PROGRAM |
| [C] COMPARISSON | LEVEL OF SELF-CARE |
| [O] OUTCOMES | RN CARE RESULTS |

1.1 Materials: Concepts

The concept of Daily Life Activities (DAA) is defined by the "basic skills you need to possess to take care of yourself" (Hoeman 2011). Self-care in an overview can be seen as people's ability to take care of themselves, to take care of their own health, to prevent and face up to illness, and to take responsibility for their own well-being (Martins and Rocha 2016).

1.2 Methodology

A survey was conducted through the scientific search platform EBSCO-HOST, accessing the databases CINAHL Complete and MEDLINE Complete, conducted in September 2019. The research was based on the use of the following descriptors according to the research question: Nursing, Rehabilitation, Self-care, Neurological disorder, Education, Blood pressure, Stroke, Neurology, Cerebrovascular disorders and Cardiovascular diseases. The Boolean descriptors "AND" and "OR" were used. The following inclusion criteria were defined: articles whose publication date is between January 2010 and September 2019.



The methodology used is a qualitative case study methodology, based on Robert Yin's (2018) Case Studies model, in which the author defends this method as a necessity to know a certain complex social phenomenon, allowing an in-depth analysis of the holistic perspective. Associated with these study methods, this work will be complemented by Lopes' Medium-Range Theory (2011), which is based on the therapeutic relational intervention between nurse-patients, supported by two concepts that characterize the nature of this relationship: diagnostic evaluation and therapeutic intervention, having as strategy, the development of a process of mutual influence and interaction.

The selection criteria were taken into account, in order to select five people, over 65 years old, with neurological alterations and with a degree of dependence on self-care and who is the target of specialized care in rehabilitation nursing. The sample can be characterized as a non-probabilistic and convenience sample, i.e., a sample made up of people who meet the selection criteria outlined, having been constituted as they emerged

in the care provision until the desired number was reached (Fortin 2009). The selection of the population was based on the knowledge of the student and the supervising nurse according to their clinical situation and the need for RNS intervention regarding the deficit of self-care.

2 Results and Discussions and Conclusions

2.1 Discussion of Results

| Title of the Study/Authors/Methodology/Participants | Objetivos | Resultados e Conclusões |
|---|---|---|
| Title: Can users' practice be increased simply by implementing agreed national guidelines? Authors: Huijben-Schoenmakers, M; Rademaker, A; Scherder, E; Methodology: Observational study; Participants: 17 people with strokes, including 8 men, 9 women, with an average age of 75.8 and 17 individuals with the same characteristics who participated in a previous observational study; Year: 2018 | Increase the exercise time of elderly people in the stroke unit | The time spent on therapeutic activities increased significantly from 103.5 min measured in the previous study to 156.5 min in this study. The average Barthel Index score was $8.8~(\mathrm{SD}\pm4.1)$. The most active people had a significant positive relationship in the Barthel Index |
| Title: Nursing interventions to the user with stroke in rehabilitation Authors: Cavalcante, F Tahissa; Nemer, L; Peixoto, A; Moreira, R.; Ferreira, J; Methodology: Integrative review; Year: 2018 | Present the knowledge produced about the Nursing interventions aimed at people with strokes in rehabilitation; | Among the assistance interventions of nursing, the motor and functional rehabilitation stood out. In the educational interventions, it was observed the teaching of the person about the disease. Nursing interventions directed to the caregivers were found. It was identified a greater number of nursing interventions for the person, caregivers in which the interventions of nurses focused on education |
| Title: Predictors of functional and walking outcomes for post-STROKE people in home rehabilitation Authors: Asiri, Faisal Y; Marchetti, Gregory F; Ellis, Jennifer L; Otis, Laurie; Sparto, Patrick J; Watzlaf, Valerie; Whitney, Susan L. Methodology: retrospective study Participants: Individuals who received home care after stroke: 213 (mean age 76.5 ± 9 years, 51% female); Year: 2014 | Describe the results of rehabilitation care at home focusing on functional and walking performance in people after a stroke and the associated factors that contribute to better outcomes after treatment | Change in walking speed and ADL performance between admission and discharge from home health services. Walking speed and ADL scores at the beginning of the treatment had more influence on functional and walking improvement. Post-discharge home conditions, confusion, and housing environment had an effect on the outcomes of home rehabilitation for people who had strokes |

(continued)

(continued)

| (continued) | | |
|--|---|---|
| Title of the Study/Authors/Methodology/Participants | Objetivos | Resultados e Conclusões |
| Title: Strengthening the role and functions of nursing in 24/7 stroke rehabilitation: a study of mixed methods assessing the feasibility and acceptability of an educational intervention program Authors: Loft, M. I; Poulsen, I; Martinsen, B; Mathiesen, L. L; Iversen, H. K; Esbensen, B. A; Methodology: Systematic review Year: 2014 | Evaluate the feasibility of an educational nursing intervention for inpatient stroke rehabilitation and its acceptability from the perspective of the nursing team | High level of satisfaction with the educational program in terms of acceptability and feasibility. The qualitative results revealed the nursing team's experiences with the educational program |
| Title: Task oriented training in rehabilitation after stroke: systematic review Authors: Rensink, M; Schuurmans, M; Lindeman, E; Hafsteinsdóttir, T.; Methodology: Selected randomized clinical trials and systematic reviews were evaluated for quality. Important characteristics and results were extracted and summarized. Level of evidence: Year: 2009 | Provide an overview of the evidence in the literature on task oriented training of stroke survivors and its relevance in daily nursing practice | Task oriented training for people who have had a stroke leads to improvements in functional outcomes and overall health-related quality of life Nurses can and should play an important role in creating opportunities to practice significant functional tasks outside of regular therapy sessions |
| Title: The role of the community nurse in stroke rehabilitation Authors: McGinnes, A; Easton, S; Williams, J; Neville, J; Methodology: systematic review Participants: Portsmouth Hospital Community Year: 2016 | - To enable the whole team to consider their roles; - Encouraging dialogue between all team members of work | The team was able to evaluate the results in relation to current practice. The project confirmed that the rehabilitation nurse has a unique and fundamental role in the team and strengthens the interdisciplinary teamwork model |
| Title: A Systematic Review of Therapeutic Interventions for Post-Stroke Depression and the Role of Nurses Authors: Man-van Ginkel, J. M; Gooskens, F; Schuurmans, M. J; Lindeman, E; Hafsteinsdottir, T. B Methodology: Systematic literature review Year: 2010 | Exploring the role of nursing in the treatment of post-stroke depression and identifying effective non-pharmacological interventions that nurses can use in the daily care of people with strokes | There was strong evidence that providing information reduces the severity of depression. Other interventions with positive effects were the motivational interview, a specific nursing support program and physical exercise Post-stroke depression is a major problem with adverse effects on a person's ability to participate in rehabilitation and its outcome |

(continued)

(continued)

| Title of the Study/Authors/Methodology/Participants | Objetivos | Resultados e Conclusões |
|--|--|--|
| Title: Nursing interventions to improve the nutritional status and outcomes of stroke patients: descriptive comments of processes and outcomes. Authors: Perry, L; Hamilton, S; Williams, J; Jones, S Methodology: Systematic literature review Year: 2013 | - Identify nursing interventions to improve the nutritional status and related outcomes of stroke survivors; - Observe the results of nursing interventions related to nutrition, including food intake, functional status, complications, activities of daily living, mortality and quality of life | This evaluation indicated the parameters of nursing nutritional care, and provided a framework for future research |
| Title: Nursing interventions in stroke care: a review based on clinical evidence. Authors: Theofanidis, D; Gibbon, B Methodology: Systematic literature review Year: 2016 | - Prioritize nursing interventions for acute stroke; - Update nursing roles; | To facilitate a person's rapid recovery, nursing care should include the routine practice of a wide range of specific interventions, such as sphincter continence management, swallow management, and early mobilization. Other important nursing interventions include prevention of pulmonary thromboembolism and antiplatelet therapy The entry of highly specialized nursing is of utmost importance to achieve high quality outcomes and involvement with the multidisciplinary team |
| Title: The nursing interventions to the user with stroke in Rehabilitation Authors: Frota Cavalcante, Tahissa; Lima Nemer, Amanda Peixoto; Moreira, Rafaella Pessoa; de Sousa Maciel Ferreira, José Erivelton; Methodology: Integrative review with qualitative approach. Year: 2018 | To present the knowledge produced about nursing interventions directed to people with stroke in rehabilitation | The interventions of nursing, were highlighted those of motor and functional rehabilitation. In the educational interventions, it was observed the education of the person about the disease and the caregiver Among the managerial interventions, it was highlighted the motor coordination |

According to Huijben-Schoenmakers et al. (2018) the increase in stimulation to motor and cognitive elderly, makes them have greater gains translated into motivation to want to do more and better in their rehabilitation process. Thus, for Cavalcante et al. (2018) and Frota et al. (2018), the education of the person also plays a crucial role in the success of the entire rehabilitation process. Another aspect worked on in the rehabilitation of the person with neurological alterations are ADL, which will always be influenced

in the environment the person finds after discharge. Asiri et al. (2014), states that the conditions of the home after discharge and the mental state, have effects on the results of home rehabilitation. ADL training both at home and in an inpatient setting must be guided (Rensink et al. 2009) to be effective, in which the RNS is responsible for creating opportunities for the practice of significant functional tasks outside of regular therapy sessions. RNS establishes an important role in the community with the person (McGinnes et al. 2010). Thus Theofanidis et al. (2016), confirms that RN plays an important role in achieving the results that people propose to achieve, providing a comprehensive, interactive and holistic approach for the person in rehabilitation (Frota et al. 2018).

Synthesis Chart

| Domain | Intervention |
|--------------------------|--|
| Physical | Motor and functional rehabilitation (Calvacante et al. 2018); Supervision of physiological functions (Calvacante et al. 2018); Assessing whether the consistency of the person's diet is adequate (Perry et al. 2013); Carrying out rehabilitation programs (Man 2010); ADL training (Rensink et al. 2009) and (Huijben-Schoenmakers et al. 2018); Mobilization (Rensink et al. 2009); Oral hygiene (Calvacante et al. 2018); Vigiar a deglutição (Theofanidis et al. 2016); Early mobilization (Theofanidis et al. 2016); |
| Cognitive and behavioral | Educate and instruct the person about the management of the disease (Calvacante et al. 2018); Promotion of self-care - Training and instruction of caregivers (Calvacante et al. 2018); Educational interventions, at the level of the education of the person for his health problem (Calvacante et al. 2018); Articulating with the multidisciplinary team (McGinnes et al. 2010); Educational programs (Loft et al. 2019); Verification of post discharge home conditions (Asiri et al. 2014); Planning the discharge of the person (Calvacante et al. 2018); |
| Emotional/psychosocial | - Motivational interview (Homem 2010); - Emotional care (Calvacante et al. 2018); |

2.2 Implications in Professional Practice

Based on the above, we can integrate the results showing that practices of Rehabilitation Nursing to the person with stroke plays a major role in the return to their home and their daily routine. RNS should seek to respond to the person's needs and refer them to existing resources in the community where they are inserted.

There is a need for Rehabilitation Nursing to mirror the work it does, through the publication of new studies, so that there is increasingly a practice based on scientific evidence.

2.3 Conclusion

RNS plays a fundamental role in promoting self-care to the patient with neurological changes from motor and functional rehabilitation, ADL training, education about the disease and promotion of self-care. It recommends necessary support products, supporting the support network of the elderly person, such as the family/career. The main conclusions drawn from this SLR relate to the role of RNS in rehabilitating the person with neurological changes and maintaining self-care, in people over 65 years of age. In order to be effective the rehabilitation process must have as its basic point the motivation, the knowledge of the difficulties the person has in his/her home for the realization of his/her ADL. Thus, interventions in the different domains (physical and cognitive), must cover all these components, so that the person can achieve the maximum functional capacity.

References

- Asiri, F.Y., Marchetti, G.F., Ellis, J.L., Otis, L., Sparto, P.J., Watzlaf, V., Whitney, S.L.: Predictors of functional and gait outcomes for persons poststroke undergoing home-based rehabilitation. J. Stroke Cerebrovasc. Dis. 23(7), 1856–1864 (2014)
- Gautério, D.P., Zortea, B., Costa Santos, S.S., da Silva Tarouco, B., Lopes, M.J., Fonseca, C.J.: Risk factors for new accidental falls in elderly patients at traumatology ambula-tory center. Investigacion y Educacion En Enfermeria 33(1), 35–43 (2015)
- De Man-van Ginkel, J. M., Gooskens, F., Schuurmans, M. J., Lindeman, E., Hafsteinsdottir, T. B., & Rehabilitation Guideline Stroke Working Group: A systematic review of therapeutic interventions for poststroke depression and the role of nurses. J. Clin. Nurs. 19(23–24), 3274–3290 (2010)
- Fortin, M.F.: Fundamentos e etapas de processo de investigação. Lusodidata, Loures (2009)
- Hoeman, S.P., Liszner, K., Alverzo, J.: Mobilidade Funcional nas Atividades da Vida Diária. In S. P. Hoeman (Ed.), Enfermagem de reabilitação. Prevenção, intervenção e resultados esperados. (4ª ed.). Loures: Lusodidacta (2011)
- Loft, M.I., Poulsen, I., Martinsen, B., Mathiesen, L.L., Iversen, H.K., Esbensen, B.A.: Strengthening nursing role and functions in stroke rehabilitation 24/7: a mixed-methods study assessing the feasibility and acceptability of an educational intervention programme. Nurs. Open 6(1), 162–174 (2019)
- Goes, M., Lopes, M.J., Oliveira, H., Fonseca, C., Marôco, J.: A nursing care intervention model for elderly people to ascertain general profiles of functionality and self care needs. Sci. Rep. 10, 1770 (2020). https://doi.org/10.1038/s41598-020-58596-1
- Martins, T., Rocha, M.: Autocuidado-Foco central para a prática de enfermagem. In: Morim, A., Gomes, B., Martins, C., Araújo, F., Bastos, F., Petronilho, F., Brito, M., Rocha, M., Lumini, M., Peixoto, M., Martins, M., Sousa, M., Moura, N., Machado, P., Freire, R., Soares, S., Martins, T. A pessoa dependente & o familiar cuidador (1ª edição), pp. 13–28. Porto: Escola Superior de Enfermagem do Porto (2016)
- McGinnes, A., Easton, S., Williams, J., Neville, J.: The role of the community stroke rehabilitation nurse. Br. J. Nurs. **19**(16), 1033–1038 (2010)
- Perry, L., Hamilton, S., Williams, J., Jones, S.: Nursing interventions for improving nutritional status and outcomes of stroke patients: descriptive reviews of processes and outcomes. Worldviews Evid. Based Nurs. **10**(1), 17–40 (2013)
- Fernandes, S., Silva, A., Barbas, L., Ferreira, R., Fonseca, C., Fernandes, M.A.: Theoretical contributions from orem to self-care in rehabilitation nursing (2020). https://doi.org/10.1007/978-3-030-41494-8_16

- Moguel, E., Berrocal, J., Murillo, J.M., García-Alonso, J., Mendes, D., Fonseca, C., Lopes, M.: Enriched elderly virtual profiles by means of a multidimensional integrated assessment platform. Procedia Comput. Sci. 138, 56–63 (2018). https://doi.org/10.1016/j.procs.2018. 10.009
- Jiménez, B.R., Caballero, D.C., González, B.M., García-Alonso, J., Fonseca, C., Juárez, L.M.: Los enfoques culturales en la alimentación de personas mayores rurales. Una necesidad multidimensional para la agenda del cuidado. Index de Enfermería, 28(3), 125 (2019)

Health Interventions to Support Caregivers of Elderly People



Technological Solutions and Informal Care Culture for the Elderly: An Intervention Proposal for Training Actions

L. López-Lago Ortiz¹(⊠) , S. Arroyo Chacón¹ , C. Cipriano Crespo² , J. Bonilla Bermejo¹ , and B. Muñoz González¹

 University of Extremadura, Cáceres, Spain luislopezlago@unex.es
 University of Castilla-La Mancha, Talavera de la Reina, Spain

Abstract. This article proposes an intervention from the field of social sciences to improve the knowledge of informal caregivers about care for the elderly. We analyze the social and cultural relationships that support the informal care culture in Spain. Some of the most important factors that are an obstacle to the professionalization of the sector are presented. The profiles of the informal caregivers are established, highlighting that most of them are women, whether they are family members or not. Furthermore, we find a prominent role of immigrant women in the non-professional care sector. We also analyzed the different relationships that groups related to informal care of the elderly have with technologies, highlighting mobile phones and instant messaging applications. With this result, we proposed the public policies of care for the elderly to contemplate training actions transmitted through the mobile phone and messaging applications.

Keywords: Informal care · Technology · Caregivers · Aging · Instant messaging

1 Introduction

Like other Western countries, Spain has experienced a series of demographic changes characterized by increased longevity and decreased fertility, which has led to significant aging of the population [1]. Other social processes have accompanied this phenomenon in recent decades, such as the incorporation of women into the labor market, transformations in the family model, and cultural changes in forms of leisure that have led to a decrease in intergenerational levels of coexistence in domestic space. All this has directly affected the socio-cultural processes related to the care of the elderly [18]. Despite these changes, there is a solid cultural base in Spain that encourages the care of the elderly to continue within the family, in what we have called "informal care culture" and will analyze next. Besides, in the 90s of the last century, a phenomenon took on particular importance in informal care, the incorporation of non-professional caregivers of immigrant origin [34].

The IMSERSO¹ estimates informal caregivers within the family nucleus that would reach 950,528 people, and the population that this group serves would be 1,226,181 people over 65 years old. This institution also recognizes the difficulty in estimating the number of informal workers who do not belong to the family nucleus, a fact that is further complicated in the case of people of foreign origin in an irregular situation [13].

In this scenario of informal care relationships, how can the qualifications of caregivers be improved to make their work as professional as possible? Can public policies be developed that contemplate the training of this group that is so difficult to access from the public administrations? Moreover, can technology help to transmit training content to the informal caregivers? In this article, we make a first approach to these issues.

2 Objectives and Methodology

This article is part of the Project "International Institute for Research and Innovation on Ageing (4IE+)". This is a cross-border project, which from a multidisciplinary perspective, aims to improve the quality of life of older people and their caregivers in Alentejo (Portugal) and Extremadura (Spain). Within this project, the line of research on Public Policies on Aging has one of its objectives to define cross-border policies for informal and family caregivers, detecting the needs for intervention and making proposals for creating innovative services [15]. In this spirit, this article aims, from the knowledge of the culture of informal care in Spain, to explore how technology could provide training and information to informal caregivers regarding the care of the elderly.

With this objective, we have reviewed the existing literature on care models to characterize the culture of care in Spain. We have also reviewed the scientific literature on informal caregivers to establish the different profiles most frequently found in this sector. Considering these results, we have contrasted the uses of technology that the groups we have detected as the main ones in the informal care sector have. Furthermore, with the evidence of that process, we proposed intervention for the training of informal caregivers through technologies.

3 The Culture of Informal Care for the Elderly in Spain and the Difficulties for the Professionalization

The persistence of informality and the difficulties for the professionalization of the care sector for the elderly in Spain have their origin in multiple factors. However, the cultural weight of the care model in which the family is the main provider has a fundamental influence [19]. There is general agreement in qualifying this model as "familist" or "familiarist" [4, 16, 24].

The "familist" model of care for the elderly in the Welfare States is particularly rooted in the societies of Southern Europe or the Mediterranean [20]. And although it is undeniable that the socio-cultural changes experienced by these societies in recent decades have transformed the forms and intensity of relationships within the family

¹ IMSERSO: Institute for the Elderly and Social Services, attached to the Ministry of Social Rights and 2030 Agenda, through the Secretary of State for Social Rights.

sphere, in the "familist" model, the nuclear family is the main social space providing care in cultural terms [8]. Thus, this model is projected in the social imaginary as a "must be" of care behaviors. Families have a sort of "moral obligation" concerning the care of the elderly. In this cultural pattern, the burden of care falls mainly on women [21], with a high emotional cost [10]. In short, the cultural norm imposes an ideal model of care in which the woman is responsible for providing care to the elderly. This makes it difficult to professionalize the care sector for the women, especially in environments with an intense weight of tradition, that naturally assume their role as caregivers within the family setting [19].

However, we must point out that we are talking about a "familist" cultural model with numerous socio-cultural changes and permanent transformation. Although its main ideas underlie the ideological basis of family relations and condition behaviors concerning the care, and therefore the professionalization of caregivers. Thereby, it should be noted that a phenomenon such as the incorporation of women into the labor market, the changes in the patterns of coexistence within the family nucleus or the extension of the long term care system have relativized the weight of the "care ideals" typical of the "familist" model. Thus, at present, in Spain, beyond the cultural imaginaries of care, we find that public resources for the elderly care are available in many formats (nursing homes, teleassistance, home care, etc.). There is also a wide range of services provided by companies and self-employed people and, to a lesser extent, by non-profit organizations, such as NGOs, associations, foundations, etc. [7, 23, 29]. Therefore, in cultural terms, the care of the elderly falls to the family. Still, when they cannot provide it or decides not to assume it, it is the public resources that occupy that place. Where the State does not reach, or if by its own decision or that of the family, the resources of the public administration are not chosen, there is a wide range of private provision of care. In this regard, it should be mentioned that older persons with mobility difficulties, chronic illnesses, or those over 80 years of age have become preferable to provide care in nursing homes [1, 23]. However, residential care resources present some problems in terms of access, such as the time required to allocate public places or the high prices of these resources in the private sphere. These factors lead to situations of informality, whether in family care or through informal caregivers. In the latter case, this is because professional care for the elderly with reduced mobility or the very old may have very high prices, even more so when the care is permanent, and broad social sectors cannot afford it without complementary help from the State.

The "familist" model of care in Spain is perpetuated by the need for solidarity within the family because institutional developments for long-term care do not cover the real needs of an increasingly aging population [8, 21, 30]. In this regard, several authors agree that the precarious implementation of the LAPAD², resulting from the economic crisis of 2008, had as one of its consequences in the continued informal employment of caregivers, especially women [14, 19, 30]. This Law brought substantial improvements to the situation of people who were engaged in long-term care of the elderly, by decisively assuming the responsibility of the State in this type of care [19], which should have led to a broad professional regulation in the sector. However, the severe funding problems

² Law 39/2006, of December 14, on the Promotion of Personal Autonomy and Care for Dependent Persons, also known as Long Term Care Law [11].

caused by the economic crisis of 2008 made it impossible to properly implement the benefits and services outlined in the Law [30], resulting a highly unstable sector with a high level of precariousness among its workers [5]. Thus, although there have been notable advances, thanks to the LAPAD, the institutional setting in charge of caring for the elderly is precarious, and this work will be carried out on numerous occasions by the family environment in conditions of informality [30].

This precarious institutional development fits into the Southern European models of the Welfare State. Moreno-Colom et al. [19] mention for the Spanish case that the services that attend to the care of the elderly take advantage of the "family culture of the country" for their design. These authors point out the "hybrid" nature of the Spanish model of care for dependent adults, with policy proposals that are in line with the social democratic tradition of the Welfare States, while their development has been the subject of liberal policies in which family and culture are the mainstays of care. On the contrary, García-Faroldi [9] places Spain entirely in the "familism" typical of the conservative and Mediterranean models, with a high degree of informality in contrast to the liberal and social democratic models based on professional care. In both positions, the "familistic" character of the culture of care for the elderly favors labor informality. Also, Spijker and Zueras [30] point to that the high rates of unemployment in Mediterranean societies as a factor in the persistence of informality in care, which on the one hand, reduces the capacity of families to hire formally, while at the same time allows these jobs to be carried out in the informal economy.

Other factors that contribute to the persistence of informality have to do with the characteristics of those who demand the services. For example, Cantarero et al. [2] emphasize that living in a rural area, being a woman, and having a low income is associated with the demand for informal care. Likewise, Spijker and Zueras [30] consider that age is a factor that influences the care, and that between the ages of 65 and 79, there is a preponderance of informality linked to the care of the couple within the home, with the help of social services, and formal care in the form of visits to support domestic and care tasks, but with very limited schedules, which is a complement to informal help. From the age of 80 and related to the difficulties for personal autonomy, we find increasingly important the resource of the nursing homes.

In summary, the informality of care for the elderly in Spain is based on two fundamental elements: on the one hand, cultural inertia and, on the other hand, the weakness of the welfare system. This leads to high levels of informality in care, which is, in most cases, falls to the family unit. There we find that women are the main care providers. These can be couples, mainly before the age of 80, daughters, even daughters-in-law. There is also a type of informality with caregivers outside the family unit who are women, in many cases of immigrant origin [3, 22]. In the following section, we will analyze how these groups of informal caregivers relate to technology.

4 Technologies and Informal Caregivers

The different groups that we have identified as main actors in informal care culture have a problematic relationship in the access to technologies. According to the Barometer of e-quality in Spain [17], digital inequalities exist between men and women. Especially in

labor and digital skills, where patterns of disadvantage are found for women, especially in the cohorts from 1951 to 1970. In the access of older groups, there is not so much difference between genders, but access is significantly unequal compared to younger groups. Similarly, González Oñate et al. [12] point out the low penetration of technologies in the population over 65. This specifically affects the group of female caregivers over 65 years of age, who carry out their care work within the family nucleus. At the same time, it should be noted that the device most used by the over-65 s in Spain is the mobile phone. In their work with elders, 81% of those surveyed stated that they used it regularly [12]. Therefore, it seems that if we want to develop training activities on care aimed at this collective, the cell phone may be the most appropriate tool because it is the most widespread.

Likewise, for informal caregivers from outside the family nucleus, access to technologies can pose various difficulties. It is often linked to economic precariousness and the obstacles to achieving adequate devices and a good connection to the network. It would also be interesting to know the levels of technological literacy of this collective, particularly heterogeneous. However, the high number of migrant women who participate in informal care in Spain [20, 22] gives us a clue as to how to investigate their relationship with technologies by establishing a relationship with the migrant group in general, since no data disaggregated by sex has been found in this regard. In Spain, immigrants are increasingly using new technologies, with the predominance of cell phones [31]. Riezu et al. [25] state that immigrants show levels of technologies use similar to those of the local population. These authors emphasize that using technologies in the immigrant collective increases its social capital, although with a risk, which is the binding social capital. That is, to strengthen relations with countries of origin and compatriots in the host society by reinforcing the isolation of communities by country, creating virtual communities that satisfy the needs of interaction. However, as Viruela [31] indicated, this creation of community through technology also contributes to the creation of solidarity networks that can positively impact the development and social inclusion of immigrant people, including the promotion of associationism. Thus, in the informal caregivers of immigrant origin, we can find communication circuits through technologies that can be used to disseminate training material for care work.

Finally, it may be interesting to note that women's use of technologies is linked to health-related activities, unlike men's, where uses related to electronic banking or online commerce predominate [17]. This differential use can facilitate disseminating content on care for the elderly in a sector as feminized as informal care.

5 Proposal of Intervention

Our proposal of intervention is directed to a collective that informally develops its work. This does not mean that we justify that situation. On the contrary, we believe that the ideal would be the professionalization of the sector and that the caregivers would have adequate working conditions, something that does not happen at present. However, considering the persistence of the phenomenon of informality in the care of the elderly in Spain, we believe that there are actions that can be taken by the public administration to improve the health and long-term training of caregivers in the informal sector.

From the analysis of the scientific literature we find some starting points that can be useful for public administrations to develop strategies to transmit training contents in care to the different groups of informal caregivers. For example, mobile phones are the most appropriate technological tool because of its wide dissemination among the groups involved. In this sense, it should be noted that there is a whole line of research and development of technologies, the m-health, which is based on mobile devices in health, care, and welfare of people [27]. Specifically, about aging we can highlight the work of the anthropologist Daniel Miller and the research group Anthropology of Smartphones and Smart Ageing. And in our closer environment, we point out the line of research of the 4 IE project for the development of an application for mobile devices for food and nutrition studies (Feedelio), especially interesting to address the relationship of these issues with aging and loneliness [26]

Likewise, instant messaging applications can be the most appropriate means of disseminating such content, given its enormous expansion among mobile phone users, with Whatsapp being the preferred one in Spain³. Marilia Duque [6] states that Whatsapp is an exceptionally user-friendly application, with a simple design that makes it inclusive of people who are unfamiliar with technologies, such as a large sector of older caregivers. It also highlights a greater probability of attending health advice from an application that users know and use habitually than from new applications that have to be installed and do not know how they work. These advantages of Whatsapp as an information disseminator have been used by the World Health Organization, which has developed a Whatsapp alert service on COVID-19 with the potential to reach 2 billion people with accurate information about the pandemic [33]. An excellent example to consider for Spanish public administrations to disseminate care information.

For informal caregivers of foreign origin, this instant messaging service offers two obvious advantages. The first is the availability in more than 60 languages on Android and 40 on iPhone [32]. The second is the possibility of organizing groups by users, which is very functional to the organization in groups by nationality characteristic of immigrant socialization networks and facilitates disseminating messages.

6 Conclusions

From these reflections, our proposal for those responsible for care policies, if they want to send training material on the subject to informal caregivers, is creating specific content to be disseminated through the WhatsApp. The contents can also be messages, documents, and graphics, but the most didactic would be short videos that are adapted pedagogically on attention issues and are suitable for people without professional training. It can address nutrition, communication, manual mobilization techniques, well-being, or therapeutic adherence, among many others. Alarm systems can also be opened to disprove rumors or false news that may affect the care of the elderly, as is the case with the current COVID-19 campaign. Finally, we propose an ethnographic investigation that provides us with more detail about the universe of relationships between informal caregivers and

³ According to the CNMC in 2019, approximately 9 out of 10 Spaniards with a cell phone have a Smartphone, with WhatsApp messaging application being the most used, with a 93% of users [28].

their interaction with technologies to develop an intervention plan that will guide public administrations when using technologies to improve the training of informal caregivers.

Acknowledgment. This work was supported by the 4IE+ project (0499-4 IE PLUS 4 E) funded by the Interreg V-A España-Portugal (POCTEP) 2014–2020 program.

References

- Abellan, A., Perez, J., Pujol, R., Sundstrom, G., Jegermalm, M., Malmberg, B.: Partner care, gender equality, and ageing in Spain and Sweden. Int. J. Ageing Later Life 11, 69–89 (2017). https://doi.org/10.3384/ijal.1652-8670.16-305
- 2. Prieto, D.C., Sáez, M.P., Rodríguez, B.S.: Differences in the provision of formal and informal care services after the implementation of the dependency act: the Spanish case. Papeles Trab del Inst Estud Fisc. **5**, 1–36 (2019)
- Casado-Mejía, R., Ruiz-Arias, E., Solano-Parés, A.: El cuidado familiar prestado por mujeres inmigrantes y su repercusión en la calidad del cuidado y en la salud. Gac. Sanit. 26, 547–553 (2012). https://doi.org/10.1016/j.gaceta.2012.01.012
- Casanova, G., Lamura, G., Principi, A.: Valuing and integrating informal care as a core component of long-term care for older people: a comparison of recent developments in Italy and Spain. J. Aging Soc. Policy 29, 201–217 (2017). https://doi.org/10.1080/08959420.2016. 1236640
- Deusdad, B.: COVID-19 and nursing Homes' crisis in Spain: ageism and scarcity of resources.
 Res. Ageing Soc. Policy 8, 142–168 (2020). https://doi.org/10.17583/rasp.2020.5598
- Duque, M.: Learning from WhatsApp Best Practices for Health Learning from WhatsApp Best Practices for Health. Communication Protocols for Hospitals and Medical Clinics. ASSA, London (2020)
- Durán Bernardino, M.: La regulación de la dependencia en el derecho interno de la Unión Europea. Modelos de protección ciudadana para los residentes en la Unión Europea. Rev derecho Migr y Extranj. 38, 317–337 (2015)
- 8. Fernández-Alonso, M., Ortega, M.: Gender and informal social support in Spanish culture. Res. Ageing Soc. Policy 6, 118–146 (2018). https://doi.org/10.4471/rasp.2018.3212
- García-Faroldi, L.: Welfare states and social support: an international comparison. Soc. Indic. Res. 121, 697–722 (2015). https://doi.org/10.1007/s11205-014-0671-1
- Perales, N.G., Jiménez, B.R., Caballero, D.C., Juárez, L.M.: Informal cares and caregivers in rural elderly: emotional costs in public health policies. In: Handbook of Research on Health Systems and Organizations for an Aging Society. IGI Global, pp. 263–273 (2019)
- de España, G.: Ley 39/2006, de 14 de diciembre, de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia. Boletín Oficial del Estado, España 299 (2006)
- González Oñate, C., Fanjul Peyró, C., Cabezuelo Lorenzo, F.: Uso, consumo y conocimiento de las nuevas tecnologías en personas mayores en Francia, Reino Unido y España. Comunicar XXIII. 23, 19–28 (2015). https://doi.org/10.3916/c45-2015-02
- Instituto de Mayores y Servicios Sociales (IMSERSO) Cuidados a las Personas Mayores en los Hogares Españoles. El entorno familiar. Ministerio de Trabajo y Asuntos Sociales (2005)
- De La Fuente, Y.M., Sotomayor, E.M., Martín, M.C.: Vulnerabilidad sobrevenida en personas en situación de dependencia en España. Scr NOVA Rev ELECTRÓNICA Geogr Y CIENCIAS Soc XX, 1–29 (2016)

- 15. López-Lago, O., Jiménez, B.R., Fonseca, C., García Alonso, J., Lopes, M., Murillo, J.M.: Instituto Internacional de Investigación e Innovación del Envejecimiento (4 IE): Experiencia de un proyecto de investigación interdisciplinar entre España y Portugal. Iberografías
- 16. Lorenzo Carrascosa, L.: Ageing population and family support in Spain. J. Comp. Fam. Stud. **46**, 499–516 (2015). https://doi.org/10.3138/jcfs.46.4.499
- Martínez, J.L.: Nuestras vidas digitales. Barómetro de e-igualdad de género en España. Ministerio de Igualdad. Ministerio de Asuntos Económicos y Transformación Digital, Madrid (2020)
- Martinez Riera, J.R.: Cuidados informales en España. Problema de desigualdad. Rev Adm Sanit Siglo XXI 1, 275–288 (2003)
- Moreno-Colom, S., Recio Caceres, C., Torns Martín, T., Borràs Català, V.: Long-term care in Spain: difficulties in professionalizing services. J. Women Aging 29, 200–215 (2017). https://doi.org/10.1080/08952841.2015.1125699
- Moreno Domínguez, A.: El familiarismo cultural en los Estados del Bienestar del Sur de Europa: transformaciones de las relaciones entre lo público y lo privado. Rev. Sist. 182, 200–215 (2004)
- Di Novi, C., Jacobs, R., Migheli, M.: The quality of life of female informal caregivers: from Scandinavia to the Mediterranean Sea. Eur. J. Popul. 31, 309–333 (2015). https://doi.org/10. 1007/s10680-014-9336-7
- 22. Oliva Salomé, P.L., Llopis, L.O., Golart, P.P.: Análisis de género desde la enfermería en cuidadoras inmigrantes de personas mayores. ENE Rev. Enfermería 11 (2017)
- Osorio Bayter, L., Salinas Ramos, F., Cajigas Romero, M.: Responsabilidad social y bienestar de la persona mayor. CIRIEC-España, Rev Econ pública, Soc y Coop, 223–252 (2018). https:// doi.org/10.7203/ciriece.92.8959
- Recio Cáceres, C., Moreno-Colom, S., Borràs Català, V., Torns Martín, T.: La profesionalización del sector de los cuidados. Zerbitzuan, 179–194 (2015). https://doi.org/10.5569/1134-7147.60.12
- 25. Riezu, X., Oiarzabal, P., Aretxebala, M.E., Maiztegui, C.: El uso de las TIC por parte de los migrantes y sus consecuencias para el capital social. In: Crisis y cambio. Propuestas desde la Sociología: actas del XI Congreso Español de Sociología. Universidad Complutense de Madrid, pp. 1370–1378 (2014)
- Jimémez, B.R., Jesús-Azabal, M., Caballero, D.C., Beatriz. M.G., Juárez, L.M.: Technology for anthropological research. feedelio: an application for food and nutrition studies. in: gerontechnology. IWoG 2019. Communications in Computer and Information Science. Springer (2019)
- 27. Rodríguez-Pulido, F., Rodríguez-Quintero, L., Rodríguez-Pulido, J., Rodríguez-García, Á.: Approach to the use of technologies in health systems: ehealth and mhealth. Rev. Fac. Med. **67**, 457–462 (2019). https://doi.org/10.15446/revfacmed.v67n4.68850
- 28. Samaniego Sánchez, R.: Panel Hogares CNMC: Los españoles llaman desde el móvil y (queman) el Whatsapp. In: Blog la Com. Nac. los Mercados y la Competencia (2019). https://blog.cnmc.es/2019/10/31/los-espanoles-llaman-desde-el-movil-y-queman-el-whatsapp-panel-hogares-cnmc/
- de Souza Minayo, M.C.: The imperative of caring for the dependent elderly person. Cienc e Saude Coletiva 24, 247–252 (2019). https://doi.org/10.1590/1413-81232018241.29912018
- Spijker, J., Zueras, P.: Old-age care provision in Spain in the context of a new system of long-term care and a lingering economic crisis. J. Popul. Ageing 13, 41–62 (2020). https:// doi.org/10.1007/s12062-018-9232-8
- 31. Viruela, R.: Migración y nuevas tecnologías de la información y la comunicación: inmigrantes rumanos en España. Migraciones **21**, 259–290 (2007)
- 32. WhatsApp Cómo cambiar el idioma de WhatsApp. https://faq.whatsapp.com/general/account-and-profile/how-to-change-whatsapps-language/?lang=es. Accessed 13 Sept 2020

- 33. World Health Organization (WHO) WHO Health Alert brings COVID-19 facts to billions via WhatsApp (2020). In: World Health Organization Newsroom (2020). https://www.who.int/news-room/feature-stories/detail/who-health-alert-brings-covid-19-facts-to-billions-via-whatsapp. Accessed 30 Mar 2020
- 34. Zabalegui, A., Juandó Prats, C., Sáenz de Ormijana, A., Ramírez, A.M., Pulpón, A., López, L., Bover, A., Cabrera, E., Corrales, E., Gallart, A., González, M.A., Gual, M.P., Izquierdo, M.D., Díaz, M.: Los ciudadores informales en España: perfil y cuidados prestados. Rol Enfermería 30, 33–38 (2007)



Components of Care Models that Influence Functionality in People Over 65 in the Context of Long-Term Care: Integrative Literature Review

Bruno Morgado^{1(⊠)}, César Fonseca^{1,2}, Manuel Lopes^{1,2}, and Lara Pinho^{1,2}

University of Évora, Évora, Portugal
 Comprehensive Health Research Centre, Évora, Portugal

Abstract. Introduction: We verified the existence of a greater number of people over 65 years of age, with associated multimorbidity and in need of care. Cares that in previous times were provided by the extended family, at home. Nowadays, with the need for women to enter the labor market and the transition to nuclear families, this assistance becomes complicated, which is why institutionalization has been increasingly used.

Institutionalization, in turn, often leads to the breakdown of social relationships among the elderly and, consecutively, to the loss of their own identity.

Objective: To identify the components of care models that influence functionality in the context of long-term care.

Methodology: Integrative Review of the Literature, for which research was done at EBSCO selecting the databases Cinahl, Medline.

Results: We selected 10 articles from which resulted, two systematic reviews of the literature; two cross-sectional studies; Two Descriptive Studies; a cross-sectional cohort study; a randomized controlled trial and an Opinion Article.

Conclusions: Identify essentially three models of care, being a model focused on self-care with a major focus on the person with impaired functionality, the chronic disease management model, more associated with the elderly with comorbidities, but with the ability to develop their daily living activities and the economic model in order to develop the improvement of the economic model of the health system itself. Among these various components, we can find both process and outcome indicators that first influence the quality of care itself and the functionality of people in the context of long-term care.

Implication in Professional Practice: With the applicability of these components, comes the permission to apply and structure care models and as a thread of all care process, such as the structuring of individual care plans, involving the patient himself., and abolishing the current working method that currently focuses much on the task method.

Keywords: Care model · Nursing · Self-care · Elderly · Long-term care

1 Introduction

If we look at the path of humanity, it is easily said that today we live moments of glory when it comes to the longevity that a human being can live. We overcome infections and epidemics; we develop economically. However, the increase in average life expectancy cannot continue to be a mere trophy of health gains, but as a new challenge, and perhaps even a concern.

At the heart of this new challenge, I point out two phenomena that must be considered, the profound changes resulting from the demographic and epidemiological level, where we observe older populations with multimorbidity's.

Starting with the first, this demographic change is explained essentially by three subphenomena, namely the decrease in fertility rates, the isolated event of the increase in average life expectancy and migratory movements. According to data from PORDATA, fertility in Portugal decreased from 957 children for every 1000 women in 1961, to 379 children for every 1000 women in 2018, so soon we can see with these data a sharp decrease in live births in the last 50 years. These data, which in intersection with the increase in average life expectancy, which in Portugal, stood at 81.6 years in 2017 according to the latest Health Profile Report in Portugal, indicate a decrease in the population replacement rate, which at this moment in Portugal it stands at 2.1. Which is a cause for alarm because if we weigh this value, these two children serve to replace the parents and only those 0.1 are left to replace an individual who looks like before reaching reproductive age, so we conclude that Portugal is at the threshold of the population replacement rate and with a tendency to decrease, thus becoming an aging population. Currently, about 21.1% of the Portuguese population is over 65 years old, above the rest of the European Union, which stands at 19.4%. Accompanying this demographic change, we observe another phenomenon that is directly proportional, epidemiological changes.

To explain this epidemiological transition, we can indicate three key changes, in the health panorama, the replacement of communicable diseases by non-communicable diseases; the displacement of the morbidity and mortality burden from the younger groups to the older groups; and the transformation of a situation in which mortality predominates, for which morbidity dominates. Therefore, in the top 10 of the pathologies that kill the most in Portugal, we find in the first 5, cardiovascular diseases, such as stroke and ischemic heart disease, followed by pneumonia, diabetes, lung cancer and colorectal cancer. Therefore, within this panorama we find a very important change. With the increase in population aging, we observed an increase in diseases or chronic conditions, which will affect the quality of years that individuals have acquired with the increase in average Life Expectancy. In 2017, the 65-year-old Portuguese expected to live another 20 years. However, about 13 of those 20 years would probably be lived with some form of disability. Therefore, a change in the focus of care is necessary. Once the contagious infectious diseases are overcome, the living conditions of the young populations are improved, the need to care for the aging populations is raised, the need for self-care is raised [1].

We have now reached an era in which educating is fundamental before aging. Educate about the risk factors that we face daily such as food, tobacco and alcohol. Teach about the best lifestyle habits such as balanced diet and physical exercise. And later, after reaching the age stage of elderly people over 65 years old, the model that best influences the person's self-care should reign. Understanding care models not as descriptions of reality, but as instruments to reflect the practice. discerning its usefulness for guiding a quality care provision, these should focus on the self-care of the individual subject to care. Self-care that must meet principles such as individual aspects (self-confidence, empowerment, autonomy, personal responsibility, self-efficiency), as well as the community (community participation, involvement and empowerment).

As such, we identify the need to identify the components corresponding to the care models that influence functionality in people over 65 years of age in the context of long-term care.

2 Concepts

As the main concepts to be defined for the framing of this study, it is relevant to address the models of care, the self-care and the long-term care. The care models represent an important structure of knowledge in Nursing, translating, guiding and supporting care. Models whose focus should be on self-care, which, according to Orem, is a human regulatory function that individuals have to perform for themselves, or that someone else performs for them, to preserve life, health, development and well-being, being learned and executed deliberately and continuously according to the needs of individuals. This view is consistent with the growing need for long-term care, being included in a mix of health care and social support belonging to different sectors, in which the border between these two components of care is difficult to discern.

3 Methodology

After defining the theme to be addressed, the formulation of the problem was built through a starting question based on the PICO methodology. And, FINER criteria (Feasibility, Interesting, Novel, Ethical, Relevant) were also considered, in order to develop a good research question. That is, to be viable, interesting, original, respect ethical principles and be relevant to nursing practice. Thus, the following starting question was posed: "What are the components of care models (Intervention) that influence functionality (Outcomes) in people aged 65 and over (Population) in a context of long-term care (Context)?".

In order to respond to the objectives outlined for this integrative literature review, the descriptors that guided the research were (Aging OR Elderly OR Frail elderly) AND (long term care OR nursing home OR homes for the aged) AND (self care OR self management OR self care deficit), obtaining 486 articles in the MEDLINE database and

358 articles in CINAHL. After a temporal criterion between the dates from 01/01/2014 to 2019/12/31, where 156 articles were obtained in the MEDLINE database and 127 in CINAHL, where after the Full Text criterion, 121 articles were obtained in the MEDLINE database and CINAHL 96 articles. Resulting in total after searching 217 articles.

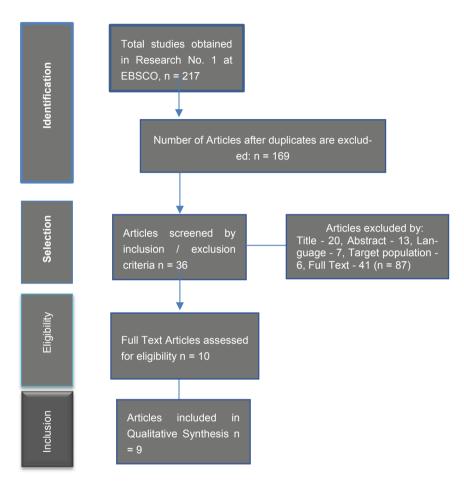


Fig. 1. Flow diagram describing the process followed in performing the ILR

4 Results

See Table 1.

Table 1. Summary table with articles obtained by research.

| Author/Level of evidence | Aims | Results | |
|--|---|--|--|
| Author: Petronilho, F., Pereira, C., Magalhães, A., Carvalho, A., Oliveira, J., Castro, P., Machado, M. (2017) Methodology: Descriptive and exploratory study Level of evidence: VI Participants: 891 dependent people | Assess the potential for rebuilding autonomy, and the evolution of commitment in bodily processes and dependence on self-care of dependent people admitted to the National Care Network. [2] | The potential for rebuilding autonomy is between low to moderate. There was a positive evolution in the commitment in the bodily processes and in the level of dependence in self-care. Greater potential for rebuilding autonomy is associated with less commitment to bodily processes and greater independence. [2] | |
| Author: Metzelthin, S. F., Verbakel, E., Veenstra, M. Y., Exel, J. Van, Ambergen, A. W., & Kempen, G. I. J. M. (2017) Methodology: cross-sectional study Level of evidence: V Participants: 5197 Dutch dyads | 1) compare characteristics of informal caregivers and recipients of care and results of caregivers - at home and at the ILTC; 2) to study the association between these characteristics and the caregiver's positive and negative results; 3) investigate the moderating effect of the configuration (at home vs. ILTC) on these associations [3] | Informal care does not stop with admission to ILTC (institutionalized long-term care) facilities. Both configurations need a care delivery policy, which is 1-adapted to the individual characteristics of the recipients and caregivers; 2- pays attention to the identified risk groups; and 3- reduces negative caregiver results and emphasizes positive results at the same time. [3] | |
| Author: Bozkurt, Ü. Yılmaz, M. (2016) Methodology: descriptive study Level of evidence: VI Participants: 81 elderly people living at home | Determine the functional independence and quality of life of the elderly aged 65 or over in the elderly in the nursing home [4] | The results of the study show that support for physical functions in the elderly can be important in increasing quality of life and functional independence. Also, a holistic view of the need for cognitive and emotional support is just as important as it is for solving health problems. [4] | |

(continued)

 Table 1. (continued)

| Author/Level of evidence | Aims | Doculto | |
|---|---|--|--|
| Author/Level of evidence Author: Thingstad, P., Taraldsen, K., Saltvedt, I., Sletvold, O., & Vereijken, B. (2016) Methodology: Randomized and Controlled Study Level of evidence: I Participants: 397 elderly people with hip fractures | Aims To evaluate the long-term effect of Integrated Geriatric Care (CGC) preand post-surgery on the ability to walk, self-reported mobility and gait characteristics in patients with hip fractures. [5] | Results The pre- and postoperative CGC showed an effect on gait up to 1 year after hip fracture. These findings include pointing out the importance of targeting the vulnerability of these patients early in order to avoid long-term decline in gait. As currently, the majority of patients with hip fractures are | |
| | | treated in orthopedic wards with a greater focus on fracture than fragility, these results are important to inform new models for the treatment of hip fractures. [5] | |
| Author: Pego, M. Henriques, M. (2016) Methodology: Literature review Level of evidence: I | Identify, in the literature, the fundamental factors for the promotion of the elderly person's self-care, in the home context, in activities of daily living [6] | We conclude that there is a need to understand the phenomenon of inability to manage activities of daily living at its various levels: intrapersonal, interpersonal and contextual [6] | |
| Author: Murphy, C. M., Whelan, B. J., & Normand, C. (2015) Methodology: Cross-Sectional Study Level of evidence: IV Participants: 3507 seniors over 65 | The aim of this study was to provide a population-based estimate of the use of publicly funded formal home care by elderly people in Ireland and to identify the main characteristics of those using formal home care [7] | This study found that a very small proportion of the elderly use formal home care in Ireland. The three most important factors in the use of home care were difficulties with an IADL, old age and living alone. Although difficulty with an IADL is a predictor of care, almost half of all formal home care provided by the state was provided to individuals without difficulty with ADL or IADL. [7] | |

(continued)

 Table 1. (continued)

| Author/Level of evidence | Aims | Results |
|---|--|---|
| Author: Wallack, E. M., Wiseman, H. D., & Ploughman, M. (2016) Methodology: Cross-sectional study Level of evidence: IV Participants: 683 people over 50 | The aim of this study was to determine which factors contributed most to healthy aging with multiple sclerosis (MS) from the perspective of a large sample of elderly people with MS. [8] | With this study, the authors concluded that social connections, attitudes and life perspectives, lifestyle choices and habits, health system, spirituality and religion, independence and finances. These themes had two common characteristics: multidimensionality and interdependence. Implications. Learning from the experiences of older people with MS can help young people and middle-aged people with MS plan to grow old in their own homes and communities. [8] |
| Author: Chang, H., Yang, L., & Lu, K. (2018) Methodology: Descriptive correlational study Level of evidence: VI Participants: 194 elderly people undergoing maintenance hemodialysis | To evaluate the importance of high Resilience and social support in the treatment of depression in elderly patients undergoing maintenance hemodialysis (HD). [9] | The severity of the symptoms of the disease and the ADLs were the main determinants of depressive symptoms. High resilience could alleviate depressive symptoms in elderly patients undergoing HD. [9] |
| Author: Zhu, H. (2015) Methodology: Opinion article Level of evidence: VII Participants: 3 most recent waves of China's Healthy Longevity research | Using Andersen's behavioral model of using health services, this study examines the roles of predisposing factors (demographic), facilitating factors (resources) and need (e.g., level of illness) in long-term care among older elderly people. from China. [10] | Given that the availability of informal caregivers - mainly family members - is in decline, it is crucial to provide financial assistance to elders, increase formal services, such as paid domestic services and community care services, and reduce the burden on family caregivers to reduce unmet needs of China's older elders. [10] |

5 Discussion

The exponential aging of the population, asserts itself as evidence for placing challenges to society, demanding innovative responses, both in the model of organization of health care and social support, and in the model of organization of families, with centrality in effective articulation between professional support, improving the health condition of individuals and the appropriate role of family members in the process of taking care [2]. Since more than a decade ago, we have seen the increase and development of the National Network of Integrated Continuous Care (RNCCI), in which its main objectives, taking social and political importance, are self-care as the most relevant dimension. However, there are no indicators that would make it possible to assess the impact of care provided at RNCCI, on the health condition of dependent people and their families. Through the results they obtained, we can see that dependent people admitted to ECCI and UMDR, present similar results. It can be concluded that care provided at home is economically more sustainable compared to care provided in the context of hospitalization and that it is the preferred option of families, assuming institutionalization as a resource in the absence or scarcity of formal support. Thus, there were health gains for dependent people during the follow-up period, namely, improvement in the commitment to body processes and improvement in the level of dependency in self-care [2].

Another study, carried out in the Netherlands, focused on informal care, more specifically on informal caregivers. It showed that home care recipients were younger and in better health than caregivers at ILTC (Institutionalized long-term care). [3] With the data they collected showed that, although the subjective burden increased with the age of home care recipients, it decreased with age at the ILTC. This is due to the fact that informal caregivers at ILTC get more support from professional caregivers, who take on the most challenging, intensive and essential care tasks, while informal caregivers provide voluntary, less intensive and less cumbersome help leading authors to state that professionals should be made more aware of the risks of informal caregivers and provide tools and information to support and adequately involve them in the provision of care, with involvement, education and support being highly important so that they can persevere in their task of caregivers [3].

Two Turkish authors focusing their attention on quality of life and self-care related to population aging carried out a study in which they studied 81 elderly people in a home, where the main objective was to determine the degree of functional independence and the quality of life of individuals aged 65 or over living in a nursing home. [4] They concluded that supporting physical functions is important to promote quality of life and functional independence, however, these authors also point out based on the results that cognitive and emotional support is also extremely important for achieving the same goals. Thus, recommending the implementation of approaches to improve the cognitive functionality of the elderly in order to achieve a higher quality of life and functional independence [4].

Assessing the long-term effect of pre- and post-surgical comprehensive geriatric care (CGC) on the ability to walk, self-reported mobility and gait characteristics in patients with hip fractures. They showed that the patients who received the CGC had a higher gait speed, less asymmetry, better control and a more efficient gait pattern, also reporting better mobility in the 4 and 12 months following the fracture. [5] They concluded that the real importance in an orthopedic ward should be to reach the vulnerability or fragility of patients at an early stage to avoid long-term decline in gait, and not focus only on the fracture itself [5].

Focusing on the lack of integrated responses that focus on the multidimensionality of the human person, combining the health and social vision in one, thus being able to complete interventions so that the result is the maintenance of the elderly person in their home for as long as possible with the greatest possible physical autonomy, we can also conclude that there are three major groups of factors that influence the promotion of the elderly person's self-care, intrapersonal factors such as satisfaction with life, self-esteem and functional capacity, interpersonal factors, such as, understanding and valuing the needs of the people cared for by professionals, shared vision, clear goals and commitment, open communication, and contextual factors, such as adequate material and human resources, shared procedures and coherent work culture, shared records and communication systems, effective leadership and service management and multiprofessional training [6].

Another look at publicly funded formal home care services in Ireland in order to provide a population estimate of the use of formal home care by elderly Irish adults and to identify the main characteristics of those using home care, obtains the characteristics of the elderly who use home care are those who have self-reported difficulty with an AIVD, old age and living alone [7].

As well as the factors that most contributed to healthy aging in elderly people with multiple sclerosis identified two levels of factors: primary factors, most important for elderly people with multiple sclerosis, which include social connections, attitudes and life perspectives, choices and habits of lifestyle, and secondary factors that are less prominently displayed in the model, and include effective and affordable health care, spirituality and religion, independence and financial flexibility. [8] and a capacity for self-reliance would have a positive influence on the effects of the severity of symptoms of depression, while social support has not been shown to produce the same effect [9].

Finally, a Chinese study concentrated its study by examining the roles of predisposing factors, facilitating factors and the need for long-term care among China's elderly people. [10] Evidence that the significant factors for rural and urban residents were economic status, someone who is not a family member as the primary caregiver, the willingness of caregivers to provide care, timely medication, self-rated health and self-rated satisfaction of life [10] (Table 2).

| Model | Component | |
|---|--|--|
| Self-Care [2] | Inter and transdisciplinary team management [2] Definition of Admission Criteria [2] Improvement of Functional Aspects [2] Individual care plan development [3, 5] Individualization of care [3] Improvement of body functions [4] Improvement of higher-level cognitive functions [4] Support emotional functions [4] Support in vulnerability [5] Increased IM Strength [5] Self-management of activities of daily living [6, 7] | |
| - Care Paths [2] - Functional Independence [2, 4, 9] - Increased quality of life [4] - Management of chronic disease co-morbidities - Management of AIVDS [7] - Strengthening neighborhood networks [7, 10] | | |
| Economic | - Improvement of economic results [3] - Improving context and accessibility [6, 10] | |

Table 2. Results obtained after analyzing selected articles.

6 Conclusion

As we can see through the different studies selected for this systematic review, they essentially identify three models of care, namely a model focused on self-care with a major focus on the person with reduced functionality, the chronic disease management model, more associated with the person elderly with co-morbidities, but with the capacity to develop their daily life activities and the economic model in order to develop the improvement of the economic model of the health system itself.

Due to the demographic and epidemiological changes that we observed in the world population, it is perpetual to state that the type of patient who will most seek care, will be characterized by the elderly patient with multimorbidity's. The need arises for long-term care (LTC) based on the Self-care model, which focuses on improving functional aspects, developing the individual care plan, individualizing care, improving body functions, improving cognitive functions higher level, to support emotional functions, to support the most vulnerable.

In Portugal we observe prolonged care, in the so-called Residential Structures for the elderly, or commonly referred to as homes. ERPIs were designed to respond to social needs and quickly, after opening, were filled in by sick, seriously ill elderly. What we have today is a network of homes for social situations full of patients with no capacity in the health field to respond to problems. Observing medication administration by untrained personnel, lack of stimulating activity for the elderly, among other things. Legislation itself is based on a social model when care and needs are health. Therefore,

home medical care and the determination of 1 nurse for every twenty residents is not mandatory, however, without mentioning how many nursing hours must be performed.

We see ERPIs as authentic deposits for the elderly. It is necessary to invest in a care model that guides the practice, and which translates into a set of operations that promote continuity of care and the improvement of the functional and health status of institutionalized elderly people. Like the Self Care model.

Implications in Professional Practice

In view of what was found and exposed, we can say that some of the structures currently used in Portugal in the context of long-term care, do not include many of these components of care models, or even a model itself. I speak of institutions such as ERPIs, residential structures for the elderly and CDs, day care.

With the applicability of these components, there is the permission to apply and structure care models and as a guiding thread of all the care process, such as the structuring of individual care plans, involving the patient himself, and abolishing the current working method that currently focuses a lot on the task method.

Then, there is a need for more studies about the needs and conditions of care in this type of health institutions, in order to allow, with greater accuracy, the development of care models for them.

References

- 1. OECD. Health profile report in Portugal (2019)
- Petronilho, F., Pereira, C., Magalhães, A., Carvalho, D., Oliveira, J., Castro, P., Machado, M.: Evolution of self-care dependent individuals admitted to the National Network for Integrated Continuous Care, 39–48 (2017). https://doi.org/10.12707/RIV17027
- Metzelthin, S.F., Verbakel, E., Veenstra, M.Y., Van Exel, J., Ambergen, A.W., Kempen, G.I.J.M.: Positive and negative outcomes of informal caregiving at home and in institutionalised long-term care: a cross-sectional study. BMC Geriatr. 17(1), 1–11 (2017). https://doi. org/10.1186/s12877-017-0620-3
- 4. Bozkurt, Ü.: The determination of functional independence and quality of life of older adults in a nursing home. Int. J. Caring Sci. **9**(1), 198–211 (2016). www.internationaljournalofcarin gsciences.org
- Thingstad, P., Taraldsen, K., Saltvedt, I., Sletvold, O., Vereijken, B.: The long-term effect of comprehensive geriatric care on gait after hip fracture: the Trondheim Hip Fracture Trial — a randomised controlled trial. Osteoporos. Int. 27(3), 933–942 (2016). https://doi.org/10.1007/ s00198-015-3313-9
- Pego, M., Henriques, M.: Uma abordagem socioecológica ao problema do autocuidado nas ativida-des de vida diária das pessoas idosas em contexto domiciliário a socioecological approach to self-care issues related to activities of daily living of home-dwelling older people, 20, 16–27 (2016)
- Murphy, C.M., Whelan, B.J., Normand, C.: Formal home-care utilisation by older adults in Ireland: evidence from the Irish Longitudinal Study on Ageing (TILDA). Health Soc. Care Community 23, 408–418 (2015). https://doi.org/10.1111/hsc.12157
- 8. Wallack, E.M., Wiseman, H.D., Ploughman, M.: Healthy aging from the perspectives of 683 older people with multiple sclerosis. Multiple Sclerosis Int. **2016**, Article ID 1845720, 10 (2016). http://dx.doi.org/10.1155/2016/1845720

- 9. Chang, H., Yang, L., Lu, K.: Role of resilience and social support in alleviating depression in patients receiving maintenance hemodialysis. Ther. Clin. Risk Manage. **14**, 441–452 (2018). https://www.dovepress.com/ by 202.164.43.126 on 14-Apr-2018
- 10. Zhu, H.: Unmet needs in long-term care and their associated factors among the oldest old in China. BMC Geriatr. **15**(1), 1–12 (2015). https://doi.org/10.1186/s12877-015-0045-9



Transitional Care in Times of COVID 19: Opportunities for e-Health Interventions

Cristina Lavareda Baixinho^{1,2(\omega)} . Luís Sousa³ . and Óscar Ramos Ferreira¹

Abstract. People admitted to hospitals are vulnerable to experiencing care continuity loss when there are alterations in their health condition or when they are transferred between care institutions. This is a challenge for health systems to guarantee the execution of a set of actions whose objective is ensuring care continuity between different care levels. This studied aimed to understand the influence of the current pandemic on the continuity of care between the hospital and the community. The participants were five nurses, who gave free and informed consent to participate. Content analysis was the technique used in data analysis. Data anonymity and confidentiality were ensured, and the data was coded without identifying customers and their families. An ethic commission authorized the study. The findings shows that transitional care has become a missing care during the pandemic, due to the need to reorganize the services and teams to provide care to the COVID patients and by the limitations of visits to hospitalized elderly. Professionals note that not only the discharge preparation and caregiver training were affected, but also communication with primary health care became more difficult, with clear defragmentation in the transitional care. In the professionals' discourse, the need to rethink ways of ensuring continuity of care emerges, with e-health interventions being seen as an opportunity to ensure the safety of the elderly and their caregivers, the articulation with colleagues in primary health care and continuity of rehabilitation care. Despite the limitations of the study, several recommendations for the clinic and investigation emerge.

Keywords: Aged · Transitional care · e-Health · Pandemics

Introduction

The complexity of the health-disease, associated and increased vulnerability processes of an aging population with comorbidities and functional changes resulting from the aging and disease processes, is a real challenge for the integration of care because of the transition from the hospital to the community. A previous research has found that not only hospitalized people are vulnerable to experiences of loss of care continuity when health conditions change or when they move between care organizations, what has implications for their functionality and quality of life, but the caregivers also have

Nursing School of Lisbon, Lisbon, Portugal crbaixinho@esel.pt

² Center for Innovative Care and Health Technology (ciTechcare), Leiria, Portugal

³ Comprehensive Health Research Center, University of Évora, Évora, Portugal

vulnerability, and this has consequence in their health, in the emotional, physical and social overload associated with the role of caregiver [1–3].

In this sense, it should be noted that the acute illness of a family member, accompanied by disability, dependence and/or in need of managing a therapeutic regime, may involve the preparation of one or more family members or significant people to support him and this caregiver. They experience a situational transition, in which they seek to adapt to the new role and the continuous provision of care, needing the support of health professionals for the transition to be successful [1, 3].

The fragmentation of continuity of care can result in confusing treatment guidelines for the person, with a strong probability of non-compliance with good practices and duplications, in an inadequate follow-up, as well as a lack of preparation/information for the user and informal care providers [4].

In previous studies, the authors are unanimous in advocating that difficulties in communication and articulation between primary and differentiated health care are an obstacle to responding in an integrated manner to the needs of the population with complex health-disease problems [4–7].

The bet on the safe hospital-community transition, guaranteeing continuity of care and improving its quality, contributes to reducing costs and can be an appropriate strategy and policy to be followed by health services [4, 5].

In view of the above, a clear challenge to health systems is guaranteeing a set of actions aimed at ensuring continuity of care between different levels of care [1], with a set of care planned and started at the time of admission, which remain throughout the hospital stay and after discharge to enable the participation of this binomial (elderly person with dependence and their caregiver), helping to adapt to the new reality of care [1–3]. In addition, continuity of care contributes to lower costs and presents itself as an appropriate strategy and policy to be followed by health services [1, 2].

An integrative review that aimed to identify evidence from scientific production on hospital transition care provided to the elderly people shows that this care is beneficial for seniors with complex chronic and therapeutic conditions, as well as for their family members, as they often become vulnerable to a breakdown or failures in care due to lack of guidance. They affirm that this care is still scarce, with few elderly people being able to benefit of their advantages [3].

This question extends not only to the person who is admitted to a hospital, but also to their informal caregiver (IC), given that the increase in the elderly population and the incidence of disabling diseases, translate into self-care and support needs in activities of daily life, for a high percentage of elderly people, often dependent on a family member. In the face of dependence, caregivers may experience some difficulties associated with the demand for care, financial or social problems, lack of resources and poor reaction to care [1, 3].

The current challenges to health systems and the organization of care, due to the SARS-CoV-2 Pandemic, to ensure the safety of patients, professionals and the community, have imposed changes to the process of continuity of care between the hospital and the community. The decrease in the average hospitalization delay in a population with pluripathology and polymedication is a clear challenge to rethink the ways of avoiding defragmentation of care.

In view of the above, the objective of this study is to understand the influence of the current pandemic on the continuity of care between the hospital and the community, in the perception of nurses involved in homecoming preparation projects.

2 Methodology

This is a study with a qualitative, exploratory, transversal and descriptive approach. The participants were 5 newly graduated nurses who were involved in the Safe transition project in the last clinical teaching of their degree.

The safe transition (ST) project is a Knowledge Translation (KT) project that involves, in a partnership work, the Vila Franca de Xira Hospital (VFXH), the Lisbon Nursing School (LNS), and the Grouping of Health Centers of the Tagus Estuary (GHCTE), is based on a simultaneous process of problem solving, training, research and action, in which the primary purpose is the Translation of Knowledge for the resolution of problems of different inpatient services to increase knowledge and empower patients and their families in the process of transition from hospital to the community, favoring communication circuits that promote continuity of care, reducing readmissions after hospital discharge, and promoting rehabilitation and insertion in the community [8].

The project team, since its conception, has involved the finalist students of the nursing degree course in the project. The involvement of professionals in the clinical areas, academics and nursing students, aimed to promote an Evidence-Based Practice (EBP), from production to the use of emerging knowledge in clinical areas [8, 9].

Based on the question "How did the pandemic affect transitional care for elderly people with self-care dependency and their caregivers?", the study design and subsequently the semi-structured script that enabled data collection were defined.

Participants were contacted individually by one of the researchers, to request participation and to ensure that they met the defined inclusion criteria: having participated in the safe transition project, following the changes in the organization of services resulting from the National Plan for Preparing and Responding to the disease by new coronavirus (COVID 19) and the internal guidelines of the institutions for the organization of care and having started their professional activity at the partner hospital.

The option for a convenience sample is related to the objectives of the study. The interview guide was developed based on the literature, to allow understanding the changes to transitional care for the elderly people with dependence and their caregivers, at different times (hospitalization; hospital discharge; in the hospital-home transition; in the first 30 days after return the house). This option is based on the recommendations that interventions to manage the transition from hospital to home can take place in three distinct stages: before the person leaves the hospital, at the time of hospital discharge and finally, within 48 h until 30 days after discharge [3].

The content analysis [10] was the technique used to describe and to interpret the participants' discourse. The protocol followed included the preparation of the information; the transformation of content into units; categorization; description and interpretation.

In order to ensure that the methodological processes were correctly applied and to verify that the categories are valid, adequate, relevant, exhaustive, homogeneous and objective, two judges were used to validate the entire process.

This study is authorized by an Ethics Committee (Opinion - 09/HVFX/201). The institutions involved have a formalized partnership protocol that authorizes research. All ethical and formal assumptions were respected since the authorization of nurses to integrate the project, as an extracurricular activity, to the ethical issues inherent in the development of the investigation. All participants were guaranteed anonymity and data confidentiality.

3 Results

The sample consisted of 5 nurses (N), recently graduated, who completed the last Clinical Teaching of the Nursing Degree Course at Lisbon Nursing School, in the services of a hospital in greater Lisbon, during the first wave of the COVID-19 pandemic that has plagued the country. This clinical education ended in July, 2020. The average age of nurses is 21.8 years-old, with 80% of them being 22 years-old.

In order to perform this CT, the respondent nurses had undergone clinical teaching by the services of Urgency, Intensive Care, Surgical Specialties and Medical Specialties.

From the analysis of the participants' discourse, 3 categories emerged: 1) Influence of the pandemic in the preparation for discharge of people with needs for continuity of care; 2) Influence of the conditioning of visits on the preparation of the family caregiver for the safe transition of dependent people from the hospital to the community and 3) Influence of the pandemic on the continuity of care from the hospital to the community.

In relation to the Category: Influence of the pandemic in the preparation for discharge of people with needs for continuity of care, the analysis of the responses of the participants shows that the pandemic affected the preparation for discharge of people with needs of continuity of care, which is illustrated in the speech of a nurse referring that "the preparation for discharge was carried out taking into account some of the conditions imposed by Pandemic" (N4).

Failure to plan discharge affects the information given to the person, hinders training (for example the training of daily life activities) during hospitalization, with an increased risk of omitting information and not confirming how the message was perceived by patients.

On the other hand, "the discharge started to take longer due to the fact that it is necessary to have a negative result in the COVID test and with a validity of 48 h" (N3). The pandemic affected the average length of hospital stays that became more prolonged due to the need to test patients with scheduled discharge and wait for the result. On the other hand, people with less critical clinical conditions, and previously had short hospitalizations, went to home hospitalization or clinical discharge to the home, without the time necessary to carry out an adequate discharge planning.

Regarding the Category: Influence of the conditioning of visits on the preparation of the family caregiver for the safe transition of people dependent on the hospital to the community, the conditioning of the visits seems to have affected in some way the preparation of the family caregiver for the safe transition of the patients dependents, from the hospital to the community. However, the teams endeavored to alleviate the difficulties that arose. For the nurse who did an internship in the emergency service (ES) for example "the lack of visits harmed the patients a lot, as they had many doubts and

questions associated with the information that was being transmitted to family members" despite the continuity of care in his opinion, it was not very affected "since the period the patients stayed in the ES was short" (N1).

The presence of families at extended hours in services is essential for health professionals to be able to inform about care when returning home, but also to enable the family to perform a set of instrumental care and professionals are aware of this need.

On the other hand, one of the nurses who underwent clinical teaching in medical specialties stated that "the fact that the family is not always available during visiting hours and is unable to schedule an hour to call for information about a family member or to know the conditions of the home and the family's ability to take care of their relative" (N4) affected the preparation; "however, the best was always done so that this transition could take place safely" (N5). Another, from a similar service, said that "there were visits at the service, [so he did not find] a problem in preparing the discharge of the client and family" (N5).

In the Category: Influence of the pandemic on the continuity of care from the hospital to the community, difficulties in articulating between different levels of care are expressed when the pressure on their ability to respond is increased in a situation that is hardly timely due to its unpredictability and sudden appearance.

According to 80% of the participants, the pandemic affected the continuity of care from the hospital to the community, given that "primary health care is not providing the usual and necessary response that the population needs" (N2); "contact with the health center was greatly reduced. (...) [Formal contact between hospital and health center] did not take place, calling into question the continuity of care" (N1).

This situation is of concern for the security of information transmission between levels of care and to prevent defragmentation in care, especially in rehabilitation, so one of the participants warns that "there needs to be a more formal contact between the hospital and care primary health.... which sometimes does not occur, jeopardizing continuity of care" (N1).

The pressure that the pandemic exerts on primary health care also conditions their response to people and families in need of continuity of care. And if the pandemic conditions the preparation for the discharge of these patients, the fact that it has also conditioned the ability of primary health care to respond in a timely manner to their needs, will have left these people and families in serious difficulties in the face of the problems they face after discharge.

4 Discussion

With this study, it was possible to understand the impact that the pandemic caused by COVID-19 brought to the preparation of discharge of people in need of continuity of care; the restriction of visits to avoid social contact, thus limiting the involvement of family caregivers in the preparation of the safe transition of dependent people and, on the other hand, the defragmentation in the communication circuits between institutions that jeopardized the continuity of care between the hospital and the community.

The pandemic has raised new and challenging questions in preparing for the safe transition to the community and halting the spread of COVID-19. Successful responses

have emerged to address these challenges such as the development of a hierarchical system for identifying patients and forwarding clinical messages [11] and virtual care models have been widely accepted by patients and represent a key component for providing safe and timely health care during this pandemic [12]. In addition, students can be involved in conducting a health education session, as in a previous study in which trainees in their final semester and who used motivational interviews to help patients set goals in managing the disease. As a result of this model, the readmission rate of patients who participated in the program in the initial 7 months was reduced by 72% [13].

One of the measures implemented to control the spread of COVID-19 was to prevent social contact. However, it is not intended to prevent social contact as it has important implications for mental health, but to prevent physical contact. The use of communication and information technologies, video calls, videoconferences can be an important solution to maintain contact between patients and family members and also to provide information/prepare family caregivers for their relative's return home, depending on care needs. Telemedicine combines the convenience, low cost and easy accessibility of information and communication related to health using the Internet and associated technologies, namely telephone and videoconference [14].

Internet-based solutions can facilitate routine, predictable and structured communication, which is essential for family-centered care during restricted physical contact during the pandemic, was a solution found to maintain family integrity [15]. However, there are other issues that deserve room for debate, namely the issues of equity, ethics and privacy related to telehealth and remote monitoring [15, 16].

With regard to defragmentation in communication between the institutions of the health system, there are questions related to equity in accessibility, transition of care, quality and socio-economic/environmental impact [17]. These issues were already a concern before the pandemic, and in the current context, they are more relevant due to the increase in disparities and the exclusion of patients in access to safe and quality health care in this process of hospital-community transition.

In this sense, some authors propose an evidence-based Transitional Care model to be applied in the context of COVID-19 in elderly people in order to facilitate a more immediate and holistic response to the care of these people so that they return to the community. These components include: increasing screening, building trusting relationships, improving patient involvement, promoting collaboration between care teams, performing symptom management, increasing family caregiver care/education, coordinating social and health services and improve continuity of care [18].

So that the continuity of care is not broken, it is necessary for health professionals to ensure follow-up and facilitate the transition home [19, 20]. This can be done either through telephone calls [14, 21] or through home visits. In any case, the nurse's role will be to identify the needs of the family caregiver and dependent elderly person, responding accordingly to the problems detected. The differentiated care nurse's intervention must consist of carrying out a follow-up that assesses the effectiveness of interventions related to the caregiver's training. Such a strategy has benefits such as reducing caregiver burden, better access to care, reducing unanswered needs, improving the ability to live at home or in the community, reducing hospitalizations and care in residential structures for the

elderly people, reducing costs, stress and increasing well-being, as it provides support, information and continuing education [22, 23].

The findings suggest that there are difficulties in articulating with primary health care, which compromises the success of homecoming and continuity of care. After a period of hospitalization, people become vulnerable to experiences of loss of continuity of care whenever their health status changes, or when they move between care organizations, and this has implications for their functionality and quality of life [5].

The bet on the safe hospital-community transition, guaranteeing continuity of care and improving its quality, contributes to the reduction of costs and presents itself as an appropriate strategy and policy to be followed by health services, even in situations of pandemic [1, 3, 4, 6, 19, 24, 25], because the lack of articulation can result in confusing treatment guidelines for the person, with a strong probability of non-compliance with good practices and duplications, in an inadequate follow-up, as well as in a lack of preparation/information for the user and informal caregivers [4–6, 22–25]. In this sense, it should be noted that the acute illness of a family member, accompanied by disability, dependence and/or in need of managing a therapeutic regime, may involve the preparation of one or more family members or significant people to support it. The caregiver then experiences a situational transition, in which he tries to adapt to the new role and the continuous provision of care that is associated with it. The lack of preparation for continuity of care during hospitalization, combined with the difficulty of accessing primary health care, does not allow the latter to develop the necessary skills to provide safe care to his family [1, 6].

But the question is more complex than it may seem because in addition to the situational transition, some of the caregivers are simultaneously experiencing other transitions that need a different look and an individualized intervention. Some studies report that the average age of caregivers is 65.8 years-old [25], which indicates that they may be in a developmental transition, associated with advancing age and with other factors of increased vulnerability. In addition to this, about 80% of them take at least one chronic medication and about 54% are polymedicated [25], which suggests that many are also experiencing a health-disease transition and that the provision of care can in itself only trigger the aggravation of the disease process.

5 Conclusions

This qualitative study made it possible to understand some of the influences of Pandemic COVID-19 on transitional care for dependent elderly people and their caregivers.

In the analysis of the speech of the 5 participating nurses, the following categories emerged: 1) Influence of the pandemic in the preparation for discharge of people with needs for continuity of care; 2) Influence of the conditioning of visits on the preparation of the family caregiver for the safe transition of dependent people from the hospital to the community, and 3) Influence of the pandemic on the continuity of care from the hospital to the community.

The restrictions imposed by contingency plans on visits by family members associated with pressure on health services and difficulties in the management of human

resources due to the emergence of care for patients infected by SARS-CoV-2 hinder transitional care in all its activities (hospitalization; hospital discharge; in the hospital-home transition; in the first 30 days after returning home).

The findings open the door to public discussion about the opportunity for e-health interventions to ensure continuity of care and support for caregivers. Since there is no tradition in its use, and sometimes it is even devalued by professionals who prefer a face-to-face approach, the use of this can lessen the impact of the discontinuity of care for dependent, vulnerable and complex health situations, who are at risk of loss of functionality, disuse syndrome and increased likelihood of readmissions, perfectly avoidable with proper planning of transitional care.

This research has limitations associated with the context and the nature of the study that does not allow generalizations to other realities. However, in an area where research is still scarce, the option for a qualitative study made it possible to explore the phenomenon under study and the categories that emerged make it possible to guide future studies.

References

- Ferreira, E., Lourenço, O., Costa, P., Pinto, S., Gomes, C., Oliveira, A., Ferreira, O., Baixinho, C.L.: Active Life: a project for a safe hospital-community transition after arthroplasty. Rev. Bras. Enferm. 72(1), 147–153 (2019). https://doi.org/10.1590/0034-7167-2018-0615
- Everink, I., van Haastregt, J., Tan, F., Schols, J., Kempen, G.: The effectiveness of an integrated care pathway in geriatric rehabilitation among older patients with complex health problems and their informal caregivers: a prospective cohort study. BMC Geriatr. 18(285), 1–13 (2018). https://doi.org/10.1186/s12877-018-0971-4
- 3. Menezes, T.M.O., Oliveira, A.L.B., Santos, L.B., Freitas, R.A., Pedreira, L.C., Veras, S.M.C.B.: Hospital transition care for the elderly: an integrative review. Rev. bras. enferm. **72**(Suppl 2), 294–301 (2019). https://doi.org/10.1590/0034-7167-2018-0286
- Mendes, F.R., Gemito, M.L., Caldeira, E.C., Serra, I.C., Casa-Novas, M.V.: Continuity of care from the perspective of users. Ciênc Saúde Coletiva 22(3), 841–853 (2017). https://doi. org/10.1590/1413-81232017223.26292015
- Allen, J., Hutchinson, A., Brown, R., Livingston, P.: User experience and care for older people transitioning from hospital to home: patients' and carers' perspectives. Health Expect 21(2), 518–527 (2018). https://doi.org/10.1111/hex.12646. epub 9 Nov 2017
- Paniagua, D.V., Ribeiro, M.P.H., Correia, A.M., et al.: Project K: training for hospital-community safe transition. Rev. bras. enferm. 71(Suppl.5), 2264–2271 (2018). https://dx.doi.org/10.1590/0034-7167-2018-0190
- Hahn-Goldberg, S., Jeffs, L., Troup, A., Kubba, R., Okrainec, K.: "We are doing it together"; the integral role of caregivers in a patients' transition home from the medicine unit. PLoS ONE 13(5), 1–14 (2018). https://doi.org/10.1371/journal.pone.0197831
- Baixinho, C.L., Ferreira, Ó., Marques, F.M., Presado, M.H., Cardoso, M.: Transição segura: um projeto da transferência do conhecimento para a prática clínica. In: Costa, A.P., Sánches-Gómez, M.C., Cilleros, M.V.M. A prática na Investigação Qualitativa: exemplos de estudos. Oliveira de Azeméis, Ludomédia, pp. 57–80 (2017)
- Kitson, A., Brook, A., Harvey, G., Jordan, Z., Marshall, R., O'Shea, R., Wilson, D.: Using complexity and network concepts to inform healthcare knowledge translation. Int. J. Health Policy Manag. 7(3), 231–243 (2018). https://doi.org/10.15171/ijhpm.2017.79
- 10. Bardin, L.: Análise de conteúdo. Lisboa, Edições 70 (2008)

- Landor, M., Schroeder, K., Thompson, T.A.: Managing care transitions to the community during a pandemic. J. Nurs. Adm. 50(9), 438–441 (2020). https://doi.org/10.1097/nna.000 000000000913
- 12. Crane, S.J., Ganesh, R., Post, J.A., Jacobson, N.A.: Telemedicine consultations and follow-up of patients With COVID-19. Mayo Clin. Proc. Innov. Qual. Outcomes **95**(9), S33–S34 (2020). https://doi.org/10.1016/j.mayocp.2020.06.051
- Heaton, P.C., Frede, S., Kordahi, A., Lowery, L., Moorhead, B., Kirby, J., Kunze, N., Luder, H.: Improving care transitions through medication therapy management: a community partnership to reduce readmissions in multiple health-systems. J. Am. Pharm. Assoc. 59(3), 319–328 (2019). https://doi.org/10.1016/j.japh.2019.01.005
- Vidal-Alaball, J., Acosta-Roja, R., Hernández, N.P., et al.: Telemedicine in the face of the COVID-19 pandemic. Aten. Primaria 52(6), 418–422 (2020). https://doi.org/10.1016/j.aprim. 2020.04.003
- 15. Hart, J.L., Turnbull, A.E., Oppenheim, I.M., Courtright, K.R.: Family-centered care during the COVID-19 Era. J. Pain Symptom Manage. **60**(2), e93–e97 (2020). https://doi.org/10.1016/j.jpainsymman.2020.04.017
- Brody, A.A., Sadarangani, T., Jones, T.M., Convery, K., Groom, L., Bristol, A.A., David, D.: Family-and person-centered interdisciplinary telehealth: policy and practice implications following onset of the COVID-19 pandemic. J. Gerontol. Nurs. 46(9), 9–13 (2020). https://doi.org/10.3928/00989134-20200811-03
- Sivashanker, K., Duong, T., Resnick, A., Eappen, S.: Health care equity: from fragmentation to transformation. NEJM Catal. Innov. Care Deliv. 1(5) (2020). https://doi.org/10.1056/cat. 20.0414
- Naylor, M.D., Hirschman, K.B., McCauley, K.: Meeting the transitional care needs of older adults with COVID-19. J. Aging Soc. Policy 32(4–5), 387–395 (2020). https://doi.org/10. 1080/08959420.2020.1773189
- 19. Baixinho, C.L., Ferreira, Ó.: From the hospital to the community: the (un)safe transition. Rev baiana enferm. 33, e35797 (2019). https://doi.org/10.18471/rbe.v33.35797
- Pindus, D., Mullis, R., Lim, L., Wellwood, I., Rundell, A., Aziz, N., Mant, J.: Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services a systematic review and meta-ethnography. PLoS ONE 13, 1–23 (2018). https://doi.org/10.1371/journal.pone.0192533
- Quinn, W., O'Brien, E., Springan, G.: Using telehealth to improve home-based care for older adults and family caregivers. Real Possibilities Public Policy Inst. 36(5), 909–917 (2018)
- 22. Toye, C., Parsons, R., Slatyer, S., Aoun, S., Moorin, R., Osseiran-Moisson, R., Hill, K.: Outcomes for family carers of a nurse-delivered hospital discharge intervention for older people (the Further Enabling Care at Home Program): single blind randomised controlled trial. Int. J. Nurs. Stud. 64, 32–41 (2016). https://doi.org/10.1016/j.ijnurstu.2016.09.012
- Cunha, L.F., Baixinho, C.L., Henriques, M.A.: Preventing falls in hospitalized elderly: design and validation of a team intervention. Rev Esc Enferm USP. 53, e3479 (2019). https://doi. org/10.1590/S1980-220X2018031803479
- 24. Baixinho, C.L., Ferreira, Ó.: Defragment or integrate care? a challenge for the international year of the nurse. Rev baiana enferm. **34**, e35856 (2020). http://dx.doi.org/10.18471/rbe.v34. 35856
- Brigola, A., Luchesi, B., Rossetti, E., Mioshi, E., Inouye, K., Pavarini, S.: Health profile of family caregivers of the elderly and its association with variables of care: a rural study. Rev. Bras. Geriatr. Gerontol. 20(3), 409–420 (2017). https://doi.org/10.1590/1981-22562017020. 160202



Partnership of Care in the Promotion of the Care-of-the-Self: An Implementation Guide with Elderly People

Idalina Gomes^{1,2(⊠)}

¹ Escola Superior de Enfermagem de Lisboa, Lisbon, Portugal idgomes@esel.pt
² UI&DE, ESEL, Lisbon, Portugal

Abstract. There are some theories in the gerontology field that, sooner or later, will be integrated and its use facilitated by technological applications. An example is the model by Gomes [1], who argues that nurses and elderly people must work in partnership to promote the Care-of-the-Self. To help health care professionals in interpreting and implementing the model in practice, the need of a guideline document was suggested by professionals. Thus, the objective of this manuscript is to propose a guideline document to help nurses, elderly people, and their family in working in partnership, promoting the Care-of-the-Self and integrate it in the gerontotechnological care. A research-training-action project was adopted and sixteen case studies were performed to develop the final guideline document, where the interrelations of fundamental concepts in Partnership and Care-of-the-Self are highlighted and structured on the five stages of aforementioned model. As a conclusion, instruments that facilitate the understanding and implementation of nursing concepts by nurses and other health care professionals can help to focus the care on the elderly person, allowing the Care-of-the-Self by looking at the person as a whole and taking into account its uniqueness, contributing to a profounder humanization in the gerontotechnological care.

Keywords: Partnership · Script · Elderly people · Selfcare · Care-of-the-Other

1 Introduction

The progressive aging of the world's population has led to the development of policies and strategies to manage this trend. Many institutions place emphasis on the need for the elderly people to have the ability to control its own health, intervention capacity and community participation [2]. Despite technological developments have facilitated and improved the daily life of elderly people and the care provided to him/her, it is important that humanization in gerontotechnological care is not omitted.

Quality of life of elderly people is expected to evolve in the same direction as life expectancy, implying that health policies should appraise the costs, ethics and the right to live and die in dignity as a whole. This vision leads to the acceptance of a "non-cure", which in turn leads to a shift in traditional relationships with patients. It has become necessary to negotiate with patients their treatment, measures to take in relation to their quality of life and the possibilities that they or their families have regarding the Care-of-the-Self. As part of this assumption, it is necessary for patients and their families to be care partners. Therefore, in this new philosophical, social, and political trend, the health care professionals and namely the nurses need to effectively distance themselves from practices based on a pragmatic philosophy and to strive for a philosophy of care that is more focused on people and families, even when some type of technological support occurs in this process. In fact, a pragmatic philosophy where actions are based on a technical-professional model that places particular value on bio-physiological and technical know-how it is far from what is most respectable and dignified for people, specifically their eminent dignity.

The interrelationship between the problems of the chronic disease management process and the need to see the patient as a partner is a contemporary reality demand. Nowadays, a new health perspective is emerging and proposing methodologies that are more in line with the complexity of human experience, in which health care professionals must respect and promote the autonomy and individuality of the patient. For this purpose, this paper introduces a guideline document for interventions with elderly people and families for promoting in partnership the Care-of-the-Self.

The remaining of the paper is structured as follows: Next section reviews the Care-of-the-Self model by Gomes [1]; Sect. 3 includes the approach followed to develop the final guideline document; Sect. 4 shows the results and its discussion is presented in Sect. 5; Conclusions are included in Sect. 6.

2 Care-of-the-Self Model Review

Relevant theories that are fundamental to care, namely that proposed by Pepin et al. [3], Tomey and Alligood [4], and Meleis [5], were structured considering the increasing complexity of human experience, in which health care professionals must respect and promote the patient's autonomy and individuality, and drew inspiration from concepts that emerged in nursing during the 80s. These theories are an inalienable legacy, since respect for people's values, beliefs, way of life and culture became essential concepts of the discipline of nursing and their daily mobilization serves as a premise for the care provided by nurses. Those nursing concepts include recognition of the inner power of human care that is based on non-paternalistic values that promote Care-of-the-Self in patients (people). Notice that Care-of-the-Self does not mean that people are left to their

own devices. The intention is to place emphasis on the reflexive process that must be promoted in people to give them autonomy and allow them to make decisions based on clear information, regardless of their condition of care, in the context of their existence [1]. In this regard, Foucault [6] tells us that "the idea that people should take care of themselves (...) is in fact a very ancient theme in Greek culture, where Care-of-the-Self had an implicit double meaning, besides referring to having inherent care for oneself, it also came to mean care that should be shown towards Others."

In this context, care needs to be guided by the person's life project, that is, what is essential, prioritary, and valued by him/her. Thus, nurses and other health care professionals must find out about, support, and reinforce the person's life project. This includes the development of person-centered care [7], so it is essential for nurses to stop focusing on themselves and manage to intervene in partnership with the person, patient and family, because there can be no care without encountering the Other that allows to share the meaning of the experience [8]. In this sense, we carried out a study with the aim of understanding the nature of the partnership process in the care relationship between nurses and elderly person, and we concluded that an essential condition of the partnership process is to see the elderly person as a being of project and care [9, 10]. This condition leads to attention being paid to the elderly person's potential and development for Care-of-the-Self, which implies looking at the elderly person as more than a being with needs. Another essential condition that emerged from the study was the need of time and space availability to build up a quality relationship that enable the establishment of a relationship of trust that reaches out to the elderly and helps to create a climate for making compromises.

The conditions on which the partnership process is based have the potential to vary or change the nature of the action or interaction. Therefore, when the elderly person has the capacity for autonomy, the strategy for building up the nursing care partnership process results in the construction of a joint action aimed at training the person to assure Care-of-the-Self. When the elderly person is dependent and does not have the capacity for autonomy, the strategy involves the construction of an action in which the nurse ensures the Care-of-the-Other, by taking responsibility for the care that the Other should take of himself/herself, based on the principles and knowledge of the profession, or by training the family or significant person to do so. The consequence of these strategies is assuming responsibility or control for the Care-of-the-Self with the aforementioned double meaning, contributing towards care more focused on the elderly person, making possible for them to gain more control over its life project or to continue their path through life.

Figure 1 illustrates the nature of the structure of the partnership process between the nurse and the elderly person in the care relationship, setting out the dynamic and complex nature of a partnership process construction for promoting Care-of-the-Self. The partnership process includes the following five phases: Reveal oneself; Get involved; Train or Enable; Commit; Ensure Care-of-the-Self or Ensure Care-of-the-Other.

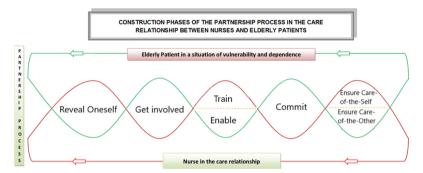


Fig. 1. Construction phases of the partnership process between the nurse and the elderly person for promoting Care-of-the-Self. Source: [9].

This model of care is being used in some hospital services, including in nursing consultations [11], and primary care units, in addition to have been proposed as a tool by The European Dialysis and Transplant Nurse Association/European Renal Care Association and published in the Guide to Clinical Practice to renal care professionals [10]. However, we do realize the importance of making it operational so that all phases and inherent concepts and practices are meaningful for health care professionals, namely for nurses, and for the elderly person in any care situation. In this context, the following question arose: How can the intervention model be implemented to promote Care-of-the-Self in a clinical practice? To answer this question, it was proposed the development of a guideline document for interventions with elderly people and families for the promotion in partnership of Care-of-the-Self, which is presented in next sections.

3 Method

A research-training-action project was launched to draw up the guidelines, where ethical considerations, confidentiality and anonymity of information and data were also taken into account to. As a preliminary instrument, a guideline document was used during case studies in hospital services, including in nursing consultations [11], and primary care units. Eight nurses, students of a Master's degree in Nursing - area of the elderly, with a minimum of 2 years of clinical experience, and 16 elderly people participated in the study, and an informed consent form was signed by each elderly person who participated in the case study.

After drawing up the guideline document, based on the Gomes's model [1, 9], it was used in sixteen case studies. Two case studies by nurse were carried out in hospital services, including in nursing consultations, and primary care units. The care situations were based on various geriatric syndromes (visual and hearing deficits; insomnia; depression; pain; fatigue; delirium; isolation; falls; pressure ulcers; constipation; urinary incontinence; anorexia; infection; weight loss; polymedication; weakness; abuse of the elderly.). Notice that informed, clarified, and free consent was requested from elderly people for conducting the clinical case studies.

The implementation of the guidelines was followed-up by practice analysis meetings to adjust them to the situations and difficulties that were encountered. As example, difficulties were experienced when transposing the concepts to the clinical practice, and due to a shortage of time for obtaining in-depth knowledge of the person and giving the person time and space to take a decision. Training meetings were also held with nurses from the clinical settings, involving the submission of case studies aimed at training the nurses to understand the philosophy of the model and to implement the guidelines document.

The difficulties experienced by novice non-specialized nurses with using the guidelines were not included, thus this is a study limitation.

4 Results

The assumptions of a partnership intervention aimed at promoting Care-of-the-Self were taken into account when drawing up the guidelines, and proved themselves to be of a structural nature for the practice of providing care to elderly people, specifically in situations of vulnerability and dependency. This is because it allows to see the person as a "being of action" whose power, resulting from his/her uniqueness as a person, is valued regardless of his/her circumstances. His/her autonomy and potential for fulfillment are promoted and he/she is not just seen as a "being of needs". Therefore, the explanation and the interrelationships of concepts that characterize partnership process and promote the Care-of-the-Self with a double meaning, that is, the Care-of-the-Self and the Care-of-the-Other (see Fig. 1), will allow the guidelines to be drawn up based on the five phases of the partnership model and consequent Care Plan, such as shown in Table 1. It is important to remember that model phases are not independent, they are interconnected, and the implementation of the model will be facilitated by using the guidelines shown on Table 2.

Table 1. Phases of the model of nursing intervention in partnership with the elderly person for promoting the Care-of-the-Self.

| | | | | G .: 6 . 6 | |
|-------------------|---|----------|---|---|---------------------------------|
| | | | | • | iprocity and the establishment |
| REVEAL ONESELF | | AL | of time and space to develop a high-quality relationship, | | |
| | | | promoting care in a safe en | vironment. | |
| ONESELF | | | | Find out about the uniquen | ess/life project of the elderly |
| | | | person and family. | | |
| | | | Find out about the life | context of the elderly per- | |
| | | | | son/psychosocial profile | · . |
| | | | | | al history/current condition of |
| GET | IN | VOLVE | D | the elderly person, family background and the meaning | |
| GLI | ' | , OL , L | | that the patient finds in his/her life path. | |
| | | | | | |
| | | | | -Identify the needs and potentials of the elderly person | |
| | | | | for promotion of Care-of-the-Self. The person is looked upon as a being with a project and to be cared. | |
| | | | | | |
| | | | | ` ` ` , | e elderly person in all dimen- |
| | | | | sions. | |
| | | | | | ilities, knowledge, and devel- |
| | | | | | Care-of-the-Self of the elderly |
| | | | | person, family carer, and fa | |
| | | | | -Identify and validate the n | ursing diagnoses and prioritiz- |
| | | | | es them in conjunction wi | th the person and family. Fo- |
| | TI | RAIN O | R ENABLE | cuses care on the person ar | nd family. Adapt interventions |
| | | | | in the life and health plan | s of the elderly person by in- |
| | | | | volving the person and fam | ily in the action and decision. |
| | | | | | notes Care-of-the-Self in the |
| | | | | elderly person and Care-of-the-Other among the fami- | |
| | | | | ly/significant person by building a negotiated joint action. | |
| | | | | -Enabling: the nurse enables care of the person when the | |
| | | | | person does not have the capability to do it or trains the | |
| | | | | family carer to provide the care. The nurse acts according | |
| | | | | | es of therapeutic and profes- |
| | | | | sional effectiveness. | es of therapeutic and profes- |
| | | | | | mitment made by the alderly |
| | | COL | MMIT | Help to support the commitment made by the elderly | |
| | | CO | VIIVII I | person/family member/significant person, based on inter- | |
| | | | | ventions planned in accordance with whatever makes | |
| | | | | sense for the person. | 190. |
| | | EN | SURE CARE- | | e capability acquired by the |
| | | | -THE-SELF | | or ensure Care-of-the-Self and |
| | | Ŭ, | | gain control over his/her lif | * |
| | | EN | SURE CARE- | | aired by the family or signifi- |
| | | | THE-OTHER | * | f-the-Self and to ensure Care- |
| | | OI. | THE-OTHER | of-the-Other (the elderly pe | erson) |
| CARE PLAN | | | | | |
| Identi | Identify nursing Negotiate the ex- Negotiated the nursing Assessment of the per | | | | Assessment of the per- |
| diagn | - | _ | pected results in the | | son's/family's capability to |
| valida | | | * | d lished commitments | Ensure Care-of-the-Self or |
| vanda | | | long term | nonea communento | Care-of-the-Other |
| | long term | | rong term | | Carc-or-unc-Oulci |
| | | | | | |
| | | | | 1 | 1 |

Table 2. Guidelines for nursing interventions in partnership with the elderly person and family when promoting Care-of-the-Self.

REVEAL ONESELF GET INVOLVED

The nurse makes himself known to the Elderly Person/Family or Significant Person

- Carry out the welcome (nurse says his/her name; explain the objectives of the meeting and terms of the relationship; introduce the hospital service or care unit where he/she works; promote an environment conducive to interaction).
- Offer his/her availability (to listen and provide care focused on person) and show respect to the elderly person/family/significant person.

Find out about the uniqueness/life project of the elderly person

- Collect socio-biographical data (name, name by which the person likes to be addressed; gender, age, education, marital status, telephone contact; nationality/residence; (current/previous) professional activity; reference person (name, kinship, telephone contact) are collected:
- Record the reasons for requesting nursing care as well as person's institution and physician, medical diagnosis, beliefs, values, spirituality, and other information that motivates and gives meaning to the elderly person's life.
- Ask for significant experiences and developmental transitions in the elderly person's life.

Find out about the life context of the elderly person/psychosocial profile

- Characterize the family and support network (household, family network and neighborhood, role in the family, economic situation, family doctor, social support, day care center, family carer, genogram, eco-map), housing conditions (house type, owned or rented, architectural barriers, adapted bathroom, heating), and lifestyle (Leisure activities; addictive behaviors).

Find out about the history and current condition health of the elderly person and its meaning for his/her life path

- Characterize the current disease (start, signs and symptoms; tests performed).
- Confirm that the elderly person, family member and/or significant person is aware and understand of the diagnosis and prognosis; have and which are the expectations in view of the disease and treatment situation, think and accept the disease, have other current concerns, and keeps hope.
- Characterize the adaptation to the disease/dependency situation; which facilitates or prevents adaptation, usual/habitual treatment plan (pharmacological measures; use of supplementary therapies; responsible person; adhesion to treatment, treatment management)
- Characterize the person's and family's background health problems; past surgery; allergies and intolerances, medication and previous treatments and hospitalizations; how he/she experienced them.

Identify the Needs and Potentials of the Elderly Person for the Promotion of Care-of-the-Self

- Characterize the standard of daily life: how does he/she experience each of his/her fundamental human necessities, his/her daily life activities (DLA), his/her instrumental daily life activities (IDLA), and how, when and why he/she carry them out, as well as what are his/her day-to-day desires from life.
- Assess (using scales) of all physical, psychological, spiritual, social and cultural dimensions of the elderly person, namely the assessment of geriatric syndromes (visual and hearing, insomnia, depression, pain, fatigue, fragility, delirium, isolation, falls, pressure ulcers, constipation, urinary incontinence, anorexia, infection, weight loss, polymedication; abuse).

(continued)

Table 2. (continued)

- Find out about the capabilities, knowledge and development potential for Care-of-the-Self:
- Assess (using scales) the functional capability of elderly person to manage his/her life.
- Identify what the elderly person, family member or significant person can do alone, with help, and what they cannot do alone to promote Care-of-the-Self/Care-of-the-Other.
- Identify what the elderly person, family member and/or significant person knows, does not know, what he/she wants to know to promote Care-of-the-Self/Care-of-the-Other, and his/her motivation to do so.

TRAIN/ENABLE

The nurse promotes Care-of-the-Self in the elderly person and Care-of-the-Other among the family/significant person by building a joint action or building an action in which ensures the Care-of-the-Other when he/she does not have the capability to do so, by taking responsibility for the care that the Other should take of himself/herself, based on the principles and knowledge of the profession, or by training the family or significant person to do it.

- Reflect on the compiled data, the way in which he/she got involved in the process, identifies the nursing diagnoses, and validate them.
- Meet the priorities of the elderly person/family/significant person, adapts (based on scientific evidence) the interventions to the life and health plans of the elderly person, involving him/her in the action and decision, providing information and clarifications;
- Promote reflection, negotiates care considering values and beliefs, and respects the decision-making of the elderly/family/significant person;
- Promote proactiveness by valorizing the knowledge and feelings of the elderly person/family/significant person, stimulates and welcomes their ideas, validating them;
- Coordinate with other health care professionals the necessary cares according to the needs of the elderly person/family/significant person;
- Respect the times of the elderly person/family/significant person, by waiting, not imposing and keeping their preferences in mind;
- Encourage the elderly person/family/significant person to adhere to the treatment plan;
- Anticipate complications and involve the family/significant person in care (clarify doubts).

COMMIT

The nurse helps to support the commitment made by the elderly person/family/significant person, based on planned interventions, considering the scientific evidence and adjusting it to what makes sense for the elderly person.

- Help the elderly person to make choices (aimed at a progressive transition from a potential capability to a real capability), respect them, and carry out necessary interventions to support him/her decision-making.
- Validate the interventions for the promotion of Care-of-the-Self. Seek to find out the expectations of the elderly person/family member/significant person. Set out and explain the expectations within the envisaged limits. Promote continuity of care with personalized records.

ENSURE CARE-OF-THE-SELF (Care-of-the-Self or Care-of-the-Other)

The nurse assesses and reflects on the capability of the elderly person to ensure Care-of-the-Self and of the family or significant person to ensure Care-of-the-Other

- Assess whether the elderly person/family/significant person holds information that allows him/her to make decisions on Care-of-the-Self and/or Care-of-the-Other;
- Allow the elderly person to decide on the best path for him/her, manage his/her situation,

(continued)

Table 2. (continued)

and deal with it in terms of comfort and well-being;

- Provide or Ensure to the family/significant person the capability to assure the required care to the elderly person;
- -Allow to the elderly person continuing along his/her life path, and to remain as a resource to provide or ensure care to the elderly person.

5 Discussion

One of the characteristics of nursing care is the great complexity of the situations that the nurse has to be able to manage in order to help the person to pursue his/her life project. To this end, the nurse has to focus his/her intervention on Care-of-the-Other, viewing him/her as a care partner. It is this understanding that transforms small acts of daily life intrinsically linked to fundamental care into nursing care, insofar as it is given meaning when adapted to the uniqueness of the person, helping to promote the Care-ofthe-Self and integrate it in the gerontotechnological care. According to the nurses who participated in the work presented here, the implementation of guidelines helped them to focus on the elderly person and family, helping them to find out about person's identify, to understand how the disease happened and its meaning for the person's life path and, therefore, to identify the knowledge, resources, and context for dealing with his/her situation. This attitude of the professional provided to the elderly person and the family a desire and willingness to participate. It made them ask for information, willing to talk and share different dimensions of their life narrative, namely the physical, biological, spiritual, cultural, sociological, and existential dimensions that are interconnected, that make up the person, and that could indicate the best way to care for him/her. The nurse's concern about the involvement of the elderly person helped to identify his/her needs and potentials, or in other words, to identify the lack of knowledge, functional limits resulting from the disease in terms of (no)instrumental daily life activities. It helped to recognize situations and to work with elderly people to seek their motivations and what gave meaning to their lives in order to allow the professional and the elderly person the identification of their possibilities and resources needed to promote the Care-ofthe-Self. It was therefore necessary to make a joint effort to seek to achieve the set objectives in order to assume or ensure control or continuation of the elderly person's life and health projects, based on the meaning of his/her experience in the context of his/her human responses to a critical event, which gave meaning to his/her life. In this way, the professional helped by supporting the commitment made by the person, based on what made sense to him/her. The implemented actions are aimed at a progressive transition from a potential capability to a real capability, or to promote health and ensure that the elderly person can continue his/her life path. The professional is committed to caring for the elderly person, forcing him/her to be creating and to look for whatever made sense in relation to his/her knowledge of the person, the situation and its evolution. The aim was for the elderly person to be able to assume control of his/her own Careof-the-Self; to gain control over his/her life and health plans; to ensure that he/she was informed, that he/she was able to decide on the best path for him/her and that he/she is

capable of managing his/her situation and express his/her comfort and well-being. If the elderly person did not have the capability to be autonomous, the nurse made every effort to ensure the Care-of-the-Other to allow the elderly person to continue his/her life path. To this end it was very often necessary to train the family carer to help to care for the elderly person. Where this was not possible, the nurse assumed responsibility for care, based on the principles, values and know-how of the profession, with an emphasis on ensure that the person cared for himself/herself, with the nurse remaining as a resource. Similarly, this helped the professional to develop self-awareness and his/her human, relational and technical skills, because taking joint responsibility for Care-of-the-Other forces him/her to be create and constantly seek out the vital forces that drive the life of that person, allowing him/her to regain the power of being and existing. The professional also learns from the experience of the elderly person to overcome vulnerability, which in the current context of the pandemic has proven to be fundamental.

It should not be forgotten that the capacity to care for ourselves and others falls within the double meaning of Care-for-the-Self that characterizes humanity. Hence we corroborate Edgar Morin [12] when he says that "care-for-the-self requires a necessary (re)connection between the person and his/her essence, with his/her inner self; it requires a movement towards a (re)connection with the other, (re)connection with the community, (re)connection with society and, at its limit, (re)connection with the human species".

Nursing care, defined as Care-of-the-Self, is about facilitating conditions to allow a person to manage his/her own Care-of-the-Self, considering his/her health and life plans. It is also an act that lends itself to ensure the Care-of-the-Other who needs partial or complete help to meet his/her fundamental needs and to fulfill his/her health and life plans in the cultural context of his/her existence and the World of which he/she is a part. This implies taking care with how the person should care for himself/herself in the context of his/her existence [13], which requires in-depth knowledge of people and their life and health projects.

Nurses need to be able to create conditions to enable and/or train people, families, and populations to maintain and manage Care-of-the-Self in situations of health, disease and death. Nurses need to work in partnership with them to provide help and to promote their potential for health and life in the cultural context of their existence in relation to others, the nature, and the World. What we have stated above points out the complexity of the fields of competence in nursing care the need for nurses to have scientific knowledge, ethical and deontological knowledge, technical ability and complete knowledge about the Self and the Other. It is impossible to talk about care if all this knowledge is not present.

6 Conclusion

A lot of knowledge has been produced about nursing care, but it is not always easy to transform this knowledge into specific interventions that work well in practice. Gerontotechnological care has becoming a current practice, which have many advantages widely accepted by health care professionals, but one cannot ignore or minimize the required humanization in health care in this new reality. Nurses are aware that they have to engage in reasoning on the basis of specific nursing knowledge in order to make

appropriate or adequate intervention, but they encounter serious obstacles in terms of the context of practices to be able to do it, even when modern technology and technological applications are used to. This is, in fact, the major challenge facing nursing today; how to transform the knowledge to give meaning to what nurses do in practice and to their decision-making. Therefore, nursing practice needs practical instruments that help nurses to focus on caring for the Person in the day-to-day practice of care.

The concept of Care-of-the-Self can allow the elderly person to be looked at as a whole, seeking to transform a potentiality into an actual capability, without forgetting aspects that may have been lost over time. Considering the aging trend of the world population, often accompanied with a great deal of chronic illness, this shows us the importance of educating everybody about Care-of-the-Self with a view to the sustainable promotion of the health of populations. The adoption of the proposed model and guidelines by nurses and other health care professional as a multidisciplinary team can improve the quality of care that is provided to person and family as well as to increase the well-being of elderly people and family. This improvement in the quality of care could avoid many hospital and nursing home admissions and readmissions, which have positive economic repercussions and clear gains in health. This requires a different sort of organization of care and health institutions more friendly of the elderly people. The use of modern technology and technological applications is also required. Thus, in future work, it is planned to provide the guideline document in a technological support or integrate it in existing technological applications with the purpose of contributing to a profounder humanization in gerontotechnological care as well.

References

- Gomes, I.: To Promote self-care: a partnership between the nurse and the elderly person. The
 construction of the partnership process in a context of vulnerability and dependency. New
 scholarly editions, Saarbrucken/Deutsche (2016)
- World Health Organization: Decade of Healthy Ageing (2020–2030). Homepage (2020). https://www.who.int/docs/default-source/decade-of-healthy-ageing/final-decade-proposal/decade-proposal-final-apr2020-en.pdf?sfvrsn=b4b75ebc. Accessed 21 Aug 2020
- Pepin, J., Kèrouac, S., Ducharme, F.: La pensée infirmière, 4th edn. Chenelière Éducation, Montréal (2017)
- 4. Meleis, A.: Theoretical Nursing: Development and Progress. 3rd edn. Lippincott-Raven Publishers (2007)
- 5. Tomey, A., Alligood, M.: Teóricas de Enfermagem e a sua obra: modelos e teorias de Enfermagem. Lusociência, Loures (2004)
- Foulcaut, M.: História da sexualidade III: o cuidado de SI. Edições Relógio D'Água, Portugal (1994)
- McCance, T., McCormack, B., Dewing, J.: An exploration of person-centredness in practice. Online J. Issues Nurs. 16(2), 1, PMID: 22088150 (2011)
- Gomes, I. (ed.): Parceria e cuidado de enfermagem uma questão de cidadania. Formasau, Coimbra (2007)
- Gomes, I.: Cuidado-de-Si: A natureza da parceria entre enfermeiro e o doente idoso no domicílio. Dissertação de Doutoramento) Instituto de Ciências da Saúde, Universidade Católica Portuguesa, Lisboa (2009)

- Gomes, I.: Meeting the elderly patient in the Renal Clinic: a partnership in care with the multidisciplinary team. In: European Dialysis and Transplant Nurse Association/ European Renal Care Association (EDTNA/ERCA), Madrid, pp. 43–65. Imprenta Tomás Hermanos (2011)
- Gomes, I., Martins, M., Guerreiro, D., Lopes, P., Gomes, B.: Script for nursing intervention on elderly people with chronic pain by telephone consultation. In: Garcia-Alonso, J., Fonseca, C. (eds.) IWoG2019, Communications in Computer and Information Science, vol. 1185, pp. 213–218. Springer, Cham (2020)
- 12. Morin, E.: O Método 6: Ética. Sulina, Porto Alegre (2005)
- 13. Gomes, I.: Promover o Cuidado-de-Si: património da enfermagem para o desenvolvimento sustentado, bem-estar e saúde das populações. Revista Pensar Enfermagem **23**(2), 7–15 (2019)



Lean Methodology in the Process of Prescribing and Administering Therapeutics in the Intensive Care Unit

Maria do Céu Marques¹(⋈), Luís Sousa¹, Rui Cortes², Liliana Silva², Ermelinda Rebola³, and José Aguiar³

Comprehensive Health Research Center, ALT20-03-0145-FEDER024140 and POCTEP 0499_4IE_PLUS_4_E, University of Évora, Évora, Portugal

mcmarques@uevora.pt

² Lean Health, Lisbon, Portugal

³ Hospital do Espírito Santo, Évora, Portugal

Abstract. A very common problem in Intensive Care Units lies in healthcare provision risks. Intensive care units where there is sophisticated technology, and developed in the Cardiac Intensive Care Unit (CICU) of Hospital in Portugal. The project aimed to detected gaps in the drugs prescription and administration process. **Methods:** We used the Lean methodology to diagnose the CICU issues, by mapping the process, identifying wastes, monitoring them and defining strategies to eliminate the wastes, with healthcare professionals. Results: We identified wastes in 71.4% of the process, being 60% of them "defects". Theses wastes were monitored to understand their incidence in the process. Lastly, we identified the root-causes of wastes with the healthcare professionals and possible improvement measures. Conclusions: The wastes of "defect" can easily generate error in the drugs administration process to patients. In root-cause analysis, we detected that every defect were caused by the same main reason – the lack of a system that allows an easy visualization of the updated prescription. This way, two improvement measures were established – a short-term and a long-term improvement measure. The healthcare professionals' involvement in the improvement project is essential, because they know better the process, and they manage the implementation and sustainability of the improvement measures in the CICU. Their involvement in this type of projects motivates them to actively participate in improvement projects in the hospital.

Keywords: Quality of health care \cdot Lean methodology \cdot Intensive care unit \cdot Therapeutics

1 Introduction

Intensive Care Units (ICUs) provide more complex care for patients of severe illness. The medication for these patients is also more complex and it is administrated several times per day, increasing the probability of errors' events by healthcare professionals.

In the ICUs, 78% of the medical errors are related to medication errors [1]. Medications errors can be originated by different causes [2], attending that the responsibilities inherent to the medication process is divided among healthcare professionals, such as pharmaceuticals, physicians and nurses [3]. Medication errors include errors of prescription, storage, preparation and administration [4]. In most cases, medication errors are not detected because its consequences are insignificant to the patients' health; however, some consequences may worsen the patients' critical health situation [5]. Healthcare professionals tend to have a busy schedule and little time to think about improvement measures to increase the efficiency of processes in an ICU.

Lean production is a philosophy of process management that examines organizational processes from the customer's perspective, with the aim of reducing the use/allocation of resources to processes that create value for the end customer. Lean manufacturing emphasizes increasing efficiency, decreasing waste and using methods that help to decide what matters, rather than accepting pre-existing practices [5].

The Lean methodology has an approach based on the 6 S (sort, simplify, sweep, standardize, self-discipline and security) that allows an examination of the product (or service), the process and the analysis based on defects in order to remove it or reduce it immediately, the approach is completed through continuous performance monitoring. In operational terms, the application of this methodology to a process allows to identify the causes that can lead to waste, to eliminate these causes and to reduce the waste found [6, 7].

Lean tools were recently introduced in the health area, mainly in hospitals and with an emphasis on leadership and lean methodology in a global way [8]. In addition, the evidence suggests that Lean can improve the operational effectiveness of clinical care. However, empirical studies show that the implementation is very localized, and has only minor successes. Most of the changes found in these studies are focused on the use of one or two Lean tools that mainly target the patient's waiting time, and the evidence on their sustainability is minimal [9, 10].

Despite the limited evidence, the main benefits cited in the literature include greater operational efficiency; reduced error rate, waste and operational losses; reduced delay and better cycle times; better quality of service; positive change in culture, unnecessary steps or without added value in the process; greater customer or patient satisfaction; and reduced operating costs. The other benefits mentioned in the literature are increased profits, superior performance to competitors and reduced complaints [11].

The healthcare professionals of Cardiac Intensive Care Unit (CICU) of Hospital in Portugal, detected some difficulties in their daily work. These problems are mainly related to prescription and administration of medication. For that reason, we defined as objective to analyze the process of prescription and administration of medicines using the Lean methodology. We started the process diagnosis in the CICU, in which we worked alongside with the CICU team of healthcare professionals, including nurses, physicians and the nurse-chief of CICU.

2 Methodology

It is a descriptive and exploratory organizational case study [12]. It started from the following research question: How is the process of prescribing and administering drugs

carried out at the CICU of the Hospital, in Portugal? Can the use of Lean methodology contribute to improving organizational performance in terms of prescription and medication administration in the CICU? This research methodology is appropriate to address these research questions [12].

The study was approved by the Ethics Committee for Research in the Areas of Human Health and Welfare at the University of Évora, as well as by the Ethics Committee of the Hospital in the south of Portugal where it was developed.

A Lean process improvement is based on four steps: Planning, Doing, Checking and Acting. This step is performed in a cycle, called the PDCA cycle [5], which means that after finishing the fourth step, a second improvement cycle can be performed, given that the improvement is continuous. In the first step, we observe and map the process, identify the problems of the process, most known as wastes in Lean methodology, measure the significance of wastes, prioritize them and, finally, identify the causes of those wastes and select improvement measures for eliminating or reducing wastes, considering their causes. There are eight wastes in the Lean thinking: talent, waiting time, inventory, transportation, movement, defects, overproduction and overprocessing [5]. The second step of the PDCA cycle is the implementation of the improvement measures for each waste considered a priority to solve. These measures must be implemented only in one part of the process, in order to recognize the possible impacts of the changes in the remaining parts of the process, as one improvement change can worsen one or more steps of the same process or even a different one, if it is related to the first one [13]. For the third step, we checked if the improvement measures are effective and if the effects are positive or negative in other parts of this or other process. The fourth and last step of the PDCA cycle is when the improvement measures are applied to the rest of the process, if the test presents good results. Because this is a diagnosis project, the only step performed of the PDCA cycle is the first one.

For this study, we analyzed the CICU of Hospital, in Portugal, starting with the first stage of a Lean project – the Gemba Walk. This is a direct observation of the process in the CICU, with the objective of getting to know the workspace and the healthcare professionals and observing the every-day processes related to medication or drugs [14]. We performed these tasks inside the CICU for seven days, but always in such a way that we didn't jeopardize the physicians, nurses and operational assistants' work. This tool provided the necessary information to start mapping the process of drugs prescription performed by physicians and the drugs preparation and administration performed by nurses. The process map was created based on the Value Stream Map tool of Lean methodology. The Value Stream Map differs from other maps in the way that the first one provides information, not only on the tasks performed, but also on the specifics of those tasks, such as workspace, worker who performs the task and other important information [14, 15]. The Value Stream Map together with the observation of the process, allowed us to identify the wastes in the various steps of the drug therapy process.

After knowing the process in study and its problems (wastes), we started two different tasks: monitorization of wastes and identification of its causes. There were two types of monitorization: one performed manually, for a week, by nurses, and another performed by us, by measuring the time of tasks or steps performed by nurses. We elaborated the identification of possible causes of wastes, by discussing each waste together with the

team. The prioritization step was not implemented, since all wastes were approached. The last part of this project was to present improvement measures, given the causes of the wastes. In this part, we mapped two different processes: the short-term improvement process and the long-term improvement process.

3 Results

Value Stream Map of the Current Process and Waste Identification

The Value Stream Map is shown in the Fig. 1. This map represents the process of the drug therapy, from the moment the prescription is created until the administration of the medication. The Value Stream Map indicates, below each step, the healthcare professional involved in the task and the area where each step is performed. The blue symbols in the top right of each step of the process illustrates the presence of wastes. We identified wastes in five of the seven steps, meaning that 71.4% of the process steps have wastes. We identified a total of five wastes, being 60% of them a waste of defect.

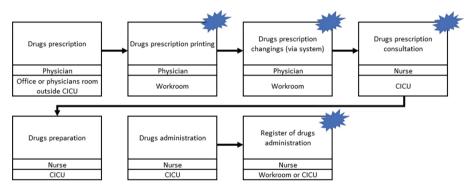


Fig. 1. Value Stream Map of the drug therapy process with the illustration of wastes.

The wastes identified in the Value Stream Map of the current process and illustrated by a blue symbols are categorized according to the seven types of wastes of the Lean methodology and explained in the Table 1.

Monitorization of Wastes

In this part of the project, we monitored each wastes in specific ways. Each monitorization is explained in Table 2. for each waste. There were two wastes, whose monitorization was performed at the same time and in the same way.

For these wastes, there were two types of monitorization. The first method was manually monitorization, where nurses register an occurrence of the waste whenever it was detected by drawing a dash in a monitorization board. The second method was monitored with a chronometer for us to measure the time between administrating and registering the drugs. The waste of movement was simply monitored by counting the steps of nurses when they walk from the CICU to the workroom.

| Step | Waste | Description of waste |
|----------------------------------|----------------|--|
| Drugs prescription printing | Overproduction | Whenever there is a change in the prescription, this must be printed again |
| | Movement | The printer is in the workroom, while the computer is in the CICU |
| Drug prescription consultation | Defect | Some changes on the drugs prescription are made by hand or orally in the prescription paper, meaning that if another drugs prescription is printed, it may come outdated |
| | Defect | Because there are various drugs prescription changes, the prescription that the nurses have may be outdated without knowing |
| Register of drugs administration | Waiting time | The register of drugs administration is performed with delay comparing to the time the drugs were administrated to the patient, which means the nurse may have administered outdated drugs but registered the right ones |

Table 1. Type and description of wastes in the therapy process.

Table 2. List of the monitorizations performed for each type of waste.

| Wastes | Monitorization | | |
|--|--|--|--|
| Necessity of printing the drugs prescription, whenever there is a change | Number of changes in the drugs prescriptions considering that there is no alert system for | | |
| Changes in drugs prescription made orally or by hand in the old prescription | any of them | | |
| Computer and printer are in different rooms | Number of steps between the CICU and the workroom → 15 steps | | |
| Nurses don't know when there is a change to the drugs prescription | Number of times a nurse almost administers the wrong drug or dose, because of missing alerts whenever a change in the drugs prescription is performed | | |
| Delay between drugs administration and its registrations | Time between the administration and the register of drugs | | |

• Monitorization of "almost or near miss" medication errors

We created a board to perform the monitorization of "almost" medication errors, where nurses would use the first manual method of monitorization. We monitored it for a week, but there were no results achieved with this monitorization.

• Monitorization of the number of changes of drugs prescriptions

Two types of changes in drugs prescriptions were monitored: written changes with no alerts from physicians and changes with oral alerts from physicians. The results are shown in the Table 3. We can verify that of a total of 31 changes in prescriptions, 87.1% were performed during the morning shift and only 12.9% were performed during the afternoon. No changes to the prescriptions were made during the night shifts. The results also show that 25.8% of the total changes were performed orally by physicians.

| Shift | Monday | | Tuesday | | Wednesday | | Thursday | | Friday | |
|-----------------------------------|-----------|-------------------|-----------|-------------------|-----------|-------------------|-----------|-------------------|-----------|-------------------|
| | # changes | # oral changes |
| Morning shift (8 h–16 h) | 3 | 3 | 4 | 0 | 6 | 1 | 9 | 2 | 5 | 1 |
| Afternoon shift (16 h–24 h) | 0 | 0 | 2 | 1 | 0 | 0 | 2 | 0 | 0 | 0 |
| Night shift (24 h–8 h) | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |

Table 3. Results of the monitorization of written and oral changes in drugs prescriptions.

• Monitorization of time between drugs administration and its registration

We monitored the time between drugs administration and drugs registration by observing the two moments in the process: when nurses performed the administration of medication and its register, we wrote the time those actions happened. This was performed during a morning shift and five different registrations were observed. The median of the delay between the begging of the drugs administration (9 am) and the drugs registration was 3 h and 42 min.

Root-Cause Analysis

The root-cause analysis of wastes was performed with the healthcare professionals' team and the results of this analysis were, for each waste:

Waste: Necessity of printing drugs prescription whenever there is a change

• Lack of technology that provides a constant consultation of the most recent drugs prescription

Waste: Computer and printer are in different rooms

- Lack of space in the CICU for a printer
- The printer is not essential for the CICU operation

Waste: Changes in drugs prescription performed orally or by hand in the old prescription

• Lack of technology that provides a rapid and easy change of the drugs prescription, without the necessity of the physician having to go to the CICU

Waste: Nurses don't know when there is a change to the drugs prescription

• Lack of technology that provides a constant consultation of the most recent drugs prescription

Waste: Delay between drugs administration and its registrations

- Lack of technology that provides a possibility of registering the drugs administrated right after the actual administration
- Lack of time for nurses to perform the registration of medication in the workroom computers right after its administration to each patient

Improvement Measures for Wastes

We worked with the team in founding a possible improvement measure for the wastes in the process. After brainstorming, there was one improvement measure identified that could easily eliminate any of the wastes identified: tablets for physicians and nurses perform their daily tasks whenever consulting the most updated prescriptions.

We considered two processes improvements, a short-term improvement process and long-term improvement process, since the improvement measure identified is not possible to be implemented in short-term. Each of the process improvements (short-term and long-term) are illustrated with a Value Stream Map in Fig. 2 and Fig. 3, respectively.

- Short-term improvement process: the utilization of a communication channel (e.g. a WhatsApp group), so physicians can easily alert nurses for new changes in the drugs prescriptions, by mentioning the bed number of the patient to whom the prescription changes were made.
- <u>Long-term improvement process:</u> the use of tablets by nurses and physicians to perform their tasks. Consequently, each nurse can consult updated drugs prescriptions and register the necessary information without leaving the CICU.

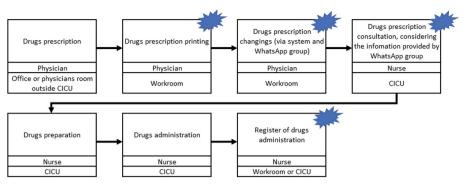


Fig. 2. Value Stream Map of the drug therapy short-term improvement process.

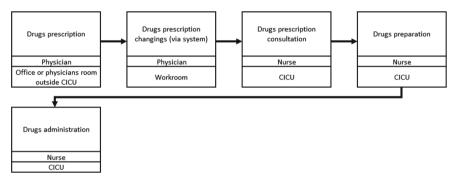


Fig. 3. Value Stream Map of the drug therapy long-term improvement process.

4 Discussion

Value Stream Map of the Current Process and Waste Identification

Although the Gemba Walk had provided us critical information for the beginning of the improvement process, it may provide us some biased information on the process, given that the healthcare professionals may feel "observed", performing there tasks differently. However, the wastes that were found in the process were not problems that could be easily avoided, thus providing us solid information about the process wastes. The Value Stream Map of the current process has seven steps, performed by physicians and nurses between the CICU and the workroom, for most of the tasks. We confirmed and worked through the improvement project with the team to validate the wastes that were identified. 40% of the wastes (two out of five) were considered defects, this is, the steps in the process were structured in such a way that allowed mistakes to happen, such as providing the wrong therapy to the patient. The other three wastes were identified as overproduction, movement and waiting time. In a study that analyzes four judged cases in which Lean is a process improvement methodology that allows identifying and reducing medication

errors, increasing patient safety and reducing financial costs. A systematic review also found a reduction in medication errors, especially in the increased countries [16, 17].

Monitorization of Wastes

Each waste was monitored in order to corroborate their existence and to create a baseline of the process. The movement performed by nurses between the CICU and the workroom was 15 steps. The objective was after the improvement measures being implemented, to turn to 0 the number of steps by eliminating the task of printing the drugs prescriptions. The monitorization of wastes related to "almost" medication errors was not successful in obtaining any results, although all healthcare professionals know that "almost" medication errors happened during the monitorization week. We believed that the concept of "almost errors" did not help the monitorization process, because the healthcare professionals may feel guilty and judged by admitting this type of errors.

The monitorization of wastes related to the changes in drugs prescriptions occurred for one week and it was performed manually by the nurses of the three different shifts (morning, afternoon and night shift). The total of 31 changes in a week means that there could be a possible outdated therapy being administered to a patient for 31 times in one week, providing significant opportunities for medication errors. It's important to understand the period of most prescriptions' changes, not only to describe better the problem, but also to have more alerted nurses when they perform the drugs administrations task during that period, in this case the morning period, while the problem isn't solved.

The monitorization of the delay between drugs administration and its registrations have demonstrated that nurses who work during the morning shift are not able to perform the registration until the end of the shift, because of many tasks they need to do during the shift and because the registration process takes some time. For this reason, the delay is on average 3 h and 43 min. In the registration process, the nurses need to check the boxes for the drugs that were administered during that shift. These drugs are already listed and updated according to the prescriptions' changes. The fact that the nurse only performs the registration in the end of the shift can also originate errors in the registration because, if some drugs were wrongly administrated, the nurse may not notice when they register the drugs, because of the delay associated to the process. In a study carried out in Thailand, there was also an improvement in the results in which it was found that the number of distribution errors decreased from 6 to 2 incidents per 20,000 patient days per month, representing a 66.66% reduction [16, 17].

Root-Cause Analysis

We analyzed the root-causes for each waste with the team of healthcare professionals of CICU by discussing the possible origins of each waste. For all wastes, the major cause was the non-existence of an appropriate technology or system that provided:

- Alerts whenever a change in the drugs prescriptions is made
- The possibility of healthcare professionals easily register the medication administered
- The possibility of always consulting the most updated prescription, without needing to be printed.

In a study carried out in Thailand, there was also an improvement in the results in which it was found that the number of distribution errors decreased from 6 to 2 incidents per 20,000 patient days per month, representing a 66.66% reduction [16, 17].

Improvement Measures for Wastes

The root-cause analysis provided the necessary insights to establish the improvement measures for the process. For the wastes are all related to the same cause, creating a single improvement measure may eliminate all wastes and be a more practical way to approach the problems for healthcare professionals, as they don't need to go through extensive changes in their daily work in the CICU. Since the ideal mapped process involves technology, and the time associated to the implementation of this type of changes tend to be longer, we identified a short-term improvement process and a long-term improvement process.

For the short-term improvement process, this is, while there is no technology implemented in the process, we suggested the creation of a communication channel (e.g. a WhatsApp group), so physicians were able to alert nurses about changes in drugs prescription. The message would be standardized and would only contain the essential information, this is, the alert for a change in a prescription (not mentioning any kind of drugs information) and the number of the patients bed, in order to associate the change of drugs prescription to the right patient. Although this improvement decreases the possibility of medication errors, it also increases the time of tasks in the process because of the message created by physicians in the communication network and the consultation of these messages by nurses. Also, the need to print the prescription is maintained with this first improvement measure and the registration of the medication is still performed after the drugs administration.

For the long-term improvement process we considered the following: tablets for each nurse in the shifts, there are three at most, from which they could consult the updated drugs prescription of each patient whenever they need to prepare the medication. Also because the consultation was being performed directly from the system, the drugs registration could be performed simultaneously, and no prescriptions would need to be printed. This improvement measure would reduce the number of tasks from 7 to 5 (reduction of 28.6%) and would eliminate completely the possibility of medication errors, increasing the safety of drugs administration. In a study carried out in Ireland it was found that the average delay of one round in the administration of oral medications was 125 min. After applying the Lean methodology, the average round-trip time for medication administration decreased by 51 min. The average number of interruptions per round dropped from an average of 12 at the baseline to 11 after the intervention, with a 75% reduction in interruptions in the supply of medicines [18].

5 Conclusion

This project was a diagnosis of the medication problem of CICU. In this way, we used the Lean methodology to implement the first part of the PDCA cycle and: studied the process, measured the inherent wastes, and suggested improvement measures for those wastes. Because this diagnosis was performed together with the team of healthcare professionals,

now they are prepared to proactively implement the measures established together, given the knowledge they've obtained with the improvement project. The involvement of the healthcare professionals in improvement projects is essential to sustainability. If we only performed the steps of the lean methodology to approach the problems, the healthcare professionals would not be able, or even motivated, to continue the improvement process and perpetuate their knowledge to other possible processes that could be improved.

From the data presented, it is considered that the implementation of the Lean methodology and the participation of the health team allowed a broad and detailed analysis of the process of prescription and administration of medication. The use of the Lean methodology allowed demonstrating the complexity of the prescription and medication administration process, giving visibility to the central role of the nursing team for the identification of problems, as well as the proposal for improvements. The adoption of the Lean methodology can help healthcare organizations to implement a successful drug circuit management process. Within the scope of a project financed by the Science and Technology Foundation, with the reference ALT20-03-0145-FEDER-024140. The authors would like to thank the Science and Technology Foundation, that financed the project and the multidisciplinary team of CICU, who welcomed the consulting team in their workspace and contributed to the success of this project.

References

- Farzi, S., Irajpour, A., Saghaei, M., Ravaghi, H.: Causes of medication errors in intensive care units from the perspective of healthcare professionals. J. Res. Pharm. Pract. 6(3), 158–165 (2017). https://doi.org/10.4103/jrpp.JRPP_17_47. Accessed 30 June 2020
- Shulman, R., Singer, M., Goldstone, J., Bellingan, G.: Medication errors: a prospective cohort study of hand-written and computerised physician order entry in the intensive care unit. Crit. Care 9(5), R516–R521 (2005). https://link.springer.com/article/10.1186/cc3793. Accessed 30 June 2020
- Tucker, A.L., Nembhard, I.M., Edmondson, A.C.: Implementing new practices: an empirical study of organizational learning in hospital intensive care units. Manage. Sci. 53(6), 894–907 (2007). https://doi.org/10.1287/mnsc.1060.0692. Accessed 30 June 2020
- Billstein-Leber, M., Carrillo, C., Cassano, A.T., Moline, K., Robertson, J.J.: ASHP guidelines on preventing medication errors in hospitals. Am. J. Health-Syst. Pharm. 75(19), 1493–1517 (2018). https://doi.org/10.2146/ajhp170811. Accessed 7 July 2020
- Kimsey, D.B.: Lean methodology in health care. AORN J. 92(1), 53–60 (2010). https://doi. org/10.1016/j.aorn.2010.01.015. Accessed 7 July 2020
- Montella, E., Di Cicco, M.V., Ferraro, A., Centobelli, P., Raiola, E., Triassi, M., Improta, G.: The application of Lean Six Sigma methodology to reduce the risk of healthcare—associated infections in surgery departments. J. Eval. Clin. Pract. 23(3), 530–539 (2017). https://doi.org/10.1111/jep.12662. Accessed 7 July 2020
- Improta, G., Balato, G., Ricciardi, C., Russo, M.A., Santalucia, I., Triassi, M., Cesarelli, M.: Lean Six Sigma in healthcare. TQM J. 31(4), 526–540 (2019). https://doi.org/10.1108/TQM-10-2018-0142. Accessed 7 July 2020
- 8. Kelendar, H., Faisal, M., McIntosh, B., Mohammed, M.A.: The use of Lean methodology in healthcare settings in developing countries: a narrative review. Br. J. Healthcare Manag. **26**(6), 1–13 (2020). https://doi.org/10.12968/bjhc.2019.0095. Accessed 7 July 2020

- Moraros, J., Lemstra, M., Nwankwo, C.: Lean interventions in healthcare: do they actually work? A systematic literature review. Int. J. Qual. Health Care 28(2), 150–165 (2016). https:// doi.org/10.1093/intqhc/mzv123. Accessed 7 July 2020
- Hallam, C.R.A., Contreras, C.: Lean healthcare: scale, scope and sustainability. Int. J. Health Care Qual. Assur. 31(7), 684–696 (2018). https://doi.org/10.1108/IJHCQA-02-2017-0023. Accessed 7 July 2020
- 11. Antony, J., Sreedharan, R., Chakraborty, A., Gunasekaran, A.: A systematic review of Lean in healthcare: a global prospective. Int. J. Qual. Reliab. Manag. **36**(8), 1370–1391 (2019). https://doi.org/10.1108/IJQRM-12-2018-0346. Accessed 7 July 2020
- 12. Yin, R.K.: Case Study Research and Applications: Design and Methods. Sage Publications, Singapore (2017)
- 13. Sullivan, P., Soefje, S., Reinhart, D., McGeary, C., Cabie, E.D.: Using Lean methodology to improve productivity in a hospital oncology pharmacy. Am. J. Health-Syst. Pharm. **71**(17), 1491–1498 (2014). https://doi.org/10.2146/ajhp130436. Accessed 30 June 2020
- Lot, L.T., Sarantopoulos, A., Min, L.L., Perales, S.R., Boin, I.D.F.S.F., de Ataide, E.C.: Using Lean tools to reduce patient waiting time. Leadersh. Health Serv. 31(3), 343–351 (2018). https://doi.org/10.1108/LHS-03-2018-0016. Accessed 7 July 2020
- Vats, A., Goin, K.H., Fortenberry, J.D.: Lean analysis of a pediatric intensive care unit physician group rounding process to identify inefficiencies and opportunities for improvement. Pediatr. Crit. Care Med. 12(4), 415–421 (2011). https://doi.org/10.1097/PCC.0b013e3181fe 2e3c. Accessed 30 June 2020
- Trakulsunti, Y., Antony, J.: Can Lean Six Sigma be used to reduce medication errors in the health-care sector? Leadersh. Health Serv. 31(4), 426–433 (2018). https://doi.org/10.1108/ LHS-09-2017-0055. Accessed 7 July 2020
- Costa, D.G.D., Pasin, S.S., Magalhães, A.M.M.D., Moura, G.M.S.S.D., Rosso, C.B., Saurin, T.A.: Analysis of the preparation and administration of medications in the hospital context based on Lean thinking. Revista Escola Anna Nery 22(4), e20170402 (2018). https://doi.org/10.1590/2177-9465-ean-2017-0402. Accessed 7 July 2020
- 18. Kieran, M., Cleary, M., De Brún, A., Igoe, A.: Supply and demand: application of Lean Six Sigma methods to improve drug round efficiency and release nursing time. Int. J. Qual. Health Care **29**(6), 803 (2017). https://doi.org/10.1093/intqhc/mzx106. Accessed 7 July 2020





Technology in the Face of the Challenges of the Long-Term Care System for the Elderly in Spain

Luis López-Lago Ortiz¹(⋈), Sara Arroyo Chacón o, Carmen Cipriano Crespo o, Jerónimo Luengo Polo o, and Beatriz Muñoz González o, and Beatriz Muñoz González o,

 University of Extremadura, Cáceres, Spain luislopezlago@unex.es
 University of Castilla-La Mancha, Talavera de la Reina, Spain

Abstract. Spanish society, as in other developed countries, is experiencing remarkable aging. The prolongation of longevity results in the existence of an increasing number of dependent older adults. Likewise, in the field of technology, outstanding advances are being made to improve the lives of the elderly. This article analyzes the relationship between the Spanish long-term care system for the elderly and technology. We identify the most relevant issues related to the long-term care system in Spain: the "familist" model of the Welfare State, the multilevel model of the LTC system, and the impact of the Long-Term Care Law and the 2008 crisis, and the informal caregivers of the elderly. We contrast each of these topics with proposals from the scientific and institutional fields related to technologies. Moreover, we establish some possible research lines related to the long-term care system for the elderly with technologies.

Keywords: Long-term care \cdot Technology \cdot Public policies \cdot Aging \cdot Elderly dependents

1 Introduction

Longevity is a significant concern in developed countries [7]. Profound socio-cultural changes have lowered birth rates, and progress in the field of health has led to increasingly longer lives. These phenomena result in an aging society [4]. In the case of Spain, the aging index has increased notably, rising from 39.47 in 1980 to 125.79 in 2020. This increase has accelerated in recent years, rising by more than two points annually since 2014 [38]. It is estimated that by 2050, people over 65 in Spain will account for over 30% of the population, with 13 million. Of these, more than 4 million will be over 80 years old [17].

To meet the needs of an increasingly aging population, States have opted for different types of public policies. In the case of older people whose physical or cognitive deterioration does not allow them to carry out the tasks of their daily lives normally, long-term care (LTC) policies for the elderly have been developed. In Spain, these public policies

were implemented in the 1980s, later than in most Western European countries, and reached a turning point with the entry into force on January 1, 2007, of Law 39/2006, of December 14, on the Promotion of Personal Autonomy and Care for Dependent Persons, also known as Long-Term Care Law or LAPAD [13]. This law was an extension of the Spanish Welfare State model, making the long-term care system its fourth pillar, alongside health care, public education, and social security [5].

The LTC system in Spain is not unconnected with advances in technology, and the LAPAD itself contemplates remote assistance and technological development in R+D+I [19]. In this sense, the European Union recommends using technology to improve the quality of life of the elderly, promoting their autonomy and independence. To this end, for more than a decade, it has launched a strategy of research and advocacy on public policies where technological platforms and devices are linked to the well-being of the elderly, within the framework of "Ambient Assisted Living" [1, 14]. In this context of demographic aging and institutional commitment to the introduction of technologies in care for the elderly, our analysis of the relationship between technologies and the long-term care system in Spain is developed.

2 Objectives and Methodology

This article is part of the research line on public policies on aging of the Project "International Institute for Research and Innovation on Ageing (4IE+)". It aims to identify the main issues related to the long-term care system in Spain and its relationship with technology. This is a first approach to this topic, where we explore the possibilities of giving continuity to the results in future research.

Regarding the methodology used, we have realized a scoping review of the long-term care system in Spain. This has allowed us to identify the main issues in the scientific literature. Subsequently, we have analyzed these issues by contrasting them with articles that address them from the field of technologies.

3 Long Term Care System in Spain

The idea that in Spain, the care of the elderly corresponds to a "familist" model of the Welfare State occupies a central place in the reflections on the long-term care system [2, 9, 18]. The main characteristic of this model is the leading role played by the family as a provider of care for the elderly [31]. This model is particularly widespread in the countries of Southern Europe [9]. It also generates significant gender inequalities by encouraging women to be responsible for the care of the elderly [25], with a cultural model that fosters this reference.

Although the "familist" model is the ideological support of the culture of care in Spain, a series of socio-cultural changes experienced in the country have relativized some of the patterns of behavior characteristic. Factors such as incorporating women into the workforce or developing the LAPAD have led to a system with a wide range of care services, both public and private, offered outside the family setting [33]. In this regard, it is worth noting the role of nursing homes, which are becoming the preferred resource for persons over 80 years of age or with severe difficulties in their autonomy

[2, 3, 33]. This phenomenon is particularly relevant in the configuration of the Spanish LTC system and is one of the guiding principles in the planning of public policies on long-term care for the elderly.

However, the high mortality due to the pandemic of COVID 19 in nursing homes has motivated a scientific, political, and social debate on deinstitutionalization. Fantova [15] proposes it to reduce the possibilities of transmission in this type of resource since fewer residents and prevention measures are facilitated. Consequently, the pressure on workers will also be reduced. In this regard, it should be remembered that any policy of deinstitutionalization of the elderly must be accompanied by reinforcements in the public services that care for them at home because otherwise, the tasks of care will fall back on the women of the family. To avoid such situations, as Deusdad points out [12], there must be clear policy guidelines with a gender perspective regarding care in the home.

Another of the issues highlighted in the analysis of the Spanish LTC system is its multilevel nature. It involves the various government levels¹ in implementing long-term care policies [9, 16, 26]. The channel for the participation of the administrations is the SAAD², where the execution of public policies is coordinated according to their competencies. Furthermore, this system includes public resources and duly accredited private-consultants to optimize the resources available for the care of dependent adults. For specifically inter-institutional coordination, there is the "Territorial Council of Social Services and of the System for Autonomy and Care for Dependency", which is a multilateral cooperation agency similar to the sectoral conferences, with the participation of the State, the autonomous communities, and, where appropriate, the local entities [19].

This multilevel model of the LTC system is highly delegated to the regional and municipal levels [11]. In this model, the services provided by city councils play an increasingly important role, which is characteristic of the most advanced systems, such as the Nordic ones. Although in Spain, the weight of regional policies is still undeniable [9].

Several authors emphasize the complementary nature of the policies on care for dependent adults implemented at different levels of government [6, 9]. However, authors such as Lozano Peña and García Bustos [26] and Sáenz Royo [36] highlight the difficulties in implementing LTC policies due to their imbalances of the statal underfunding of the regional treasuries and their limited capacity to collect funds. Moreover, since the beginning of the COVID-19 pandemic, some conflicts of competence have arisen between administrations that directly affect the LTC system, with the wide dispersion of regional regulations, especially nursing homes absence of agreed and uniform protocols [28].

The next recurring issue in the literature reviewed is the development of the LAPAD, and the impact of the 2008 economic crisis. On the one hand, there is a consensus among the authors that the entry into force of the LAPAD on January 1, 2007, represented a substantial normative advance, despite the difficulties encountered in its implementation in the form of public policies [8, 25, 39]. The Law proposed a regulatory improvement in the framework of care for dependent persons, guaranteeing universal access to a

¹ In the case of Spain, the state, regional and municipal levels.

² System for Autonomy and Care for Dependency.

wide range of public services (prevention and promotion of personal autonomy, home help, remote assistance, nursing homes, etc.) [39]. It also represented an opportunity to consolidate the decentralization of care for dependent persons and to create specialized administrative architectures in environments that are closer to citizens, such as the autonomous community and the municipality [24].

However, the full development of the LAPAD was hampered by the economic crisis of 2008. The economic slowdown led to severe difficulties in terms of revenue collection for investment in public policies. And austerity policies, which were aimed at overcoming the crisis, put a considerable brake on social spending [34].

Although there were clear signs of economic recovery from 2015 onwards, the long-term care system in Spain continued to carry over the consequences of the 2008 crisis to the present day. To this, is added a new crisis, that the COVID-19 pandemic, which in addition to causing significant stress on the resources of the LTC system, has an impact on the economy that is still difficult to measure. However, the institutional responses seem to have a different tone to that of austerity in the case of the current economic crisis. The Ministry of Social Rights has designed a shock plan to promote dependency policies, with an investment of more than 600 million euros in 2021. Nevertheless, at present³, its execution depends on the approval of the General State Budget [37].

Linked to the difficulties of implementing the long-term care policies contemplated in the LAPAD is the labor informality of caregivers in Spain. One of the main contributions of the Law was the responsibility of the administration for the care of dependent persons, in addition to the promotion of labor regulation of non-professional caregivers. However, this desire was not reflected in the labor market due to the economic crisis [30, 39]. Furthermore, the "ideal of care" of the "familist" model, which establishes specific resistance to professional care, plays a fundamental role in the difficulties of professionalization of caregivers due to the cultural importance of family care [30]. Moreover, as Spijker and Zueras point out, the high unemployment rates in Southern European societies foster care work development within the informal economy. This informality situation has made invisible the difficulties that this and other highly feminized groups in the care sector have suffered during the COVID-19 pandemic and subsequent outbreaks [10].

4 Technology and the Long-Term Care System for the Elderly

Below, we contrast the main issues related to the long-term care system in Spain, with technological solutions that are being considered in various fields such as health, aging, or loneliness.

The "familist" model tends, due to cultural inertia, to prolong the stay of the elderly at home as much as possible. This fact coincides with the idea that is being imposed, after the impact of the pandemic in the nursing homes, of the deinstitutionalization of the elderly to develop their life at home. These phenomena point to what the scientific literature refers to as "home based care", that is, overcoming the institutionalized model and a proposal for care in the home [40]. Moreover, in this field, technological solutions

³ October, 08, 2020.

emerge strongly within what we call e-healthcare; that is, technologies to improve health and care. In many cases, with determined institutional support, such as the European Union provided through the "Ambient Assisted Living" program [1].

Within the framework of e-healthcare, we find many devices and strategies that can help prolong the stay of the elderly in their homes by improving their autonomy. For example, the cell phone, a device that may be familiar to many of the elderly, has a prominent role in e-healthcare strategies. Specific applications can be created for health and care issues or use existing resources such as SMS or instant messaging applications such as Whatsapp or Telegram. SMS has proved particularly useful in the area of therapeutic adherence for the elderly, and a large sample of studies has revealed very positive results [22].

Robots are another type of technological assistance at home that is being bet. We find robots of different types. Assistance robots help with daily tasks such as personal hygiene, cooking, or cleaning the house. Robots of accompaniment to diminish the sensation of loneliness. Or surveillance robots to deal with therapeutic adherence to medication or control vital signs, among other functions. It should also be noted that many people still feel uncomfortable with this type of technology and that professionals have some doubts about its usefulness [23].

Other technological solutions, which help to prolong the autonomy of the elderly, are the "wearables". These are devices that accompany the user. They can be in the form of a bracelet, smartwatch, or be incorporated into clothing or shoes. They are especially useful for monitoring the health of the user [27].

In the field of technological assistance for the promotion of autonomy of the elderly, the International Institute for Research and Innovation on Ageing (4IE+) has several lines of research open. The use of existing voice assistants, such as Alexa, for reminding people of their medication intake [20], the Feedelio application for research on nutrition and the elderly [35], or the development of a food monitoring application for the elderly [29], are some examples. However, we would like to highlight the Assistant on Care and Health Off-line (A.C.H.O.), a voice assistant that can be used as a reminder of medical visits and medication intake, characterized by its capability to function without an internet connection. This makes it particularly interesting for working in homes where only older people live, and there is often no internet connection, or in rural areas where there is less coverage of this service [21]. This device is in the usability testing phase, with very positive perspectives for developing new functions.

On a different theme, some of the problems associated with the multilevel model of the Spanish long-term care system can be reduced with technological solutions. An e-administration, with an optimal flow of information between the different administration levels, would help avoid some of the overlapping competencies that we have seen during the pandemic. To this end, there must be clear and agreed-upon protocols for action. Deusdad and Riccó [13] point out that for workers in the care sector involved in administrative processes, such as social workers, the digitalization of bureaucratic processes increases efficiency and consequently improves care. However, they insist on the need for coordination between areas and administrations to provide adequate care. Likewise, this type of electronic administration should be adapted to facilitate its use by the elderly and their caregivers, simplifying the procedures and thus alleviating the

administrative burden that, on numerous occasions, is involved in applying for aid linked to the LAPAD.

Regarding the LAPAD, mentions of technology are few but relevant. On the one hand, telecare plays a prominent role. It has its own epigraph in the catalog of services included in article 15. Also, article 22 develops the right of dependent persons to this type of care, which the Law defines as "assistance to beneficiaries through the use of communication and information technologies, supported by the necessary personal means, in immediate response to emergencies, or situations of insecurity, loneliness, and isolation". On the other hand, the tenth additional provision, whose title is "Research and Development", expressly mentions that the public authorities shall promote research to improve the quality of life of dependent persons. Furthermore, social organizations and other agents involved in developing regulations on technologies, products, and services for dependent persons are promoted [19].

Deinstitutionalization and the "home based care" model may be an interesting key to exploring the impact of crises on the LTC system. As Woods and Kong [41] point out, this formula of domiciliary care is less costly for public administrations. This is because residential resources for the elderly have a high cost for the administration. With the extension of the stay in the homes, part of the economic resources destined to residential homes for the elderly could be allocated to deinstitutionalization programs. In this way, the budgetary items would be optimized and impact more users and with more quality.

Regarding the issue of informal caregivers, evidence points to the idea that technologies applied to care help reduce the perception of task overload experienced by this group. This also decreases the high levels of stress suffered by non-professional caregivers since the physical and psychological dependence on them is reduced [32]. However, it should also be noted that this group of informal caregivers, where we find family members of elderly dependents and workers in the informal economy, has difficulty accessing these technologies. If they have access to them, it is not because they are caregivers, but because the dependent older adult is a beneficiary of this care support technology. Therefore, it cannot be easy to train these informal caregivers in their use. Public policymakers must take this situation into account when promoting the use of technologies in care.

5 Conclusions

In the different issues that we identify as the main ones in the scientific literature on the long-term care system in Spain, we find different contributions that technology can make.

Concerning home care, typical of the "familist" system, and the commitment of public administrations to deinstitutionalization, there is a whole range of devices aimed at "home based care". The use of the cell phone either with specific applications or using existing ones, robots, or voice assistants are examples. These would not only help to promote the personal autonomy of older people but can also be a positive support for caregivers. Although in the case of informal caregivers, access to these technologies poses some difficulties that should be considered by those responsible for public policies on care.

In the field of home care and technologies, we consider that a very interesting contribution can be made with qualitative methodologies from the social sciences. Furthermore, there is a whole field of ethnographic work with assistive technology users to continue to deepen.

Also linked to the paradigm of "home based care" and its technological support is the idea that home care is more effective in terms of budget. Thus, an increase in at-home care for the elderly can help make LTC systems more resistant to economic crises. That is another way of study that we consider interesting to explore.

About the multilevel model of the long-term care system, digital administration improvements can help reduce communication problems and overlaps between different administrations. To this end, these improvements must be accompanied by clear protocols. Also, a user-oriented e-administration can help simplify the tedious procedures that accompany applications for aid related to long-term care and reduce waiting times in the granting.

Finally, although the LAPAD explicitly contemplates research in technologies and remote assistance, it would be very positive to adequate this regulatory framework to the new technological developments in the field of care for the elderly.

Acknowledgment. This work was supported by the 4IE+ project (0499-4IE PLUS 4 E) funded by the Interreg V-A España-Portugal (POCTEP) 2014–2020 program.

References

- AAL Association Ambient Assisted Living. http://www.aal-europe.eu/. Accessed 10 Sept 2020
- Abellan, A., Perez, J., Pujol, R., Sundstrom, G., Jegermalm, M., Malmberg, B.: Partner care, gender equality, and Ageing in Spain and Sweden. Int. J. Ageing Later Life 11, 69–89 (2017). https://doi.org/10.3384/ijal.1652-8670.16-305
- Abellán García, A., Aceituno Nieto, P., Fernández Morales, P., Ramiro Fariñas, D., Pujol Rodríguez, R.: Una estimación de la población que vive en residencias de mayores. In: Envejec. en red. CSIC (2020). http://envejecimientoenred.es/una-estimacion-de-la-poblacion-quevive-en-residencias-de-mayores/
- 4. Abellán García, A., Aceituno Nieto, P., Pérez Díaz, J., Ramiro Fariñas, D., Ayala García, A., Pujol Rodríguez, R.: Un perfil de las personas mayores en España, 2019, Madrid (2019)
- Alzás García, T., Fondón Ludeña, A.: La Ley de Promoción de la Autonomía Personal y Atención a Personas en Situación de Dependencia. In: Muñoz González, B. (ed.) Personas mayores en Extremadura. Un estudio de la dependencia en entornos rurales, pp. 55–75. Amarú Ediciones, Salamanca (2012)
- Atarodi, S., Berardi, A.M., Toniolo, A.M.: Comparing local policy practices to implement ICT-based home care services for aging-in-place in Finland, France, Italy, Spain, and Sweden. Gerontechnology 18, 108–121 (2019). https://doi.org/10.4017/gt.2019.18.2.005.00
- Bloom, D., Chattejeri, S., Kowal, P., Lloyd-Sherlock, P., Mckee, M., Rechel, B., Rosenberg, L., Smith, J.P.: Macroeconomic implications of population ageing and selected policy responses. Lancet 385, 649–657 (2015). https://doi.org/10.1016/S0140-6736(14)61464-1
- 8. Cantarero Prieto, D., Pascual Sáez, M., Rodríguez Sánchez, B.: Differences in the provision of formal and informal care services after the implementation of the dependency act: the Spanish case. PAPELES Trab DEL Inst Estud Fisc 1–36 (2019)

- Casanova, G., Lamura, G., Principi, A.: Valuing and integrating informal care as a core component of long-term care for older people: a comparison of recent developments in Italy and Spain. J. Aging Soc. Policy 29, 201–217 (2017). https://doi.org/10.1080/08959420.2016. 1236640
- Castellanos-Torres, E., Tomás, J., Chilet-Rosell, E.: COVID-19 en clave de género. Gac. Sanit. 34, 419–421 (2020). https://doi.org/10.1016/j.gaceta.2020.04.007
- 11. Davey, V.: Report: the COVID19 crisis in care homes in Spain: recipe for a perfect storm (2020)
- 12. Deusdad, B.: COVID-19 and nursing homes' crisis in Spain: ageism and scarcity of resources. Res. Ageing Soc. Policy **8**, 142–168 (2020). https://doi.org/10.447/rasp.2020.5598
- Deusdad, B., Riccò, I.: Professional stakeholders' views of the use of digital technologies in Spanish long-term care. Hum. Technol. 14, 382–403 (2018). https://doi.org/10.17011/ht/urn. 201811224839
- 14. European Union (EU): Ageing well in the information society: action plan on information and communication technologies and ageing, Brussels (2007)
- 15. Fantova, F.: Responding to COVID-19 in Spain: returning from care homes to live with families as an alternative? (2020)
- 16. Fernández-Alonso, M., Ortega, M.: Gender and informal social support in Spanish culture. Res. Ageing Soc. Policy **6**, 118–146 (2018). https://doi.org/10.4471/rasp.2018.3212
- 17. Fernández, J.L., Parapar, C., Ruíz, M.: El envejecimiento de la población. Lychnos Cuad la Fund Gen del CSIC 2 (2010)
- 18. García-Faroldi, L.: Welfare states and social support: an international comparison. Soc. Indic. Res. 121, 697–722 (2015). https://doi.org/10.1007/s11205-014-0671-1
- Gobierno de España: Ley 39/2006, de 14 de diciembre, de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia. Boletín Oficial del Estado 299, España (2006)
- Jesús-Azabal, M., Medina-Rodríguez, J.A., Durán García, J., García Pérez, D.: Remembranza pills: using Alexa to remind the daily medicine doses to elderly. In: García-Alonso, J., Fonseca, C. (eds.) Gerontechnology Second International Workshop, IWoG 2019, Cáceres, Spain, 4–5 September 2019, Revised Selected Papers. Springer, Heidelberg (2020)
- Jesús-Azabal, M., Rojo, J., Moguel, E., Flores-Martin, D., Berrocal, J., García-Alonso, J., Murillo, J.M.: Voice assistant to remind pharmacologic treatment in elders. In: García-Alonso, J., Fonseca, C. (eds.) Gerontechnology, IWoG 2019. Communications in Computer and Information Science, vol. 1185. Springer, Heidelberg (2020)
- Kannisto, K.A., Koivunen, M.H., Välimäki, M.A.: Use of mobile phone text message reminders in health care services: a narrative literature review. J. Med. Internet Res. 16, e222 (2014). https://doi.org/10.2196/jmir.3442
- van Kemenade, M.A.M., Hoorn, J.F., Konijn, E.A.: Do you care for robots that care? Exploring the opinions of vocational care students on the use of healthcare robots. Robotics 8 (2019). https://doi.org/10.3390/robotics8010022
- De La Fuente Robles, Y.M., Sotomayor Morales, E.M., del Carmen Martín Cano, M.: Vulnerabilidad sobrevenida en personas en situación de dependencia en España. Scr NOVA Rev ELECTRÓNICA Geogr Y CIENCIAS Soc XX, 1–29 (2016)
- 25. Lorenzo Carrascosa, L.: Ageing population and family support in Spain. J. Comp. Fam. Stud. **46**, 499–516 (2015). https://doi.org/10.3138/jcfs.46.4.499
- Lozano Peña, A., García Bustos, F.: Desequilibrios Verticales en la Financiación Autonómica: El caso de la Financiación de la Atención a la Dependencia. Rev Estud Reg Mayo-Agost 2, 41–66 (2018)
- 27. Luque Ordóñez, J.: Dispositivos y tecnologías wearables. ACTA **41**, 14 (2016)
- 28. Martín Ayala, M.: La ausencia de un modelo sociosanitario en la crisis covid 19. Estudios **30**, 47–57 (2020)

- Moguel, E., García-Alonso, J., Laso, S.: YourPantry: food monitoring through pantry analysis using the smartphone and making use machine learning and deep learning techniques.
 In: García-Alonso, J., Fonseca, C. (eds.) Gerontechnology. Second International Workshop, IWoG 2019, Cáceres, Spain, 4–5 September 2019, Revised Selected Papers. Springer, Heidelberg (2020)
- Moreno-Colom, S., Recio Càceres, C., Torns Martín, T., Borràs Català, V.: Long-term care in Spain: difficulties in professionalizing services. J. Women Aging 29, 200–215 (2017). https://doi.org/10.1080/08952841.2015.1125699
- Moreno Domínguez, A.: El familiarismo cultural en los Estados del Bienestar del Sur de Europa: transformaciones de las relaciones entre lo público y lo privado. Rev. Sist. 182, 200–215 (2004)
- Mortenson, W.B., Demers, L., Fuhrer, M.J., Jutai, J.W., Lenker, J., DeRuyter, F.: Effects of an assistive technology intervention on older adults with disabilities and their informal caregivers: an exploratory randomized controlled trial. Am. J. Phys. Med. Rehabil. 92, 297–306 (2013). https://doi.org/10.1097/PHM.0b013e31827d65bf
- Osorio Bayter, L., Salinas Ramos, F., Cajigas Romero, M.: Responsabilidad social y bienestar de la persona mayor. CIRIEC-España, Rev Econ pública, Soc y Coop 223–252 (2018). https://doi.org/10.7203/ciriec-e.92.8959
- 34. Peterson, E.: Framing caregiving work for older people in Spanish public policy: gender, power and social justice Struggles for recognition of caregiving work View project. Rev Española Cienc Política, 221–237 (2015)
- 35. Rivero Jimémez, B., Jesús-Azabal, M., Conde Caballero, D., Muñoz Gonzlález, B., Mariano Juárez, L.: Technology for anthropological research. Feedelio: an application for food and nutrition studies. In: Gerontechnology, IWoG 2019. Communications in Computer and Information Science. Springer (2019)
- 36. Sáenz Royo, E.: La estructura organizativa territorial del sistema de atención a la dependencia y relaciones de cooperación interadministrativa, Barcelona (2010)
- 37. Sosa Troya, M.: El Gobierno se compromete a inyectar 600 millones de euros en dependencia en 2021, El Pais (2020)
- 38. Spanish National Statistics Institute (INE): Índice de Envejecimiento Por Comunidad Autónoma (2020). https://www.ine.es/jaxiT3/Tabla.htm?t=1452. Accessed 7 Oct 2020
- 39. Spijker, J., Zueras, P.: Old-age care provision in Spain in the context of a new system of long-term care and a lingering economic crisis. J. Popul. Ageing 13, 41–62 (2020). https://doi.org/10.1007/s12062-018-9232-8
- Szanton, S.L., Leff, B., Wolff, J.L., Roberts, L., Gitlin, L.N.: Home-based care program reduces disability and promotes aging in place. Health Aff. 35, 1558–1563 (2016). https:// doi.org/10.1377/hlthaff.2016.0140
- 41. Woods, O., Kong, L.: New cultures of care? The spatio-temporal modalities of home-based smart eldercare technologies in Singapore. Soc. Cult. Geogr., 1–21 (2018). https://doi.org/10.1080/14649365.2018.1550584



Inclusion and the Digital Divide from the Perspective of Digital Competence Trainers

Łukasz Tomczyk^(⊠), Anna Mróz, Katarzyna Potyrała, and Joanna Wnęk-Gozdek,

Pedagogical University of Cracow, Kraków, Poland {lukasz.tomczyk,anna.mroz,katarzyna.potyrala,joanna.wnek-gozdek}@up.krakow.pl

Abstract. The text presents the ways in which the phenomenon of the digital inclusion of seniors in Poland is interpreted. Six specialists dealing with the subject of the digital education of older people participated in the research. The research was carried out among experts working in various institutions, providing educational, caring and leisure activities to seniors. The data was collected through digitally mediated interviews (e-mail, telephone, instant messenger). The data were categorised and interpreted. On the basis of the analysis of the qualitative data it was noticed that the trainers: 1) have different levels of knowledge about digital inclusion; 2) have digital competences but lack specialized methodological knowledge; 3) need new knowledge about motivating seniors to learn how to use new media; 4) note that the constant changes resulting from the development of the information society also necessitate the improvement of digital competences in the group of trainers; 5) digital inclusion significantly increases the quality of life of seniors in the domains of meeting needs, communication, safety, development of interests, health, and social and cultural life; 6) there is currently no return to a society that functions without new media.

Keywords: Digital inclusion · Elderly · Digital divide · Trainers · Poland · SELI

1 Introduction

Digital exclusion is a phenomenon that is still noticeable in certain countries [1]. Despite the intensive development of the information society in recent years, the problem of digital exclusion is still a noticeable phenomenon. On the basis of analyses carried out by EUROSTAT [25], it is considered that there is a group of countries in Europe with a still high rate of digital exclusion. The elderly are among those particularly at risk of digital exclusion. It is precisely the elderly who are the group that makes less intensive use of the Internet and requires educational support. The current exclusion rates for individual countries are presented in Fig. 1.

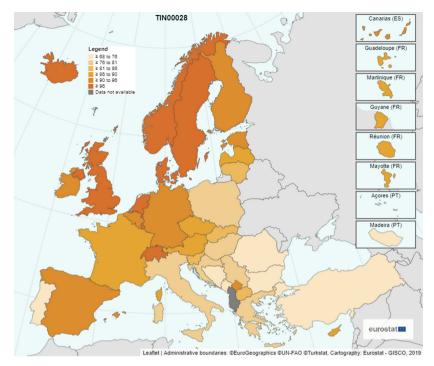


Fig. 1. Digital exclusion rate EUROSTAT

Digital exclusion, i.e. a lack of ICT skills, is minimized by many bottom-up and topdown activities. Bottom-up activities are most often associated with the self-education of seniors [2]. Top-down activities, on the other hand, consist of creating educational environments where seniors acquire skills and knowledge about using computers, the Internet and smartphones. The phenomenon of digital exclusion is therefore balanced by inclusion activities, which take the form of organised, voluntary educational activities. A key role in the process of shaping the digital competences of older people is played by teachers: trainers who shape digital competences [3]. It is these trainers who in many cases are the first people responsible for showing the seniors the possibilities of cyberspace or strengthening their existing competences. In many countries such activities are carried out by volunteers, teachers involved in formal education, or enthusiasts of new technologies [1]. It is this educational sector that requires deeper knowledge and support in preparing new geragogical staff. This position seems to be particularly important in the era of aging societies and the rising educational needs of the elderly. This article looks at the processes that take place during digital inclusion from the perspective of the educators of older people.

2 Methodology

The aim of the article is to answer the question - What is the level of knowledge about digital inclusion among educators?

The aim is related to obtaining specialist knowledge from people involved in digital inclusion, i.e. the inclusion of older people in the information society.

The research was carried out in Poland between May and June 2019 among trainers with extensive experience in shaping digital competences. The survey was conducted among seven experts with the following experience:

- R1 expert from Senior activity centre (12 years),
- R2 Teacher in a special school (3 years),
- R3 A person working in a public library, leading training in the use of ICT for seniors (24 years).
- R4 expert from nursing home for seniors and returnees from former Soviet republics (14 years),
- R5 NGO employee responsible for the vocational activation of the homeless (6 years),
- R6 expert from Senior activity club in a Culture Centre Association for the digital activation of seniors (12 years),
- R7 Trainer working with seniors in a University of the Third Age (30 years).

Interviews were carried out and archived in digital form. Each statement was categorised and interpreted according to the interpretation paradigm of qualitative research. This research is part of the need to improve the quality of the work carried out in the borderlands between media pedagogy and educational gerontology [26].

3 Results

The respondents were asked to evaluate their own level of knowledge of the methods, forms, barriers and facilitators of digital inclusion. They willingly shared what they would like to learn about the process of the activation of seniors for whom they organise workshops in the effective and safe use of new technologies.

One of the respondents (R1), who organises training activities for seniors and works in a foundation for the digital activation of older people, declared: Perhaps I need more information about some statistical data regarding the digital divide and what seniors know. I think I am effective in my work - I know the methods and forms to support the digital inclusion of seniors. I know which methods are effective, what works for our seniors. [...] The statistics give some picture so maybe it will help me to convince my seniors of something?

Another respondent, a public library employee in a town of 38 thousand residents and who organises classes in using new technologies, stated (R3): I'm lacking knowledge on how to motivate seniors to use new technologies and the psychological grounds regarding overcoming fear and resistance. I have the technical know-how, I know how it works, which software or applications are the best for the seniors I work with. But I cannot encourage them to learn.

An employee in a nursing home also signalled their insufficient knowledge on how to motivate older people (R4): I feel the most difficult thing when you work with the elderly is to motivate them to act. Especially in the areas they are not totally convinced of. Surely,

digital inclusion is one such area. What does it look like in practice? A senior declares they want to take part in the classes but when the date comes, they either feel weak or have a doctor's appointment or something else comes up - and behind this is the "I don't feel like" attitude. And here is where I lack expertise. Not many people in a nursing home are really active. I can refer to these "leaders" and say "It is worth trying", that it can be learned but I lack specific guidelines on how to keep them motivated.

Another area educators lack knowledge in has to do with technological innovations and the latest developments.

A respondent working in one of the culture centres in Cracow admitted (R6): I feel that with the new technologies everything changes at the speed of light - all the time, there are new applications, websites and even devices. I want to know how to stay up-to-date, that is, be aware of all these technological developments. [...] In general, I think I know quite a lot about new technologies and how they can be used by the people I work with.

A teacher working in a special school with students in their late adulthood and with disabilities, declared that (R2): My biggest problem related to knowledge is that it is hard for me to stay up-to-date, I have no time for this. In my area of focus, innovations come very fast. In the conditions we have, it is hard to have the latest hardware and software. [...] I think it is very important to know about new software and applications that could help my students but in the present conditions, it is impossible to keep up with everything and to know everything.

We should point out that in each institution courses are taught by educators whose methodological competences vary. Many base their approach on intuition because they have no formal training regarding courses for seniors. Such conditions generate many challenges in terms of methodology and understanding the contexts of digital inclusion. A respondent working in a nursing home admitted (R4): I have no structured knowledge of what seniors need regarding inclusion. I would use a thorough diagnosis. Because, when I work one-on-one, I diagnose the needs myself. They come and say they need this or that. If I wanted to lead a course/training program on a wider scale, I would have to have such information. I am not a senior yet so I don't know in which areas of their lives they require the support of modern technologies, for example, whether they listen to e-books online or search for events for seniors etc.

Some of the respondents gained their knowledge about digital inclusion over the course of their years of work. However, there are always some areas in which they feel insufficiently prepared and wish to expand their competences.

A trainer who organises workshops for seniors at a University of the Third Age said (R7): I think I don't have any bigger knowledge gaps. I know a lot about digital inclusion, I know the methods and techniques, and I know what seniors need. My knowledge is big. This is the result of many years of work in this area. [...] This knowledge is something I am proud of. [...] I've been working for many years as an IT specialist and thanks to training and courses I know how to get older people to be more active. I know how to connect with them, encourage them to work [...]. Perhaps I would only like to find out how to convince those who do not want to use new technologies or who hesitate. I keep telling them that the Internet is not bad, that if they are careful they will be ok but there are still people who are reluctant or who give up completely. [...] I wish to know how

to teach seniors critical thinking because this is something they unfortunately lack and that sometimes gets them in serious trouble like falling victim to fraud. Critical thinking is necessary on the Internet, so I would like to know how to protect them more effectively from, for example, being manipulated.

The analysis of the respondents' statements indicates that they represent different levels of expertise regarding the digital inclusion of the excluded and of people at risk of exclusion. They are aware of what they know and where they lack information. They know what they need to work better and more effectively. The main obstacle is the lack of time and available resources.

In the context of the knowledge of people working with the digitally excluded, the educators were also asked why they believe digital inclusion is important. This helped us to learn, partially, what motivates instructors to engage in activities that are conducive to digital inclusion.

The special school teacher said that digital inclusion is extremely important in her profession (R2): The individuals I work with are people who face many obstacles in their lives. They are people with disabilities. New technologies help them function or even do some things which, without these technologies, would be impossible. I mean, for example, speech synthesizers or reading applications for the blind. [...] Thanks to them, they are able to overcome physical limitations.

The man working with seniors in an association that helps older people become more active noticed that (R1): Today, new technologies are an integral part of our society. Everyone should have access to them in order to function normally in society. [...] They facilitate many daily affairs and allow you to do many things which otherwise would be impossible. It is extremely important to be literate in this area.

The respondent teaching computing and Internet skills in a public library shared a similar opinion (R3): I think digital inclusion is very important as it provides everyone with the opportunity to use online information resources and leads to a higher awareness of what is going on in the changing world, and this, in turn, helps them navigate better in reality. Digital inclusion will also give them more options to look for support in difficult situations, develop hobbies, participate in cultural life, maintain and initiate relationships etc. In the case of seniors, it will also facilitate communication with the younger generation.

The respondent working with seniors in an senior activity centre emphasised the exceptional role of new technologies in the lives of older people, which involves mainly facilitating their daily functioning (R1): I think the digital inclusion of the excluded is extremely important because the technological progress we can observe is very dynamic. In the last decade, thanks to wider access to technology, everything has changed. Using ICT, we can communicate with someone on the other side of the globe without extra cost. But this is a means of communication we have known about for a long time already. Thanks to Internet access, we can deal with administration issues from home, buy different products online or order them through shared shopping lists. These are trends which mark our culture but are completely foreign to the older generations. The younger generations often feel lost with so many technological solutions, so what about older people?

Despite their different institutional environments, every educator has faced similar challenges. Here, it is worth pointing out that age is a criterion thanks to which seniors, despite their diverse socio-demographical traits, share common needs connected with the digital world. The respondent training students of a University of the Third Age said (R7): The main reason why I think it is important is the fact that in the modern world it is very hard to function and navigate on a daily basis: it is necessary when it comes to access to information or even medical services and the organisation of everyday life. A certain level of skills to navigate in the digital world is a must. [...] In addition, the older people I work with sometimes have children who live far away, abroad or in some remote locations in Poland. With new technologies, they can even see their kids or grandchildren, not just talk through the phone or over Skype. Some of the seniors I work with use Viber. Thanks to new technologies older people are less lonely, [...] They feel safer and this is very important to them. [...] In general, I think that new technologies help seniors to improve the quality of their lives [...] It is definitely worth making them aware in which areas of everyday life they can use technology and what specific benefits they will experience.

The respondents are aware of how much digital inclusion may change the lives of the people they work with. We must point out that digitally excluded people - seniors, people with disabilities, immigrants, people with low material status - are a specific group of citizens whose quality of life may significantly improve when they are able to use new technologies. Educators know how important digital inclusion is for their clients/students, thus they are highly motivated to work on this area.

4 Discussion

The issue of digital inclusion is the overarching and foremost activity of educators of older people who want to raise the level of digital competence among seniors. Digital inclusion is a broad concept that is interpreted differently by teachers of older people. The data collected allow us to go beyond a simple definition of digital inclusion, which is mainly related to the inclusion of seniors in the information society. Taking into account the comments of educators, it is noticeable that this phenomenon contains many very detailed processes and challenges that educators face. Figure 2 briefly presents the issues with which digital inclusion is linked to the trainers studied.

In relation to the research problems identified, we have noticed that educators present different levels of knowledge about the digital inclusion of seniors. Generally they are passionate about new technologies but are very rarely professionally trained geragogists [4]. Oftentimes, the people who lead ICT classes for seniors treat this activity as something additional, or beyond their general scheme of working. Consequently, they often express the need to have access to didactic resources which would help them to improve their general knowledge on the digital divide or the methods of working with older people [5]. In Central Europe today, more and more focus is on the quantitative development of institutions that concentrate on non-formal senior education, but also on qualitative changes, including the professional development of adult educators [6]. The governing law still lacks proper regulations as to who can teach people in their late adulthood. This is one reproach against the institutions. The trainers declare that they need their didactic



Fig. 2. Digital inclusion in trainers' perspective

or organisational competences to be recognised and, more widely, that they need external supporting measures [7]. The respondents readily shared their experiences, which proves this professional group is open to all forms of collaboration and to the development of new forms of dedicated support. The educators' statements revealed many interesting notions and suggestions regarding different areas of activity, which may prove valuable in the context of the transmission of experience and how one learns from the mistakes and successes of other coaches [8]. The aspect of knowledge exchange is insufficiently developed both in terms of practice and research activities [9]. As one of the leading trends in adult education, learning from biography may prove a very valuable idea and practice in the context of analysing the needs, experiences and challenges faced by senior educators, and not only in the area of ICT [10, 11].

The instructors interviewed have different experiences related to digital inclusion. This is the result of different perspectives, as the respondents represented a variety of institutions. A University of the Third Age trainer will have a different perspective because in many cases his senior students are the intellectual elite [12]. This institution usually brings together seniors who have a rich biography of learning experiences. Quite often, the IT sections (courses in the use of computers and smartphones) are divided into different levels of proficiency, like in the academic system. In turn, educators working in nursing homes treat computer classes as alternative or complementary to other activities aimed at developing the intellectual ability of their patients. Non-governmental organisations most often focus on projects which are designed according to the descriptions provided in calls for applications for funds. Institutions focusing on the education of seniors from the groups at risk of social exclusion (poverty, homelessness), follow completely different standards. Every organisation has a different activity profile and this also influences the didactic methods used to develop the digital literacy of their beneficiaries. The community of ICT educators is heterogeneous.

The knowledge and skills required by seniors can be developed through different ICT-based educational solutions. It seems, however, that developing training systems

for older persons needs thorough study of the requirements both learners and trainers must meet. Thus, the design of training systems should be carefully planned. Research results show that it is time-consuming and difficult [13]. An approach based on learning while completing individual educational exercises, especially those focusing on cooperation between course participants, is particularly well received by the seniors. Practical experiences gained during the project implemented by Petter & Helling [14] suggest that educational solutions work for seniors if the didactic approach is adapted to the needs of this target group. However, we need to be aware that seniors can be a very diverse group; therefore teachers must adjust their methods to the students' needs and focus on such issues as availability of the Internet, basic learning theory, ICT tools to support learning, and relevant educational activities. In this process, the instructor also plays an important role.

Kearney [15] identifies the elements considered necessary when we think of older people's effective learning, and emphasises the role of educators: 1/course structure must be flexible enough to allow seniors to "set their own schedule within the course" and trainers need competences to support their students in meeting their learning objectives; 2/usually, seniors are relatively aware of their educational goals and with proper coaching skills related to encouraging seniors to engage in the process of designing the course, the curriculum can be adapted to their expectations; 3/ non-formal learning: learning which is not planned and is based instead on a spontaneous ad hoc approach is often more welcomed by seniors than learning planned in advance. Instructors must be able to meet the challenges of incidental learning in different places and times; 4/ reflectionbased activities - especially those which require collaboration and interactions with other learners - are viewed as positive as they provide learners with the opportunity to understand the given topic in their own way. The constructivist teaching approach proves successful, especially during the individual construction of knowledge by the seniors and when the instructors demonstrate an individual approach to the cognitive processes of the seniors and their learning needs; 5/ active learning: students readily engage in problem-based learning implemented as small educational projects. Learning by doing is a fruitful educational experience for the elderly and a challenge for educators who must prepare the initial concepts of the projects [14].

In this context, some researchers refer to the social-constructivist approach and non-formal approach towards learning, using continuous trainer-senior feedback to support the learning process in seniors. The important thing here is the scope of content (preferably not too wide) and the ability to test seniors' capacity to internalise the content, given their previous knowledge and experience [16]. Particular attention should be paid to those didactic skills which involve using relevant strategies, methods and teaching-learning techniques addressed to this specific group of students and considering the external and internal conditions of senior learning [17]. Particular emphasis is placed on the coaching skills that facilitate activities according to the concept of developing knowledge based on collaboration ("community of learners") and interactions between course participants [18]. Given that seniors need more time to obtain knowledge, make more mistakes and need more support, teaching methods must address these specific challenges and the teacher's instructions must be task-oriented and engage senior students using highly interactive teaching methods. There is a need for adequate training systems

for the educators, which would address the goals, abilities and experiences of seniors to reduce their anxiety when using computers and also to motivate them, especially when they begin to learn [19].

Research has shown that one of the main differences between the elderly and the younger participants of ICT courses is the fact that older people bring information and experience that younger people lack and, therefore, there are obvious differences in the motivation to learn between these two groups. While younger people are interested in learning mainly to find a well paid job, older people want to learn how to improve the quality of their life, and to self-develop [20]. Understanding this motivational gap is paramount for educators when designing digital courses for older students. Seniors also expect they will communicate with the training application using familiar language rather than computer jargon [18]. According to González [19], this is the reason why the attitudes and needs of seniors need to be taken into account during the development of appropriate ICT curricula for the elderly. Aspects that should be considered are related to benefits and difficulties recognised by seniors [19], the usefulness of the courses, and the barriers preventing older people from taking part [19, 21], as well as self-esteem and the ability to learn [22].

More and more often it is emphasised that educators of ICT to seniors must be properly prepared not only in terms of computer literacy but also in a whole range of competences which - apart from knowledge, skills and social competences - include their original ideas, values, motivation and predisposition to be the teacher in a group with special educational needs. One of the examples may be the EduSenior project implemented in Spain and Finland, which focused on the improvement of employees, specialists and teachers working in educational institutions for seniors. It combined practical experiences with theoretical knowledge and the development of the skills needed to use the available tools, including ICT, to support the education of the elderly [23].

5 Summary

This article fits into the discussion of the need to analyse the phenomenon of digital inclusion. The inclusion of seniors in the digital world is not a new trend. For over two decades, activities related to digital education have been conducted by specialists in adult education [24]. However, in many cases such activities are carried out by people without specialist knowledge of the methodology of the education of older people. This text allows us to understand the specifics of their work in an educational context. The results of the research here presented necessitate further analysis and practical action to improve the quality of digital education for older people [25]. The existence of institutions for senior citizens is an important first step. The next is related to equipping educators with the latest knowledge on professional digital inclusion.

Acknowledgments. This work was supported by the ERANET-LAC project which has received funding from the European Union Seventh Framework Programme. Project Smart Ecosystem for Learning and Inclusion – ERANet17/ICT-0076SELI (SELI). In Poland support for the research was provided by the National Centre for Research and Development (*Narodowe Centrum Badań i Rozwoju*).

References

- Tomczyk, L., Eliseo, M.A., Costas, V., Sanchez, G., Silveira, I.F., Barros, M.-J., et al.: Digital divide in Latin America and Europe: main characteristics in selected Countries. In: 2019 14th Iberian Conference on Information Systems and Technologies (CISTI) (2019). https://doi. org/10.23919/cisti.2019.8760821
- 2. Tomczyk, Ł., Oyelere, S.S.: ICT for Learning and Inclusion in Latin America and Europe. Pedagogical University, Cracow (2019)
- Eliseo, M.A., Oyelere, S.S., Silva, C.A., da Silveira, I.F., Tomczyk, L., Hercovici, M., et al.: Framework to creation of inclusive and didactic digital material for elderly. In: 2020 15th Iberian Conference on Information Systems and Technologies (CISTI). IEEE (2020). http:// dx.doi.org/10.23919/cisti49556.2020.9140993
- Veteška, J.: Gerontagogika: psychologicko-andragogická specifika edukace a aktivizace seniorů. Česká andragogická společnost, Praha (2016)
- Tomczyk, Ł.: Trends and contexts on education of senior in the range of information technology in Poland. In: Conference Proceedings of »eLearning and Software for Education« (eLSE) (02), 121–126. "Carol I" National Defence University Publishing House, Bucharest (2011)
- Klimczuk, A.: Universities of the third age in Poland: emerging model for 21st century. J. Educ. Psychol. Soc. Sci. 1(2), 8–14 (2013)
- 7. Šerák, M.: Zájmové vzdělávání dospělých. Portál, Praha (2009)
- Littlejohn, C.: Learning from learning from our mistakes. In: Grajner, M., Schmechtig, P., (eds.) Epistemic Reasons, Norms and Goals. De Gruyter (2016). http://dx.doi.org/10.1515/ 9783110496765-004
- Zhao, X., Wang, L., Ge, C., Zhen, X., Chen, Z., Wang, J., et al.: Smartphone application training program improves smartphone usage competency and quality of life among the elderly in an elder university in China: a randomized controlled trial. Int. J. Med. Informat. 133, (2020). https://doi.org/10.1016/j.ijmedinf.2019.104010
- Golonka-Legut, J.A., Pryszmont-Ciesielska, M.: Researcher and experiences of adults in biographical research – based on andragogical projects. Int. J. Lifelong Educ. 37(6), 734–48 (2018). https://doi.org/10.1080/02601370.2018.1552330
- Fabiś, A., Wasiński, A., Tomczyk, Ł.: Existential perspective of biography-related reflection in the intergenerational narrative messages. J. Fam. Hist. 42(3), 326–340 (2017). http://dx. doi.org/10.1177/0363199017711213
- 12. Formosa, M.: Active ageing through lifelong learning: the university of the third age. In: The University of the Third Age and Active Ageing, pp. 3–18. Springer International Publishing (2019). http://dx.doi.org/10.1007/978-3-030-21515-6_1
- Themistocleous, M., Serrano, A.E., Kamal, M.: Training senior employees for ICT skills enhancement through "Refocus": the European project. In: 5th European and Mediterranean Conference on Information Systems, EMCIS 2008, Dubai United Arab Emirates (2008)
- 14. Petter, C., Helling, K.: Designing ICT-based learning scenarios for special target groups. Meeting senior learners needs. In: Proceedings of the Workshop on Inclusive E-Learning: Special Needs and Special Solutions (IEL-2008), Maastricht, The Netherlands (2009)
- 15. Kearney, N.: Pedagogical model for the ICT4T course including a draft course structure. In: Internal Project Document (2007). http://www.ict4t.net
- Held, P., Hahner, R., Heid, S., Hetzner, S., Hetzner, U., Paulmann, E., Rohleder, S.: Gutachten zur institutionellen Verankerung von Angeboten und zur Bereitstellung entsprechender Bildungsorte und Lernwelten für eLearning im Alter. Friedrich-Alexander-Universität Erlangen-Nürnberg, FIM- NeuesLernen, Erlangen (2006)

- 17. Eggermont, S., Vandebosch, H., Steyaert, S.: Towards the desired future of the elderly and ICT: policy recommendations based on a dialogue with senior citizens. Poiesis Praxis **4**(3), 199–217 (2006). https://doi.org/10.1007/s10202-005-0017-9
- Sayago, S., Santos, P., Gonzalez, M., Arenas, M., López, L.: Meeting educational needs of the elderly in ICT. XRDS Crossroads ACM Mag. Stud. 14(2), 1 (2007). http://dx.doi.org/10. 1145/1373596.1373598. Association for Computing Machinery (ACM)
- González, A., Ramírez, M.P., Viadel, V.: ICT learning by older adults and their attitudes toward computer use. Curr. Gerontol. Geriatr. Res. 2015, 1–7 (2015). https://doi.org/10.1155/ 2015/849308
- Tam, M.: Lifelong learning for older adults: culture and confucianism. In: The Palgrave International Handbook on Adult and Lifelong Education and Learning. Palgrave Macmillan, UK, pp. 857–878 (2017). http://dx.doi.org/10.1057/978-1-137-55783-4_44
- Castilla, D., Garcia-Palacios, A., Bretón-López, J., Miralles, I., Baños, R.M., Etchemendy, E., et al.: Process of design and usability evaluation of a telepsychology web and virtual reality system for the elderly: Butler. Int. J. Hum Comput Stud. 71(3), 350–62 (2013). https://doi.org/10.1016/j.ijhcs.2012.10.017
- 22. Karavidas, M., Lim, N.K., Katsikas, S.L.: The effects of computers on older adult users. Comput. Hum. Behav. **21**(5), 697–711 (2005). https://doi.org/10.1016/j.chb.2004.03.012
- Szplit, A., Stawiak-Ososińska, M.: Modelowanie kompetencji opiekunów seniorów w pracy projektowej i coachingu indywidualnym – projekt EduCare. Rocznik Andragogiczny. Uniwersytet Mikolaja Kopernika/Nicolaus Copernicus University, vol. 21, p. 487 (2015). http:// dx.doi.org/10.12775/ra.2014.035
- Tomczyk, Ł.: Wolontariusze i seniorzy w programie Polski Cyfrowej Równych Szans: o siłach społecznych w procesie minimalizacji wykluczenia cyfrowego w Polsce. Wydawnictwo Naukowe Uniwersytetu Pedagogicznego, Krakow (2018)
- 25. EUROSTAT: Internet use by individuals[tin00028] % of individuals aged 16 to 74 (2020). http://appsso.eurostat.ec.europa.eu/nui/show.do?dataset=tin00028&lang=en. Accessed 29 Nov 2020
- Tomczyk, Ł., Mróz, A., Potyrała, K., Wnęk-Gozdek, J.: Digital inclusion from the perspective of teachers of older adults - expectations, experiences, challenges and supporting measures. Gerontol. Geriatr. Educ. 24, 1–16 (2020). https://doi.org/10.1080/02701960.2020.1824913



Loneliness in the Quality of Non-institutionalized Elderly People

Filomena Morais 1 , Helena Silva 1 , Inês Reis 1 , Jorge Ramalho 1 , Maria do Céu Marques $^{2(\boxtimes)}$, and Maria de Fátima Moreira 1

¹ Beja School of Health, Beja, Portugal
² Comprehensive Health Research Center, POCTEP 0499_4IE_PLUS_4_E, University of Évora, Évora, Portugal mcmarques@uevora.pt

Abstract. Objectives: This study aims to understand the interference of loneliness in the quality of life of non-institutionalized elderly people over 65 years old. **Methods:** A systematic literature review was carried out according to the protocol of the Joanna Briggs Institute. The search was carried out in two search engines (Bon and EBSCO) to access electronic databases for collecting articles with the latest scientific evidence. Published studies were evaluated between January 2015 and October 2019. **Results:** Six articles were selected, 5 of quantitative nature (4 cross-sectional studies, 1 randomized controlled study) and 1 qualitative study, which relate the interference of loneliness in the quality of life of non-institutionalized older adults. **Conclusions:** The loneliness strongly interferes with quality of life, as they are inversely proportional. The higher the perceived levels of loneliness, the lower the quality of life of the elderly people. Technology can be an important tool in combating loneliness.

Keywords: Aging · Quality of life · Loneliness

1 Introduction

Population aging is an undeniable reality in evolved societies, bringing with it several changes in the most varied fields. In the last century, there have been countless changes in the demographic and epidemiological profile worldwide, particularly in developed countries, and the propensity for a progressive increase in average life expectancy seems to be a trend that will continue [1]. Improvements in terms of health conditions, either through health education actions in the school context or through specific legislation for this purpose, have led to an increasingly long life [2]. However, if demographic aging was an enormous achievement for humanity [3], at the same time this situation is a challenge for today's societies, since it requires its adaptation [4].

In the last decades Portugal, as well as several European countries, has also undergone major demographic changes, which led to an increase in elderly population and the increase in longevity, but also a decrease in birth rates and the young population [5].

At this point, it is important to distinguish between aging and longevity so that we can understand the data that will be presented below. Over the centuries, the concept of aging has undergone several changes that are due to the increase in knowledge of human anatomy and physiology; on the other hand, it reflects the evolution of cultures and social relations of the various eras [6]. For Paúl and Ribeiro [2] aging happens over time after reaching adult life, longevity for the same authors is described as the durability of an organism's life and depends on the progress of aging.

The European Union's aging index was 125.8 in 2017, which means that for every 100 young people there were 125.8 elderly people. In Portugal, these figures are even more alarming, since the statistical data point to an aging rate of 153.2. This exponential increase in the index becomes even more striking when we compare, for example, the aging index of 2017 with the aging index of 1960 in our country. If in 2017 it was 153.2 in 1960 this index was only 27, that is, for every 100 young people there were 27 elderly people [7]. When evaluating the longevity index, which is defined by the number of people aged 80 and over for every 100 people aged 65 and over, we also see that this index has been increasing. In 1960, this index was 14.5 in our country and in 2017 it increased to 29.2, being higher than the European Union average of 28.28. Portugal is the fourth country in the European Union with the highest percentage of elderly people, behind Greece, Germany and Italy [5].

For successful aging, there are countless variables to take into account. Quality of life, well-being, and maintenance of mental quality are directly related to social activity, living together, feeling useful to family members and/or the community [9]. Successful aging also involves changes and adaptations at a psychological and biological level, but also changes at the level of social policies [3].

Quality of life is a concept listed in several studies, both national and international, as a concept closely linked to aging. It can be described as the perception that each person has of his/her position in life, in the context of his/her cultural system and values in which he/she is inserted, being also related to his/her goals, expectations, norms and concerns [10]. The quality of life of the elderly people is related to both health and social and economic factors [11]. It is a broad concept, which incorporates in a complex way physical and psychological health, their state of independence, their relationships personal beliefs and their relationship with important aspects of the environment. Health determinants such as social support, contact with others and, in particular, loneliness are important factors to take into account for healthy aging, since these factors are related to the cognitive level, the level of quality of life, depression and even with the mortality rate [12].

Loneliness is defined, according to the Infopedia Dictionary of the Portuguese Language [13], as "State of what is alone, isolation". If we focus only on this definition, it seems to us an easy word to define, however it is a broad concept that can have a very direct influence on the quality of life. Results of a study by Verma and Kumar in 2018 [14] reveal a significant relation between depression and loneliness. These researchers came to the conclusion that loneliness increases the risk of depression, relating to a number of factors including demographic characteristics, social status, and isolation increasing the risk of psychosocial problems. Loneliness is also often associated with other health problems. The study carried out by Dahlberg, Agahi, Lennartsson [15], between 2004

and 2014, with the participation of 2,572 elderly people, revealed that efforts should be made so that the older adults remain integrated in their community, maintaining the connection of belonging to it, since social factors are linked to loneliness, and this in turn to their quality of life. The elderly population is more likely to lose family and friends and is more vulnerable to loneliness and social isolation. These factors at an advanced age lead to a physical and mental decline [10]. Loneliness is present in the daily lives of elderly subjects in Portugal, so it is urgent to create strategies that minimize it [3]. Working to prevent loneliness should be a priority in terms of policies that promote healthy aging [15].

Nowadays the world is centered on technologies and their development in different sectors of society. There are some strategies that can help to control the phenomenon of loneliness, from communication technologies, with family and friends, such as the consumption of social media technologies. However, it has not been studied the real impact of technologies on loneliness and quality of life for older people. Considering the relevance of aging, quality of life and loneliness, we will proceed to a systematic review of the literature, based on recent scientific evidence, aiming to understand how loneliness interferes in the quality of life of the elderly people over 65 years-old who are not institutionalized.

2 Methodology

The present study constitutes a systematic review of the literature. Its construction was based on the Joanna Briggs Institute protocol [16].

It started by formulating the question, using the PICO mnemonic (Table 1). Therefore, we have as a fundamental question "Does loneliness interfere with the quality of life of non-institutionalized elderly people?".

| P | (Population/Type of participants) | Elderly people |
|---|-----------------------------------|---|
| I | (Intervention) | Interference of loneliness in quality of life |
| С | (Context) | Non-institutionalized |
| О | (Result) | Evidence on the interference of loneliness in quality of life |

Table 1. Question formulation - PICO

The inclusion criteria were defined: all studies that included elderly people aged 65 years-old or over, of both sexes and non-institutionalized, integrated all studies that evaluate the effect(s) of loneliness in the quality of life of non-institutionalized elderly people; encompassing all studies that demonstrated evidence of the effect of loneliness in the quality of life of non-institutionalized older people, excluding systematic literature reviews.

The research strategy included articles published between January 2015 and October 2019, in all languages, with full text and analyzed by peers/experts. The research took

place during the month of October 2019. The keywords were validated in the alphabetical repertoire of standardized terms, in this case in Mesh (Medical Subject Headings, 2018), and the research was conducted in English. The keywords and Boolean operators used in the research were: Aging AND Quality of life AND Loneliness NOT Institutionalizacion. The selected databases were chosen taking into account the vast number of studies found: Academic search complete, Medline complete, Cinahl complete, Psychology and Bahavioral collection, Mediclatina, ebook collection (EBSCO host). The following flowchart (Fig. 1) shows the article selection process. For their inclusion or exclusion in this systematic review, these were reviewed by two evaluators.

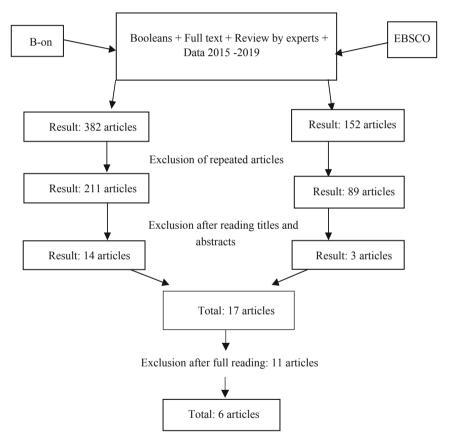


Fig. 1. Flowchart of the article selection and inclusion process

In the Table 2, there are the data regarding the levels of evidence of the studies, as well as their degrees of recommendation, according to the Joanna Briggs Institute [16].

| Article | JB level of evidence [16] |
|--|------------------------------------|
| Loneliness, Mental Health, and Quality of Life in Old Age: A Structural Equation Model [17] | 4. b – cross-sectional study |
| Aging in place and quality of life among the elderly in Europe: A moderated mediation model [18] | 4. b – cross-sectional study |
| Quality of life in The Third Age: A Research On Risk And Protective factors [19] | 4. b – cross-sectional study |
| A cross sectional study on the different domains of frailty for independent living older adults [20] | 4. b – cross-sectional study |
| A preventative lifestyle intervention for older adults (lifestyle matters): a randomised controlled trial [21] | 1. c – randomized controlled study |
| Being in a Bubble: the experience of loneliness among frail older People [22] | Qualitative |

Table 2. Levels of evidence of the analyzed articles.

3 Results and Discussion

Table 3 shows the critical evaluation of the articles analyzed based on the evaluation tables, according to the JBI protocol, having been verified the Checklist for the different types of studies (cross-sectional studies, randomized controlled studies, and qualitative studies, respectively).

Research Q1 Q2 Q5 Q7 Q8 Q9 Q10 | Q11 | Q12 | Q13 Total Q3 Q4 Q6 Y Y Y Y Y Y 75% Gerino, E. Ν Ν et al. [17] Schorr, A.V.; Y Y Y Y Y Y Ν Ν 75% Khalaila, R. [18] Gerino, E. et. Y Y Y Y Y Ν N Y 75% al [<mark>19</mark>] Verver, D. et. Y Y Y Y Ν Ν Y Y 75% al. [20] Moutain G. Y Y Y Y Y Y Y Y Y N Y Y Y 92,3% et. al. [21] Taube, E et. Y Y Y Y Y Y Y Y Y 90% Ν al. [22]

Table 3. Critical evaluation of the results of the analyzed articles (Y - Yes; N - No)

The synthesis of the articles included in this literature review can be seen in the table below (Table 4).

Table 4. Data collection grid for studies included in the literature review

| Study identification | Study objective | Participants | Results | Period |
|---|--|--|--|-----------------------|
| Loneliness, Mental Health, and Quality of Life in Old Age: A Structural Equation Model. Gerino, E.; Rollè, L.; Sechi, C.; Brustia. P. (2017) Frontiers in Psychology, v.8, 14 novembro [17] | To investigate how factors such as loneliness, resilience, mental health related to depression and anxiety affect the quality of life perceived by the elderly. Intended to explore/elaborate a multidimensional model that included the relationships between the different factors | 290 elderly people Who are 65 and 90 years-old of both sexes | Loneliness strongly influences the quality of life: through the impact associated with mental health and associated with resilience. Elderly people with higher levels of loneliness have a lower quality of life. Mental health is a mediator between resilience and quality of life; people with a higher level of resilience have a better quality of life | S/d |
| Aging in place and quality of life among the elderly in Europe: A moderated mediation model. Schorr, A.V.; Khalaila, R. (2018). Archives of Gerontology and Geriatrics, v.77, pp.196–204, 20 abril [18] | To explore the effect of the mediation of perceived accessibility factors on the quality of life of the elderly people (loneliness and relationship with the place) and two moderators (functional disability and marital status) | 13,828 people who are 65 and over | The participants obtained an average score in terms of quality of life, and a low level of loneliness. All socioeconomic variables were significantly related to quality of life. Women without a partner have a lower level of quality of life. A higher level of quality of life is attributed to younger ages and higher levels of education. Lower quality of life was correlated with health problems, physical limitations and chronic illness problems. Accessibility and connection to the place were positively associated with quality of life, while loneliness was negatively correlated with quality of life | Between 2012 and 2013 |

(continued)

 Table 4. (continued)

| Study identification | Study objective | Participants | Results | Period |
|---|--|---|---|---|
| Quality of life in The Third Age: A Research On Risk And Protective factors. Gerino, E.; Marino, E.; Brustia, P.; Dimitrios, G.L.; Rollé, L. (2015) Procedia – Social and Behavioral Sciences v.187 pp.217-222 [19] | Examine the role of protective factors (self-esteem, perceived social support, self-efficacy) and risk factors (depression, anxiety and loneliness) in terms of the various dimensions of quality of life (physical, psychological, social and environmental) in a certain group of elderly people | 464 elderly people (between 65 and 91 years-old) with an average age between 73.8 years-old. 67% women, 33% men | All correlations between predictive factors and quality of life were significant. Age was not correlated with any dimension of QOL and gender did not show a significant difference. Self-esteem and self-efficacy are good predictors while loneliness, depression and anxiety are significant predictors that generate a significant decrease in the results obtained in terms of QOL | First months of 2014 |
| A cross sectional study on the diferente domains of frailty for independent living older adults. Verver, D.; Merten, H.; Blok, C.; Wagner, C. (2019). BMC Geriatrics, 01 de março [20] | To provide information on the relation between the different domains of frailty (physical, social and psychological), and health outcomes and well-being aspects for independent elderly people | 1,768 independent elderly people, over 65 years-old | About the 1,768 participants, 68.9% were fragile in one or several domains, 51.6% were fragile based on the total score in the TFI, 10.3% were fragile in all domains and 31.1% were not fragile; the most present weakness with 18.4% was social weakness | Between January 2011 and April 2012 |

(continued)

 Table 4. (continued)

| Study identification | Study objective | Participants | Results | Period |
|--|--|---|--|---|
| A preventative lifestyle intervention for older adults (lifestyle matters): a randomised controlled trial. Moutain G., Windle, G.; Hind, D.; Walters, S.; Keertharuth, A.; Chatters, R.; et al. (2017). Age and Ageing, v.46, p.627–634, 25 fevereiro [21] | To check whether a lifestyle intervention based on "occupation" can improve the mental well-being of adults aged 65 and over, compared to usual care | 288 adults over 65, with normal cognition, 145 were the target of intervention, 127 belonged to the control group | Six months after the interventions there were no significant changes, however after 24 months there were significant changes in two scales of assessment (social loneliness scale and emotional loneliness scale) | Between December 2011 And November 2015 |
| Being in a Bubble: the experience of oneliness among frail older people. Taube, E.; takobsson, U.; Midlov, D.; Kristensson, I. (2015) fournal of Advanced Nursing. 72 3): 631–640 221 | | 12 seniors over 65 years-old; living at home; fragile and who have experienced various levels of loneliness | In the experience of loneliness among the frail elderly people there is a permanent debate to overcome physical, psychological and social barriers. Failure to overcome these barriers leads to feelings of sadness, anxiety and emptiness, called hopelessness. Loneliness can also be interpreted as a sense of freedom if you obey certain limits | December 2009 And August 2011 |

After consulting the articles, it was found that they complement the existing literature on the topic. The elderly population is particularly vulnerable to loneliness. In fact, the relational element is a very important factor at the level of QOL, and health risks (physical and mental) are directly related to this and to social isolation [19]. These data are in line with the studies carried out by Lindsay- Smith, O'Sullivan, Eime, Harvey & Uffelen

[12] as well as Verma & Kumar [14]. The higher the level of loneliness the lower the level of quality of life [17–19]. Loneliness has also a negative impact on mental health [17]. These data corroborate the data presented by the studies previously consulted by different authors [3, 9, 10, 15]. It was also observed that the higher the level of self-esteem [19], of self-efficacy [17, 19], of support perceived by friends [17, 19], and of resilience [17], the higher the level of quality of life, with the opposite occurring when correlating quality of life with depression, anxiety and loneliness, verifying that they are inversely proportional as previously described by Pocinho, Neves, Belo, Martins [3], by WHO [10], and by Lindsay-Smith, O'Sullivan, Eime, Harvey & Uffelen [12]. A high degree of resilience contributes to increase the quality of life perceived at the physical and psychological levels and, at the same time, to reduce anxiety and depressive symptoms [17, 19]. In terms of the frailty of the elderly people [19, 20, 22], it is also directly related to loneliness, that is, the higher the level of loneliness, the higher the perceived frailty levels, as indicated by WHO [10]. These results reinforce the belief that it is necessary to plan specific interventions for the elderly population in order to influence the feeling of dissatisfaction with living conditions and prevent excessive states of discomfort, particularly in important areas such as the self-efficacy and self-esteem of older people, conditions underlying anxiety and depression, pro-social behaviors that lead to reduced feelings of loneliness and social isolation [19], data corroborated by Mares, Cigler & Vachkova [11], Lindsay-Smith, O'Sullivan, Eime, Harvey & Uffelen [12], Verma & Kumar [14] and Dahlberg, Agahi & Lennartsson [15]. Environmental characteristics (perceived accessibility and connection to the place) play a vital role in determining the quality of life of the elderly people. Accessibility determines other important aspects related to the quality of life of the elderly people, namely feelings of loneliness and feelings of belonging. The possibility of them leaving home, participating in social activities influences their quality of life, health, happiness, levels of loneliness, feelings of belonging to the local community and staying active in their home environment [18, 19, 22], these data go against the WHO [10]. Loneliness was recently indicated as an element that promotes biopsychosocial stress, which contributes significantly to the degradation of health status [19]. In terms of clinical interventions, reduced loneliness can be an important factor in primary prevention or the recovery process. One way to reduce levels of mental suffering could be represented by increasing resilience and self-efficacy and reducing dissatisfaction with loneliness [17]. The results show that functional disability among the elderly and their marital status determine the levels of quality of life. Governments must be aware of these particularities in terms of health policies. Several determinants must be taken into account to make cities more "friendly" to the elderly people [18]. Studies also mention that preventive measures should be taken to reduce loneliness [21], at the political level [18], insofar as these policies can lead to the reduction of depression, stress and anxiety, increasing the quality of life in this specific age group as it is described by Pocinho, Neves, Belo and Martins [3], and Dahlberg, Agahi & Lennartsson[15]. Greater awareness of the implications of the experience of loneliness in older population and frail person is needed. Prevention and early intervention is essential, technologies can and should be used as precious tools to control loneliness and promote quality of life. The promotion of well-being, a person-centered approach and knowledge of the physical and psychological.

4 Conclusion

After consulting the literature and studies with recent scientific evidence, we came to the conclusion that the elderly people are particularly vulnerable to loneliness, and this strongly influences their quality of life. It appears that all the studies analyzed are in agreement with the consulted bibliography, where reference is made to a very marked aging of the population, mainly at the level of developed countries, with the complications that this sometimes causes, namely the increased levels of loneliness, leading to a decrease in the quality of life of older population. Loneliness is closely related to the quality of life perceived by people in this age group. There are several consequences of aging, one of which is the loss of significant people, since living more means that we will possibly lose the reference people in our life. The loss of autonomy, social isolation, the way of facing the aging of the body, the weaknesses that arise with age, added to a low self-esteem, self-efficacy and resilience capacity lead to drastic decreases in the level of perceived quality of life. It can also be seen that marital status has a marked effect on levels of loneliness and, consequently, on quality of life.

This study aimed to answer the question whether loneliness interferes with quality of life, and after consulting all this scientific evidence, it is concluded that the levels of loneliness are inversely proportional to the levels of quality of life, i.e. the higher the levels of loneliness indicated, the lower the quality of life perceived by the elderly people, the lower the levels of loneliness the greater the perceived quality of life. Thus concluding that, in fact, loneliness interferes with the quality of life of non-institutionalized elderly people.

It is considered important to carry out more in-depth studies on the topic, so that it is possible to understand the extent to which certain factors that negatively influence quality of life can be altered, which strategies using technological tools and even which health policies can be changed taken into account to combat this situation that affects so many elderly people around the world.

References

- Canhestro, A.S., Basto, M.L.: Envelhecer com Saúde: Promoção de Estilos de Vida Saudáveis no Baixo Alentejo. Pensar Enfermagem v.20, n.º1, 1º semestre (2016)
- Paúl, C., Ribeiro, O.:Manual de Gerontologia Aspetos biocomportamentais, psicológicos e sociais do envelhecimento. Lisboa/Porto: LIDEL – edições técnicas, lda (2012)
- Pocinho, R., Neves, T., Belo, P., Martins, A.: A depressão Geriátrica e a sua relação com a Solidão numa amostra de utentes com serviço de apoio domiciliário. Equitania sciencia. N.21, Ano 11, jun-dez (2017)
- 4. OMS: World Report in Ageing and Health. Suíça: Genebra. Disponível em (2015). https://www.who.int/ageing/events/world-report-2015-launch/en/
- DGS: Estratégia Nacional para o envelhecimento ativo e saudável 2017- 2025 Proposta do Grupo de trabalho Interministerial (Despacho nº 12427/2016). Lisboa Disponível em (2017). https://www.sns.gov.pt/wp-content/uploads/2017/07/ENEAS.pdf
- Sequeira, C.: Cuidar de idosos com dependência física e mental. Lisboa/porto: LIDEL edições técnicas, Ida (2010)
- FFMS: Índice de envelhecimento. Lisboa: PORDATA. Disponível em (2019) www.pordat a.pt. consultado em 2019/11/19

- FFMS: Índice de longevidade. Lisboa: PORDATA. Disponível em (2019). www.pordata.pt. consultado em 2019/11/19
- DGS: Dia Internacional das pessoas idosas 1 de outubro Envelhecimento saudável. Lisboa: Ministério da Saúde Disponível em (2008). https://www.dgs.pt/documentos-e-publicações/envelhecimento-saudavel-pdf.aspx
- 10. OMS: Active Ageing A Policy Framework. Espanha: Madrid Disponível em (2002). https://apps.who.int/iris/bitstream/handle/10665/67215/WHO_NMH_NPH_02.8.pdf?sequence=1
- 11. Mares, J., Cigler, H., Vachkova, E.: Czech: version of OPQOL-35 questionnaire: the evaluation of the psychometric properties. Health Qual. Life Outcomes **14**, 93 (2016)
- 12. Lindsay-Smith, G., O'Sullivan, G., Eime, R., Harvey, J., Uffelen, J.G.Z: A mixed methods case study exploring the impacto f membership of a multi- activity, multicentre community grupo n social wellbeing of older adults. BMC Geriatr. 18, 226 (2018)
- Dicionário infopédia da Lingua Portuguesa: Solidão. Disponível em (2019). https://www.infopedia.pt/dicionarios/lingua-portuguesa/solidão. consultado em 2019-10-27 19:33:57
- Verma, U.P., Kumar, A.: Loneliness and its effects on quality of life of old people. Indian J. Health Well-Being 9(6), 819–822 (2018)
- Dahlberg, L., Agahi, N., Lennartsson, C.: Lonelier than ever? Loneliness of older people over two decades. Arch. Gerontol. Geriatr. 75, 96–103 (2018)
- JBI: JBI Levels of Evidence Developed by the Joanna Briggs Institute Levels of Evidence and Grades of Recommendation. Australia: Universidade de Adelaide (2013)
- 17. Gerino, E., Rollè, L., Sechi, C., Brustia, P.: Loneliness, resilience, mental health, and quality of life in old age: a structural equation model. Front. Psychol. **8** (2017). artigo 2003
- 18. Schorr, A.V., Khalaila, R.: Aging in place and quality of life among the elderly in Europe: a moderated mediation model. Arch. Gerontol. Geriatr. 77, 196–204 (2018)
- 19. Gerino, E., Marino, E., Brustia, P., Dimitrios, G.L., Rollé, L.: Quality of life in the third age: a research on risk and protective factors. Procedia Soc. Behav. Sci. 187, 217–222 (2015)
- 20. Verver, D., Merten, H., Blok, C., Wagner, C.: A cross sectional study on the different domains of frailty for independent living older adults. BMC Geriatr. 19, 61 (2019)
- 21. Mountain, G., Windle, G., Hind, D., Walters, S., Keertharuth, A., Chatters, R., et al.: A preventative lifestyle interevention for older adults (lifstyle matters): a randomised controlled trial. Age Ageing **46**, 627–634 (2017)
- 22. Taube, E., Jakobsson, U., Midlöv, P., Kristensson, J.: Being in a Bubble: the experience of loneliness among frail older people. J. Adv. Nurs. **72**(3), 631–640 (2015)



Perceived Loneliness by Elderly a Systematic Literature Review

Sandra Gomes^(⊠), Manuel Lopes, and César Fonseca

Escola Superior de Enfermagem São João de Deus, Universidade de Évora, Évora, Portugal

Abstract. The aging process is associated with social changes, among all the modifications that it entails. Relationship networks are transformed and/or impoverished, they may decrease. A decrease in social activity is possible and all these accumulated changes contribute, or can contribute, to increase the vulnerability of the elderly to experience loneliness. Loneliness is a concept that has been studied by several areas of knowledge, however it remains difficult to define. Objective: describe the dimensions and indicators of the concept of loneliness perceived by elderly who use social and health institutions. Methodology: Systematic Literature Review, through research at EBSCO, selecting the CINAHL and MED-LINE databases. **Results:** After analyzing the chosen studies, 5 dimensions of the concept of loneliness were identified. Indicators were also identified by the use of expressions/reports by the elderly in the analyzed studies. Conclusion: The "Absence of significant relationships", "the lack of distraction" and "social isolation" are referred in the majority of the 9 articles analyzed. We can affirm that the relational and social isolation dimensions are valued, compared to the other dimensions identified. Health professionals must know the concept of loneliness perceived by the elderly to intervene. Moving to nursing homes can bring security and social support, but when it fails it can aggravate some of the indicators of loneliness of various dimensions. All participants in the studies analyzed were able to collaborate in the investigations, the non-verbal component was not explored, revealing a limitation in this review.

Keywords: Loneliness · Concept · Elderly · Nursing homes · Gerontechnology

1 Introduction

Someone is considered elderly if he/she is aged 65 years old or more in developed countries [1] and the arrival at this age is also linked to the retirement age, being a reference for old age. Portugal is in the same demographic evolution trend of the worldwide, there is a continued increase in elderly population. Corroborating this, data from the National Statistics [2] show that, in 2018, the resident population in Portugal was composed of 13.7% of young people, 64.5% of people of working age and 21.8% elderly. In this study we will consider that people with 65 years or more are elderly.

Aging is a process and it is associated with multiple consequences or effects of time in people. This process depends on multiple factors [3], such as: genetics; the context where

the person is inserted and develops his lifestyle. This complexity makes the research in the aging field a priority area of action in its various dimensions.

Some of the changes that occur in the aging process are associated with social changes. Over the years there is a loss of members of the social network due to the death of family and friends, leading to a relationship network that is transformed and/or impoverishes, a network of contacts that decreases. On the other hand, there is a decrease in social activity and thereby all these accumulated changes contribute, or can contribute, to increase the vulnerability of the elderly to experience loneliness [4].

The concept of loneliness has been studied by several areas of knowledge; however, it remains difficult to define. Harry Stack Sullivan, in 1950, defined loneliness as an extremely unpleasant experience that leads to an extreme and inadequate need for human intimacy [5].

In 1973, Weiss defends that each individual needs to establish and/or maintain solid and binding interpersonal relationships and that these are essential to their well-being; when the relationship is not able to satisfy these needs inherent to the human condition, the individual experience loneliness [5]. Loneliness is seen as a multidimensional experience, both for the various causes and for the many contexts in which it manifests itself.

Also in 1973, Carl Rogers considered that loneliness is more acute and blunt in the individual who, for one reason or another, finds himself without some of his habitual defenses, a vulnerable self, alone, but real, safe from rejection in a world that judge and criticize [5].

Bastos, in 2005 [6] refers to loneliness as an important experience of aging, especially in adults of advanced age, due to the consequences it has on the quality of life and well-being of these people.

Loneliness can also be defined as a painful experience that often happens when social relationships are not adequate, in which the person feels lonely, even when surrounded by people, because there is a feeling of lack of affective support [7]. This type of loneliness in the elderly seems to be related more to losses, which mean a decrease of the feeling of belonging, than to social isolation [8], with an impact in 3 main dimensions: affection; cognition; and behavior [9].

The progressive loss of autonomy is linked to the increase in the level of loneliness in the elderly living with a disease [10], such as heart failure, that increases the probability of the inability to maintain an active social life, threatening health and well-being. Functional deterioration and an increase in the self-care deficit resulting from the aging process is limitating and this can mean an inability to leave the house or have the urge of being admitted in a nursing home. The effect of being in nursing homes on loneliness varies according to the conditions of the institution itself, the quality of social moments and moments shared with the family members [8].

Paulo Santos, a CINTESIS researcher, and Catarina Rocha-Vieira, from ARS Norte, argue that it is important to realize that loneliness in the elderly leads to a greater sum of their suffering and increases the risk of being over-medicated [11]. According to the same study, loneliness leads to an increase in the use of health services, as we can see through its relationship with chronic drug consumption, especially among the elderly

over 80 years of age, explain the researchers of the study, which was published in the scientific journal Family Medicine & Primary Care Review [11].

All these data raised the interest and the importance of studying the way in which the elderly perceive loneliness in order to be able to make appropriate interventions later.

In addition to the more traditional interventions, technology can be an ally of health professionals in situation diagnosis, prevention and control of loneliness in the elderly.

However, as loneliness is a concept perceived individually, it is necessary to transform it into a universal concept.

This systematic review of the literature aims to describe the dimensions and indicators of the perceived concept of loneliness by elderly people, who use social and health institutions.

2 Methodology

The systematic review of the literature which, as referred by Cochrane Handboo [12], tries to collect all the empirical evidence that meets the pre-specified eligibility criteria, in order to answer a specific research question. Systematic and explicit methods are used, selected with the aim of minimizing bias, thus providing more reliable results from which conclusions can be drawn and then informed decisions can be made.

The research question was elaborated through the formulation PICO (P patient and/or problem of interest; I main intervention; C control, or if any, comparison intervention; O outcomes): Which are dimensions and the loneliness indicators that are perceived by elderly, users of social and health institutions?

In October 2019, research was carried out for this review, in the EBSCOhost - Research Databases database, through the reserved area of the University of Évora, Portugal. From this it was possible to access the following databases: CINAHL, MEDLINE with the descriptors: [(elderly) OR (aging) OR (frail elderly)], [(solitude) OR (loneliness) OR (isolation)], [(long term care) OR (nursing homes) OR (homes for the aged) OR (housing for the elderly)]. Subsequently, more descriptors were introduced: [(result of elderly) OR (aging) OR (frail elderly)] AND [(solitude) OR (loneliness) OR (isolation)] AND [(long term care) OR (nursing homes) OR (homes for the aged) OR (housing for the elderly)]. Inclusion criteria were defined: full text, in English and Portuguese, and scientific articles dated from 2014/01/01 to 2019/12/31.

As participants, only elderly adults receiving home care or living in nursing homes were included in the study.

Repeated articles were excluded and to make the preliminary selection of the articles, two readings were performed: first, two authors excluded some articles by reading their titles and later by reading their abstracts; second, the articles were analyzed by all the authors of this article, they were read in full in order to answer the research question as defined.

The methodological quality and reliability of the articles was elaborated through the critical analysis of the articles, for which the level of evidence presented was used, according to Melnyk and Fineout-Overhold [13], which indicate seven levels of evidence: level I (Referring to systematic literature reviews or meta-analysis), level II (randomized controlled studies), level III (randomized controlled study), level IV (case-control study)

or cohort study), level V (review systematic quantitative or descriptive studies), level VI (qualitative or descriptive study) and level VII (opinion or consensus). In this study the articles included had a level of evidence V or VI.

In total, 9 articles were analyzed using the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) [13] recommendations were used to perform the Fig. 1.

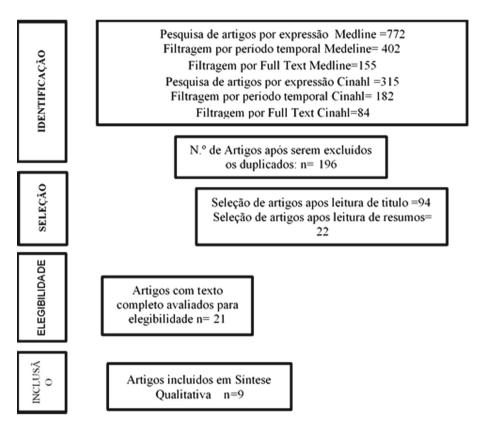


Fig. 1. Flowchart: selection of articles for SRL.

3 Results

The results of the articles found and selected for the preparation of this systematic review were summarized in the Table 1:

Table 1. Summary of the articles analyzed:

| Metadata | Objectives | Results |
|---|--|---|
| Title: Being acknowledged by others and bracketing negative thoughts and feelings: Frail older people's narrations of how existential loneliness is eased [14] Authors: Sjöberg, M., Edberg, A. K., Rasmussen, B. H., Beck, I. Method: Qualitative study had an exploratory and descriptive Evidence level: VI Participants: 22 older people, 76 to 101 years old, who were receiving long-term care and services | Describe through the narrations of frail older people how the existencial loneliness was eased | Being recognized by others, being the focus of others' concerns, facilitated the experience of existential loneliness, as well as the encounter with intimacy and the significant exchange of thoughts and feelings. In addition, existential loneliness was pushed to the background when participants were able to cluster negative thoughts and feelings. They were able to adjust and accept the current situation, see life in the rear view mirror, get in touch with the spiritual and spiritual dimensions and get distracted |
| Title: The social convoys of affordable senior housing residentes: Fellow residentes and "Time Left" [15] Authors: Drum, J. L., Medvene, L. J. Method: Quantitative study Evidence level: V Participants: 32 older people | Describe the composition of the residents' social convoys and the impact of this composition in their loneliness, social isolation and subjective health | In this study, 19.4% of the participants were considered to be at high risk of social isolation and 25.8% as being isolated Loneliness had an average value of 37 (between 20 and 80), with higher numbers indicating more loneliness |
| Title: Social networks and links to isolation and loneliness among elderly HCBS clients [16] Authors: Medvene, L. J., Nilsen, K. M., Smith, R., Ofei-Dodoo, S., DiLollo, A., Webster, N. Method: Qualitative study had an exploratory Evidence level: VI Participants: 40 older people | Explore the network types of the participants, based on the constructional characteristics of their social networks. The researchers also wanted to know how the different types of network have an actuate in the social isolation, relationship quality and loneliness | Family, diverse, restricted and religious were the four networks found Family members were almost half of participants' socials networks, and friends represented less than one-third Elderly clients that have more contact within their networks (family, diverse and religious) then to had significantly more positive relationships than those with restricted networks. Clients with restricted networks had significantly higher social isolation scores and were lonelier than clients in diverse and family networks |

(continued)

 Table 1. (continued)

| | I | T |
|--|---|---|
| Metadata | Objectives | Results |
| Title: Loneliness and Social Support Level of Elderly People Living in Nursing Homes [17] Authors: Eskimez, Z., Demirci, P. Y., TosunOz, I. K., Oztunç, G., Kumas, G. Method: quantitative study Evidence level: V Participants: 70 older people | Recognize loneliness and social support level of elderly people living in nursing homes | Social support comes mostly from the subscale of other significant people and the least from the family subscale The level of loneliness found was 41.74 "moderately lonely". There was no relationship between the level of loneliness and the participants' gender. Higher levels of loneliness in the elderly without children compared to those who had children were found. Higher levels of loneliness in the elderly who did not see their neighbors compared to those who often saw them were also found. The level of loneliness tends to be lower when the perceived social support increases |
| Title: Rumination and Loneliness Independently Predict Six-Month Later Depression Symptoms among Chinese Elderlyin Nursing Homes [18] Authors: Gan, Pei, Xie, Yan, Duan, Wenjie, Deng, Qing, Yu, Xiuli Method: Quantitative longitudinal study Evidence level: V Participants: 71 older people | Define the relationship between loneliness, rumination and depression among Chinese elderly in nursing homes | Loneliness and rumination could predict symptoms of depression (6 months later). The indirect effect between loneliness and symptoms of depression found was not significant |
| Title: The perception of the grow older in a elderly population [19] Authors Cavalcante, E.S., Freire, I. L. S., Gomes, A.T.L., Fonseca, M.F., Miranda, F.A.N., Torres, G.V Method: Qualitative, analytical and cross-sectional study Evidence level: VI Participants: 35 older people | Determine the meaning of the aging process by the elderly | Aging is considered as a burden, a moment of solitude and predisposition to disease by elderly. Some participants were grateful because they have aged and lived all that years. The study tends to encourage that the social interaction is important and that it can contribute to a higher quality of life of the elderly |
| Title: Fulfilled preferences, perceived control, life satisfaction, and loneliness in elderly long-term care residents [20] Authors: Andrew, N., Meeks, S. Method: Cross-sectional study using questionnaires Evidence level: V Participants: 65 residents in 8 nursing homes | Determine how fulfilled preferences and loneliness in nursing home residents have an impact on each other | The researchers found that a person-centered care and social-affective needs of long-term care residents are associated. Therefore, the study indicates that for making interventions in the loneliness fuild it is important to fulfill the preferences of the participants |

(continued)

Table 1. (continued)

| Metadata | Objectives | Results |
|--|---|--|
| Title: Loneliness and health care consumption among older people [21] Authors: Taube, E., Kristensson, J., Sandberg, M., Midlöv, P., Jakobsson, U. Method: Qualitative cross-sectional study Evidence level: VI Participants: 153 older people | Explore the relation between loneliness, health related quality of life (HRQoL), and health complaints and health care consumption of in- and outpatient care among frail older people living at home | In this study, 60% of the participants felt loneliness in the previous year, at least occasional loneliness. The study says that the HRQol of the most lonely participants is lower, with one higher number of health complaints and higher use of health services |
| Title: Mental Well-Being of Older People in Finland during the First Year in Senior Housing and Its Association with Physical Performance [22] Authors: Lotvonen, S., Kyngäs, H., Koistinen, P., Bloigu, R., Elo, S. Method: Quantitative longitudinal study Evidence level V Participants: 81 older people who had moved to one of the 11 senior housing | Describe perceived mental well-being of elderly and how that can be different after being in nursing homes after 3 and 12 months and how this mental well-being is influenced by the physical characteristics | The study indicates that after 12 months, the mental capacity was good or very good in 38% of the participants, however 22% of the participants experienced depressive symptoms daily or weekly. In addition, 39% of participants reported daily or weekly loneliness. After 12 months, participants also reported a significant increase in forgetting commitments, missing items and difficulties in learning new things. There was found that the opportunities to make decisions about their own life diminished significantly. In addition, dominant hand grip strength and walking speed decreased significantly and these facts were linked to the fear of falling or having an accident, but also to the opportunities to make decisions about your life, safety, loneliness, sleep problems, negative thoughts The study indicates that the physical characteristics of the older people should be considered to adapt the nursing homes and the interventions |

4 Discussion

After analyzing the chosen articles, five dimensions and seventeen concept indicators of loneliness were identified. These indicators were obtained by of expressions/reports used by the elderly, as well as interpretations by the authors in the analyzed studies. These are summarized in the Table 2.

Regarding the place where they live, only three articles refer to studies with elderly people living at home [14, 16, 21], the rest were carried out with institutionalized elderly people. This systematic review is in line with the previously consulted literature, when

| Concept dimension | Concept indicators [loneliness] |
|--|---|
| Relational (with significant people) | Absence of significant relationships [14, 16, 17] Not being considered by others [14] Lack of significant exchanges of thoughts and feelings [14] Modifications in the social network [20] |
| Relational (connection to a community) | Lack of distraction [14, 19, 20]Lack of social support [17] |
| Isolation | – Social isolation [15–17, 19] |
| Cognitive function | Negative thoughts and feelings [14, 18] Do not accept from the current situation [14, 22] Depressed mood [21] Lack of contact with the spiritual dimension [14] Lack of satisfaction about life [20] Loss of autonomy [22] |
| Health perception | Old age associated with burden, predisposition to diseases [19] Fear of falling, sleep problems [22] Quality of life related to health perception [22] Health complaints and increased demand for health services (physical and mental) [21] |

Table 2. Dimensions and concept indicators of perceived loneliness by elderly.

loneliness is referred to as a multidimensional experience. Therefore, it was possible to identify 5 dimensions and to each one of them indicators have been found and these indicators can help understand how the elderly perceive loneliness in the analyzed studies. In their study, Sjöberg, M., Edberg, AK, Rasmussen, BH, Beck, I. [14] identified two categories and seven subcategories of conditions that help in the experience of loneliness felt by the elderly: being recognized by others, with the subcategories being the focus of others' concerns, finding intimacy and having a meaningful exchange of thoughts and feelings; another category is to group negative thoughts and feelings with the subcategories adaptation and acceptance of the current situation, see life in the rear view mirror, get in touch with the spiritual dimensions and having the opportunity to get away and be distracted [14]. The shortcomings of these conditions are inserted in the relational and mental dimensions of the perception of loneliness. In the same sense, the study by Medvene, LJ, Nilsen, KM, Smith, R., Ofei-Dodoo, S., DiLollo, A., Webster, N.[16], mention the importance of social networks composed by family, diversified, restricted, religious, as these are more protective of loneliness than restricted networks. These concepts of social networks fit not only in the relational dimensions, but also in the isolation dimension.

In the dimension of health perception (named this way because it includes physical and psychological aspects of the health status perceived by the elderly), the study by Taube, E., Kristensson, J., Sandberg, M., Midlöv, P., Jakobsson, U. [21], revealed that

depressed mood [22] was associated only with seeking outpatient care. In addition to this, the same study states that those who feel more lonely have more health complaints and consequently seek more this type of care. Predisposition to the disease, physical fragility associated with falls are indicators of loneliness for the elderly in the analyzed studies.

Lotvonen et al. [22] found significant differences in the elderly when moving to nursing homes, both physically and psychically. This study offers clues as to how this change, if not successful, can bring added problems to the elderly if they are not able to make the necessary transition to the new condition [14, 22]. We must highlight the lack of autonomy reported by the elderly in the study.

Lack of satisfaction about life [20], negative thoughts and feelings [14, 18] are other indicators that professionals should recognize as predictors of loneliness. The problem is that they are not subject to direct observation by professionals, because the mental dimension is the most difficult to access.

All the indicators found in this review can be observed by professionals, some directly and some indirectly. For example, professionals can observe directly: changes in the social network [20], in situations of loss, change in accommodation; social isolation [15–17, 19]; predisposition to diseases [19], due to the vulnerability of the organism and co-morbidities; health complaints and increased demand for physical and mental health services [21]. The observation of indicators such as negative thoughts and feelings – [14, 18]; lack of satisfaction about life – [20]; quality of life related to health perception – [22]; can be done through available instruments, namely interviews, questionnaires and scales. However, it is necessary that the elderly are able to participate in these types of investigation.

In five studies [15–18, 20] the evaluation of loneliness was carried out with the support of the UCLA-loneliness scale. This scale was developed by Russel, Peplau and Ferguson in 1978 in order to assess loneliness and was originally made up of items created with phrases/expressions used by lonely individuals that characterized feelings of loneliness [23].

All the elderly who participated in the nine studies analyzed were able to collaborate in the investigations. Despite this collaboration, the non-verbal component was not explored in the search for indicators of loneliness.

5 Conclusion

The most repeated concept indicators were: "Absence of significant relationships"; "The lack of distraction" and "social isolation". Therefore, it can be said that the elderly value the relational and social isolation dimensions, compared to the other dimensions of the perceived concept of loneliness.

The move to a nursing home can bring social support and security, but when it is not successful it can aggravate some of the indicators of loneliness of various dimensions. It is important that professionals, in addition to assessing physical and psychological performance, consider the various components of the body's well-being during the adjustment to the accommodation by the elderly [22].

It is known that nowadays technology provides several tools to improve the quality of life of the elderly, namely in cognitive stimulation, since it allows the development of the necessary skills to control and regulate our thoughts, emotions and actions [24]. This type of stimulation promotes not only well-being [25] in general, but also emotional well-being [26–28].

All the elderly who participated in the analyzed studies were able to collaborate in the investigations, but the non-verbal component of communication was not explored, revealing a limitation in this review.

6 Professional Practice Implications

Health professionals must understand the concept of loneliness perceived by the elderly to intervene and they should also be able to distinguish the dimensions that exist and affect that person. The intervention will be more efficient, in our understanding, because it will be based on the elderly person and the loneliness, he/she experiences and not a general concept. This is providing person-centered care. On the other hand, it should be possible to conceptualize the concept of loneliness perceived by the elderly. A common language is necessary and for this to happen, extensive studies must be carried out in the different social contexts where elderly people are included.

The positive relationship between the use of technological means in maintaining and even strengthening social relationships, especially with family and friends [27] offers new tools to health professionals. There are also studies on the use of robots as an alternative to therapies such as animal-assisted therapy in the promotion of the health and social well-being of elderly people in elderly care facilities [29].

Health professionals should use all available resources to provide efficient care.

References

- Fonseca, A., Caldeira, E., Lopes, M.J., Marques, C., Casas-Novas, V.: Velhice: Representações Sociais Construídas por Estudantes de Enfermagem e Idosos. In: Lopes, M., Mendes, F., Silva, A., Envelecimento- Estudos e Perspectivas, pp. 131–145, Martinari, São Paulo (2014)
- Instituto Nacional de Estatística: Estatísticas Demográficas 2018, Instituto Nacional de Estatística, IP, Lisboa (2019). ISSN: 0377-2284
- 3. Lopes, D.: Solidão e Bem-estar Subjetivo na Terceira Idade: Estudo comparativo de idosos institucionalizados e não institucionalizados, Dissertação de Mestrado em Psicologia da Educação, Desenvolvimento e Aconselhamento, Faculdade de Psicologia e de Ciências da Educação, Universidade de Coimbra (2012)
- 4. Gomes, C.: A influência do meio ambiente ecológico na experiência da solidão e no bem-estar subjetivo, numa amostra de adultos mais velhos. Tese para obtenção de Grau de Mestre em Psicologia. Universidade de Lisboa, Faculdade de Psicologia Gomes (2015)
- Pocinho, M. e Macedo, E.: Solidão: Um Construto Complexo. Interações: Sociedade e as novas modernidades 32, 53–66 (2017)
- 6. Bastos, M.: A solidão e os processos de vinculação nos jovens e sua inter-relação com a utilização da internet (Tese de doutoramento não publicada). Faculdade de Psicologia e de Ciências da Educação da Universidade do Porto (2005)
- Azeredo, Z., Afonso, M.: Solidão na perspectiva do idoso. Revista Brasileira de Geriatria e Gerontologia 19(2), 313–324 (2016). https://doi.org/10.1590/1809-98232016019.150085
- Rodrigues, R.: Solidão, Um Fator de Risco. Revista Portuguesa de Clínica Geral 34(5), 334–338 (2018). https://doi.org/10.32385/rpmgf.v34i5.12073

- Stall, N.M., Savage, R.D., Rochon, P.A.: Loneliness in older adults. CMAJ 191(17), E476 (2019). https://doi.org/10.1503/cmaj.181655
- 10. Calha, A., Arriaga, M., Cordeiro, R.: Prevalência da solidão e depressão na população idosa residente na zona histórica da cidade de Portalegre, pp. 9–14. Revista Portuguesa de Enfermagem de Saúde Mental (spe1) (2014)
- 11. Seviço Nacional de Saúde in (2019). https://www.sns.gov.pt/noticias/2019/07/22/estudo-impacto-da-solidao-em-idosos/
- 12. Donato, H., Donato, M.: Etapas na Condução de uma Revisão Sistemática Acta Med. Port. **32**(3), 227–235 (2019). https://doi.org/10.20344/amp.11923
- 13. Pompeo, D., Rossi, L., Galvão, C.: Revisão integrativa: etapa inicial do processo de validação de diagnóstico de enfermagem. Acta Paul Enferm. **22**(4), 434–438 (2009)
- 14. Sjöberg, M., Edberg, A.K., Rasmussen, B.H., Beck, I.: Being acknowledged by others and bracketing negative thoughts and feelings: Frail older people's narrations of how existential loneliness is eased. Int. J. Older People Nurs. 1–9 (2019). ISSN: 1748-3743
- Drum, J.L., Medvene, L. J.: The social convoys of affordable senior housing residents: fellow residents and "Time Left". Educ. Gerontol. 43, 540–551 (2017). ISSN: 1521-0472
- Medvene, L.J., Nilsen, K. M., Smith, R., Ofei-Dodoo, S., DiLollo, A., Webster, N.: Social networks and links to isolation and loneliness among elderly HCBS clients. Aging Ment. Health 20, 485–493 (2016). ISSN: 1364-6915
- Eskimez, Z., Demirci, P.Y., TosunOz, I.K., Oztunç, G., Kumas, G.: Loneliness and social support level of elderly people living in nursing homes. Int. J. Caring Sci. 12, 465–474 (2019). ISSN: 1791-5201
- Gan, P., Xie, Y., Duan, W., Deng, Q., Yu, X.: Rumination and loneliness independently predict six-month later depression symptoms among Chinese elderly in nursing homes. PLoS ONE 10, 11 (2015). ISSN: 1932-6203
- Cavalcante, E.S., Freire, I.L.S., Gomes, A.T.L., Fonseca, M.F., Miranda, F.A.N., Torres, G.V.: La percepción del envejecer en una población de ancianos. Cultura de los Cuidados (Edición digital) 21(47) (2017)
- Andrew, N., Meeks, S.: Fulfilled preferences, perceived control, life satisfaction, and loneliness in elderly long-term care residents. Aging Ment. Health 22, 183–189 (2018). ISSN: 1364-6915
- Taube, E., Kristensson, J., Sandberg, M., Midlöv, P., Jakobsson, U.: Loneliness and health care consumption among older people. Scand. J. Caring Sci. 29, 435–443 (2015). ISSN: 1471-6712
- 22. Lotvonen, S., Kyngäs, H., Koistinen, P., Bloigu, R., Elo, S.: Mental well-being of older people in finland during the first year in senior housing and its association with physical performance. Int. J. Environ. Res. Public Health **15**, 1–20 (2018). ISSN: 1660-4601
- 23. Russel, D., Peplau, L., Ferguson, M.: Developing a measure of loneliness. J. Pers. Assement **42**, 290–294 (1978)
- 24. Lousa, E.: Benefícios da estimulação cognitiva em idosos: um estudo de caso. Coimbra, Portugal: Dissetação apresentada ao Instituto Superior Miguel torga para obtenção do grau de Mestre em Psicologia (2016). https://repositorio.ismt.pt/bistream/123456789/682/1/DISSERTA%C3%87%C3%83O.pdf
- Páscoa, G., Gil, H.: Envelhecimento e tecnologia Desafios do Século XXI. In: Coimbra, Portugal, 14th Iberian Conference on Information Systems and Technologies (CISTI) 1– 6 (2019). https://repositorio.ipcb.pt/bitstream/10400.11/6627/1/Atas_IEEExplore_GP_HG_ CISTI_2019_.pdf
- Hung, L., Liu, C., Woldum, E., Au-Yeung, A., Berndt, A., Wallsworth, C., Horne, N., Gregorio, M., Mann, J., Chaudhury, H.: The benefits of and barriers to using a social robot PARO in care settings: a scoping review. BMC Geriatr. 19, 10 (2019). https://doi.org/10.1186/s12877-019-1244-6

- 27. Ferreira, S., Veloso, A.: Reflexões sobre o impacto da utilização das TIC nas redes sociais de apoio do indivíduo sénior. In: Carioca, V. (Coord.). Envelhecer em tempos de Matrix Metáforas, Reflexões e Práticas em Gerontecnologia, pp. 93–106. Repositório Científico do Instituto Politécnico de Viseu. Capítulo em obra nacional, como autor (2020). https://hdl.han dle.net/10400.19/6269
- Fonseca, C., Lista, A., Lopes, M., Mendes, F., Marques, C., Garcia-Alonso, et al.: Dependence in self-care with comorbidity, indicators of nursing care and contributions to an ontology of aging: systematic review of the literature. In: 13th Iberian Conference on Information Systems and Technologies (CISTI), pp. 1–6. IEEE (2018). https://doi.org/10.23919/CISTI.2018.839 9236
- 29. Hung, L., Liu, C., Woldum, E., et al.: The benefits of and barriers to using a social robot PARO in care settings: a scoping review. BMC Geriatr. 19, 232 (2019). https://doi.org/10.1186/s12 877-019-1244-6



Development and Validation of a Short-Version of the European Portuguese WHOQOL-OLD Scale

Isabel Gil^{1,2(⋈)}, Paulo Santos-Costa^{1,2}, Elzbieta Bobrowicz-Campos³, Liliana B. Sousa¹, Maria Manuela Vilar³, and João Apóstolo¹

Abstract. Background: Recognizing the importance of assessing quality of life in older adults, the World Health Organization introduced in 2006 the World Health Organization Quality of Life - Older Adults Module (WHOQOL-OLD) scale, which has been adapted to several international settings. Given the need to comprehensively assess older adults in this domain, without extending the duration of this process, international recommendations have emerged to develop shortened versions of the WHOQOL-OLD scale. Purpose: To develop and validate a short version of the European Portuguese WHOQOL-OLD for older adults who resort to geriatric care facilities. Methods: Psychometric validation study, conducted in two phases. Initially, the qualitative and quantitative analyses of WHOOOL-OLD general items and facets were performed to select the items with the highest content validity and to extract the experimental reduced version of the instrument. This experimental version, comprising 18 items, was tested in a sample of nursing home residents. Based on the Classical Test Theory item-total statistics, the most representative items were identified, and the 8-item version of the instrument was proposed. This 8-item WHOQOL-OLD was administrated to 125 participants recruited in geriatric care facilities. Results: The Item Response Theory-based analyses showed that the 8-item WHOQOL-OLD has satisfactory psychometric properties, with none of the items being a source of moderate/severe misfit or revealing a differential functioning. Conclusions: The 8-item WHOOOL-OLD constitutes an interesting alternative for the assessment of the quality of life in Portuguese seniors integrating geriatric care facilities. Future studies in populations of older adults with different sociodemographic and clinical profiles are warranted.

Keywords: Older adults · Quality of life · Psychometrics

Health Sciences Research Unit: Nursing (UICISA: E), Nursing School of Coimbra (ESEnfC), Avenida Bissaya Barreto, Apartado 7001, 3046-851 Coimbra, Portugal igil@esenfc.pt

Instituto Ciências da Saúde, Universidade Católica Portuguesa, 4169-005 Porto, Portugal
 Faculty of Psychology and Education Sciences of the University of Coimbra, 3001-802
 Coimbra, Portugal

1 Introduction

With the remarkable recent demographic changes, it becomes increasingly important to reflect on the inferences of this phenomenon in the quality of life (QoL) in old age and, consequently, to move towards adopting principles of care centered on the aged person, assuring their dignity. Since the early 1990s, the World Health Organization (WHO) Quality of Life Group (The WHOQOL Group) has developed general measures for QoL assessment (such as WHOQOL-100, WHOQOL-Bref or EUROHIS-QOL-8) and, posteriorly, WHOQOL-OLD module for older adults, using as reference the multidimensional definition of this construct [1]. The instrument included 24 items integrated into six facets. In 2009, the validation of WHOQOL-OLD for the Portuguese population has started, following the methodological matrix proposed in the international studies and by the WHOQOL Group. This version comprised a new facet Family/Family life with four additional items [2], which contributed to a better understanding of older adults' perceptions and increased the psychometric robustness of the instrument. The studies on the WHOOOL-OLD conducted in Portugal identified the need to develop and validate a short version of the scale. The abbreviated versions allow establishing an individual profile without affecting the duration and validity of the assessment process, thus constituting a user-friendly and low-cost solution, sustainable in both healthcare services and research. Currently, the application of abbreviated versions of the instruments is widely suggested. In the case of the WHOOOL-OLD, the shorter options have already been proposed in different international settings [3, 4].

The aim of this study was to develop a short version of the WHOQOL-OLD from the 28-item European Portuguese version [2, 5], with one item from each facet of the original Portuguese version and a general QoL item, and to examine its psychometric properties in the aged population that resort to geriatric care facilities.

2 Materials and Methods

The study was conducted in two phases, although a preliminary effort was carried out with the objective of elaborating a reduced experimental version of the European Portuguese WHOOOL-OLD. For this purpose, the analyses of qualitative and quantitative parameters were performed and, based on the results of these analyses, the 18-item version of the instrument was created. In the first phase of the study, the 18-item experimental version of the WHOQOL-OLD was provided to the sample of older adults in order to identify the eight items most representative of the scale (one general item and one item from each of the seven facets). This process resulted in the creation of an 8-item version of the WHOQOL-OLD. In the second phase, the psychometric properties of the 8-item version of the instrument were examined through the Item Response Theory (IRT) Rasch model. The study protocol was approved by the Ethics Committee of the Health Sciences Research Unit: Nursing of the Nursing School of Coimbra (P406-03/2017). The formal authorization of each participating institution was also obtained. All subjects who agreed to participate in the study gave their written and informed consent. The study complied with the STROBE Statement for cross-sectional studies and with the principles of the Declaration of Helsinki and its recommendations.

Phase I: Development of the 8-Item Version of the WHOQOL-OLD from the 18-Item Experimental Version of the Instrument

The reduced experimental version of the European Portuguese WHOQOL-OLD was developed from the 28-item European Portuguese version of the instrument [2, 5] using a mix-method approach. First, content analysis was performed by experts from health sciences, nursing and psychology (including the first author of the European Portuguese version of the instrument), and took into account the conceptual adequacy of each item in relation to the facet in which it is represented (as well as the general items), as well as the sociodemographic characteristic of Portuguese elderly attending day centers and nursing homes. Secondly, exploratory quantitative analyses were carried out to statically confront the selected items with other WHOQOL-OLD studies [3, 4], including data from the validation study of the European Portuguese WHOQOL-OLD [2]. Based on the mixedmethod approach, the 18-item version of the WHOQOL-OLD was constructed. This 18-item version of the instrument was administrated in a sample of older adults, in order to perform the reliability analyses and, based on the item-total statistics, to choose the 8 items to be included in the reduced version of the instrument.

Sample and Measures

The convenience sample of older adults was recruited from a nursing home. The persons considered for inclusion had to be aged ≥ 65 years and be able to understand and answer the questions provided by the researchers. The initial sample included 11 males and 19 females; however, due to the non-eligibility of one male participant (age < 65 years), only results of 29 persons were considered in the analyses.

All participants completed the reduced experimental version of WHOQOL-OLD with 18 items. Rating of items was based on a 5-point Likert scale, with score 1 meaning not at all and score 5 meaning an extreme amount. The intermediate categories were a little (score 2), a moderate amount (score 3) and very much (score 4). It should be noted that in the Portuguese version of the instrument the response options for each facet vary at a semantic level; however, these options always correspond to the amount indicated in the original scale. Due to the nature of the questions, the items included on the facets Sensory abilities and Death and dying are inversely coded. The participants were also given the Mini-Mental State Examination (MMSE) [6] validated for Portugal [7] to evaluate cognitive status, more specifically, orientation, memory, ability to follow verbal and written commands, attention and visuospatial capacities. The MMSE score ranges from 0 to 30, where higher values indicate better cognitive functioning. The optimal thresholds for cognitive impairment in the Portuguese adults aged ≥65 years are ≤26 for older adults with four years or less of formal education and ≤28 for older adults who have completed at least 5 years of formal education [8].

Procedures

Data were collected in April 2017. The potential participants were identified and informed about the study by the nursing home team. The persons who showed availability to participate in the study were contacted personally by the researchers. At this time, information about the study's objectives and methods was provided in a written and verbal form, and potential participants had the opportunity to ask questions if something

was not clear. They have also been assured that their participation in the study is voluntary and that anonymity of their identity and confidentiality of data obtained will be preserved. After giving their informed consent, the participants were invited to respond to questions from the 18-item WHOQOL-OLD and MMSE.

Statistical Analysis

Data were analyzed using the Statistical Package for Social Sciences (SPSS), version 24.0. The analyses were performed to calculate item-total statistics, including corrected item-total correlations and values of Cronbach's alpha if item deleted. The data obtained fulfilled the assumptions for the use of parametric tests. Thus, Student's t-test was performed to analyze the differences between the subgroups of the study sample, and Pearson correlations to examine the associations between the 18-item WHOQOL-OLD and MMSE score. The probability levels of .05 were considered significant. For the interpretation of correlation values, the orientations of Pestana and Gageiro [9] were followed. Thus, the coefficients below ± 0.4 were considered as indicators of weak associations, ranging from $\pm .4$ to $\pm .69$ as indicators of moderate associations, varying from $\pm .7$ to $\pm .89$ as indicators of strong associations, and equal to or higher than ± 0.9 as indicators of very strong associations.

Phase 2: IRT Validation of the 8-Item WHOQOL-OLD Version

The psychometric properties of the 8-item WHOQOL-OLD (extracted in the first phase of the study) were examined through IRT analyses.

Sample and Measures

The study sample included older adults recruited in six nursing homes and nine day centers. The inclusion criteria were identical to those of the first phase of the study. A total of 125 participants were included, of whom 94 were female and 31 were male.

The participants who voluntarily accepted to participate in the study were given the 8-item WHOQOL-OLD, the 10-item Geriatric Depression Scale (GDS-10) and the 6-item Cognitive Impairment Test (6-CIT). The 8-item WHOQOL-OLD includes one general question about the overall QoL and 7 specific items that cover 7 facets of the 28-item European Portuguese WHOQOL-OLD. All items are rated on a five-point scale. The classification method for items on sensory abilities and death and dying is reversed. For the remaining six items, the classification is direct. Thus, higher scores indicate better QoL. The 6-CIT is a cognitive screening test [10]. It includes six questions that assess time-space orientation, working memory and attention, and verbal memory. The scoring system is reversed, with lower scores indicating better cognitive functioning. The cut-off points for cognitive impairment, proposed for the Portuguese population are \geq 12 for older adults with two or less years of formal education, \geq 10 for older adults with three to six years of formal education, and >4 for older adults with seven or more years of formal education [11]. The GDS-10, a brief version of the GDS-30 [12, 13], is an instrument used to assess the presence of depressive symptomatology in older adults. The internal consistency of the Portuguese version of this instrument was shown to be high ($\alpha = 0.84$). The GDS-10 items are scored on a two-point scale. The items 2, 3, 6, 8 and 10 are scored 0 in the absence of symptomology, and 1 when the symptom is present. The classification of the remaining five items is inverted. The threshold for depression is ≥ 2 [14].

Procedures

Data collection was undertaken between May 2017 and April 2018. The initial contact with potential participants was made by the institutional staff. After showing interest and availability to participate in the study, older adults were contacted personally by the research team. The procedures for presenting the study and obtaining informed consent were the same as those performed in the first phase of the study.

Statistical Analysis

Descriptive statistics were computed with the SPSS, version 24.0. Rasch analyses were performed in WINSTEPS [15]. The Rating Scale Model (RSM) for the polytomous items was used due to multiple response categories of the WHOQOL-OLD items [16, 17]. As the Rasch models are highly dependent on unidimensionality [18], 2006), the dimensionality of the 8-item WHOOOL-OLD was analyzed, using a Principal Component Analysis (PCA) of the residuals. This analysis looks for patterns in the residuals and attempt to find a component that explains the largest amount of variance in the residuals under the assumption that the residuals do not represent random noise. The criteria for fundamental unidimensionality [15] include small eigenvalue of the first component of the residuals (usually <2.0), and large percentage of the raw explained variance (usually >50%, as a rule thumb). The model fit was analyzed for persons and items using outfit (mean of the squared standardized residuals) and infit (mean of the squared standardized residuals, weighted by the information function indexes) values. For interpretation, the Linacre criteria [15] were used, with values between 0.5 and 1.5 indicating important items for the measure, values between 1.5 and 2.0 indicating that the items produce a moderate misfit to the measure, and values higher than 2.0 indicating that the items produce a severe misfit to the measure and should be excluded from it. The Rasch models assume the specific objectivity [19], considering that individuals with the same ability will have the same likelihood of correctly answering an item, regardless of whether they belong to different groups. The Differential Item Functioning (DIF) detection procedure is based on the Item Characteristic Curve (ICC; a proportion of individuals at the same ability level who answer a given item correctly). In this study, the absence of DIF was tested by the difference between the estimators of the item parameter of difficulty for each focal and reference group (Df – Dr), controlling for the possible differences between them in the latent variable. The t-test with the Bonferroni adjustment was used to analyze the significance levels [20]. Based on the analysis of the contingency tables corresponding to the different levels in which the variable has been divided, the Delta Mantel-Haenszel (MH) was established. The DIF is usually considered substantial if Delta MH value reveals size higher than .64 and significant χ2 statistic [21]. In this study, DIF analyses were performed to explore whether the 8-item WHOQOL-OLD items work differently for different categories of variables such as gender (male and female), age (65–74 years, 75–84 years and ≥85 years), education level (0–4 years and >5 years), cognitive status (with and without cognitive decline), depressive symptomatology (with and without depressive symptomatology) and setting (day center and nursing home). The DIF for variable marital status was not analyzed as

some of the variable categories were represented by a very low number of participants (e.g. divorced).

3 Results

Phase 1: Development of the 8-Item Version of the WHOQOL-OLD

Sample Characteristics and 18-Item WHOQOL-OLD Score

The mean age of the 29 participants was 82.74 ± 0.92 ; range 69-97) years, and the mean education level was 4.86 ± 4.68 ; range 0-17) years. Thirteen participants were widowed, 10 were married and the remaining six were divorced or single. The overall score on the MMSE was 20.59 ± 0.62 ; range 8-30), with 86% of the sample showing mild to severe changes in cognitive functioning.

The overall mean score on the 18-item WHOQOL-OLD was 64.07 (± 11.00 ; range 41–83) and there was no difference in the score obtained by male and female participants (t(27) = -.199; p = .844). There was no significant correlation between the 18-item WHOQOL-OLD and MMSE score (r = .124; p = .523). The lack of significant association was also verified for the 18-item WHOQOL-OLD score and age (r = -.040; p = .843), and for the 18-item WHOQOL-OLD score and education level (r = .037; p = .853).

Selection of 8 Items for the Reduced Version of WHOQOL-OLD

As presented in Table 1, the means of the 18 items included in the experimental short version of WHOQOL-OLD ranged from 2.76 (item 2) to 4.28 (items 11 and 12). Regarding the item-total correlations, four were shown to be weak (items 2, 3, 5 and 6), two were found to be strong (items 16 and 17), and the remaining 12 were revealed to be moderate. The analysis of the item-total correlations allowed the identification of the items with the highest coefficient values, either for general items or for each facet. Based on these data, and additionally considering the Cronbach's alpha if item deleted, the eight items for the reduced version of WHOQOL-OLD were selected.

The item-total statistics for the selected eight items were calculated (see Table 2). The item-total correlations of the 8-item version of the WHOQOL-OLD ranged from .357 (Death and Dying facet) to .760 (Social Participation facet), while the corrected item-total correlations varied from .251 (Death and Dying facet) to .633 (Past, Present and Future Activities facet). Internal consistency of the 8-item WHOQOL-OLD estimated by Cronbach's alpha was shown to be satisfactory ($\alpha = .756$). Exploratory analyses of combinations of items other than those listed in Table 2 showed less satisfactory results. It was therefore decided that the reduced version of the instrument would include the following items from the 28-item European Portuguese WHOQOL-OLD: items 3, 6, 10, 14, 19, 23 and 28, and the first general item of QoL.

Phase 2: IRT Validation of the 8-Item WHOQOL-OLD Version

Sample Characteristics and Fit Indexes for Items and Persons

The mean age of the sample included in the second phase of the study was 80.69 ± 7.88 ; range 65-99) years, and the mean education level was 4.54 ± 3.36 ; range 0-17) years.

Table 1. Statistics of the item and of the item with the total 18-item WHOQOL-OLD.

| Item | Item mean (standard deviation) | Item-total correlation | Corrected item-total correlation | Cronbach Alpha if item deleted |
|-----------------------|--------------------------------|------------------------|----------------------------------|--------------------------------|
| 1 (WP General item 1) | 3.24 (1.02) | .665 | .608 | .831 |
| 2 (WP General item 2) | 2.76 (1.12) | .366 | .273 | .845 |
| 3 (WP 1) | 3.03 (1.35) | .363 | .250 | .848 |
| 4 (WP 3) | 3.79 (1.29) | .478 | .380 | .841 |
| 5 (WP 7) | 3.55 (1.45) | .201 | .070 | .860 |
| 6 (WP 10) | 3.03 (1.40) | .357 | .238 | .850 |
| 7 (WP 19) | 4.03 (0.94) | .622 | .565 | .833 |
| 8 (WP 12) | 3.07 (1.00) | .517 | .446 | .838 |
| 9 (WP 22) | 4.10 (0.94) | .470 | .399 | .840 |
| 10 (WP 23) | 3.83 (0.93) | .648 | .595 | .832 |
| 11 (WP 25) | 4.28 (0.96) | .489 | .418 | .839 |
| 12 (WP 28) | 4.28 (1.13) | .584 | .510 | .835 |
| 13 (WP 4) | 3.52 (1.38) | .572 | .478 | .836 |
| 14 (WP 11) | 4.03 (0.94) | .612 | .554 | .834 |
| 15 (WP 6) | 3.07 (1.22) | .626 | .551 | .832 |
| 16 (WP 14) | 3.69 (1.20) | .760 | .708 | .824 |
| 17 (WP 17) | 3.28 (1.31) | .757 | .698 | .824 |
| 18 (WP 16) | 3.48 (1.12) | .584 | .557 | .832 |

Item-total **correlation in Bold:** significant correlation with p < .05; **(WP)**: numbering of items according the 28-item Portuguese version of WHOQOL-OLD.

Table 2. Statistics of the item and of the item with the total 8-item WHOQOL-OLD

| Item* | Item-total correlation | Corrected item-total correlation | Scale mean if item deleted | Scale variance if item deleted | Cronbach Alpha if item deleted |
|----------------------------|------------------------|----------------------------------|----------------------------|--------------------------------|--------------------------------------|
| 1. [1 (WP General item 1)] | .665 | .492 | 25.72 | 25.35 | .725 |
| 2. [4 (WP 3)] | .478 | .340 | 25.17 | 25.36 | .754 |
| 3. [6 (WP 10)] | .357 | .251 | 25.93 | 25.92 | .776 |
| 4. [7 (WP 19)] | .622 | .633 | 24.93 | 24.64 | .705 |
| 5. [10 (WP 23)] | .648 | .530 | 25.14 | 25.62 | .721 |
| 6. [12 (WP 28)] | .584 | .423 | 24.69 | 25.37 | .736 |
| 7. [15 (WP 6)] | .626 | .509 | 25.90 | 23.88 | .720 |
| 8. [16 (WP 14)] | .760 | .584 | 25.28 | 23.28 | .705 |

^{*}The item numbering provided in [] refers to the numbering of the 18-item version. Item-total correlation in Bold: significant correlation with p < .05; (WP): numbering of items according the 28-item Portuguese version of WHOQOL-OLD

Most participants (61.6%) were widowed, 24% were married, 8.8% were single and the remaining 5.6% were divorced. The mean GDS-10 score was of 3.56 (± 3.07 ; range 0–10) points, with 67.2% of the participants evidencing depressive symptomatology. The mean 6CIT score was of 10.09 (± 5.82 ; 0–25) points, with 56% of the participants displaying signs of cognitive decline. IRT item and person parameters are presented in Table 3. The difficulty parameters observed for the 8-item WHOQOL-OLD items ranged between -.67 (item 8) and .57 (item 3) logits. The reliability of this measurement was shown to be high (Standard Error: M = 0.09; SD = 0.01), with item separation reliability reaching the value of 0.93. The item-total correlations, ranging between 0.48 (item 8) and 0.65 (item 4), were also satisfactory (M = 0.54; SD = 0.06). The item fit to the model was shown to be excellent, with none of the items revealing moderate or severe misfit within the *infit* and *outfit* parameters (values below 1.5 logits). Regarding the fit indexes for persons, the person separation reliability and the Cronbach's alpha were below the acceptable (0.63 and 0.65, respectively). In addition, considering the *infit* parameters, 10.4% of items were associated with moderate misfit and 8% with a severe misfit. For outfit parameters, the moderate and severe misfit was reported in relation to 10.4% and 7.2% of items, respectively.

Table 3. The 8-item WHOQOL-OLD: statistics for items and persons

| | Item statistics | | | | | | Per | son sta | tistics | |
|------|-----------------|-----|-----|------|-------|------|----------|---------|---------|------|
| | RiX | D | SE | In- | Out- | X | В | SE | In- | Out- |
| | | | | fit | fit | | | | fit | fit |
| 1 | .62 | .11 | .09 | .49 | .53 | | | | | |
| 2 | .49 | 15 | .10 | 1.28 | 1.24 | | | | | |
| 3 | .51 | .57 | .09 | 1.28 | 1.30 | | | | | |
| 4 | .65 | .50 | .09 | .72 | .71 | | | | | |
| 5 | .51 | 28 | .10 | .80 | .77 | | | | | |
| 6 | .52 | 16 | .10 | .86 | .85 | | | | | |
| 7 | .50 | .08 | .09 | 1.39 | 1.36 | | | | | |
| 8 | .48 | 67 | .11 | 1.24 | 1.13 | | | | | |
| | | | | | Total | | | | | |
| Mean | 0.54 | .00 | .09 | 1.01 | .99 | 26.9 | .32 | .38 | 1.00 | .99 |
| SD | 0.06 | .38 | .01 | .31 | .29 | 4.9 | .72 | .07 | .61 | .62 |
| Max. | 0.65 | .57 | .11 | 1.39 | 1.36 | 38.0 | 2.88 | .78 | 2.80 | 3.11 |
| Min. | 0.48 | 67 | .09 | .49 | .53 | 14.0 | -1.42 | .34 | .06 | .06 |
| M.M | | | | 0 | 0 | | | | 10.4 | 10.4 |
| (%) | | | | | | | | | | |
| S.M. | | | | 0 | 0 | | | | 8 | 7.2 |
| (%%) | | | | | | | | | | |
| • | ISR = | 93 | | PSR | = .63 | (| Cronbach | Alpha | 1 = .65 | |

RiX: Item-total correlation; D: Difficulty parameter; SE: Standard Error; Infit and Outfit: Rasch model adjustment parameters; X: Classic results; B: Rasch results (logits); ISR: Item Separation Reliability; PSR: Person Separation Reliability; Infit/Outfit: The average of the infit and outfit mean-squares associated with the responses in each category; M.M.: Moderate Misfit; S.M.: Severe Misfit; Min: Minimum; Max: Maximum.

Dimensionality

The percentage of the raw variance explained by the Rasch measures was only 35.8%. Moreover, the eigenvalue of the first component of residuals was higher than 2.0. These results are showing that the 8-item WHOQOL-OLD has no fundamental unidimensionality. However, the unexplained variance of the first factor was only 14.4% and the latter result, associated with the lack of items with moderate and severe misfit, supports the flexible consideration of the scale's unidimensionality.

Differential Item Functioning

No DIF was associated with age, gender, education level, cognitive status and depressive symptomatology (for interpretation of p values, the Bonferroni correction was used; probability levels considered as significant were of .05/8 = .00625). Regarding the setting, although items 6 (Welch's t = -3.68, df = 103, p = .0004) and 8 (Welch's t = 3.32, df = 91, p = .0013) revealed DIF, the benefits of these items were balanced, since one of them favored the group recruited in day centers, and another favored the group recruited in nursing homes. Thus, although there were items with DIF, the variable setting did not introduce any bias in the scale functioning.

Analysis of Group Differences on the 8-Item WHOQOL-OLD Score

The 8-item WHOQOL-OLD mean score was 26.75 (± 5.02) for female participants and 26.59 (± 4.15) for male participants (Table 4). In relation to the variable age, the mean scores of the QOL measure were 25.76 (± 5.30) for the category of 65–74 years, 26.39 (± 3.92) for the category of 75–84 years and 27.87 (± 5.27) for the category \geq 85 years. The participants with education level \leq 4 years obtained the mean score of 26.09 (± 4.73) . For the remaining participants (education level \geq 5 years), the mean score on the 8-item WHOQOL-OLD was 28.41 (± 4.88) .

The average values of the scale obtained in day centers and nursing homes were 27.20 (± 4.65) and 25.98 (± 5.07), respectively. None of these variables (gender, age, education level, and setting) have a significant effect on the 8-item WHOQOL-OLD overall scores. The same was verified for the variable cognitive status, assessed through the 6-CIT (mean score on the QoL measure for the participants with cognitive decline: 26.67 ± 5.1 ; and without cognitive decline: 26.82 ± 4.46). The additional analysis of correlations between the 8-item WHOQOL-OLD and 6-CIT score confirmed the absence of significant relationships between these two variables (r = -.119). The variable depressive symptomatology was shown to have a significant effect on the distribution of the 8-item WHOQOL-OLD score. The participants with clinically relevant depressive symptoms revealed to score lower on the QoL measure as compared to participants without clinically relevant depressive symptoms (mean score for the participants with GDS-10 score \geq 2: 25.26 \pm 4.68; and for the participants with the GDS-10 score < 2: 29.85 \pm 3.37). The existence of significant relationships between the 8-item WHOOOL-OLD and GDS-10 score was also confirmed through correlation analysis. The association met was negative and of moderate magnitude (r = -.661, p < .001).

| Variable and groups | Measure | SE | Reliability | Mean difference | Welch t | | | |
|-----------------------------|------------|-----|-------------|------------------|----------------|--|--|--|
| Gender | | | | | | | | |
| 1 (female) | .35 | .08 | .73 | .07 | t(66) = 0.56 | | | |
| 2 (male) | .27 | .11 | .58 | | (p = .578) | | | |
| Age | | | | | | | | |
| 1 (65–74 years) | .16 | .13 | .70 | 1 <i>vs</i> 2:07 | t(45) = -0.45 | | | |
| 2 (75–84 years) | .22 | .07 | .48 | 1 <i>vs</i> 3:40 | (p = .653) | | | |
| $3 (\geq 85 \text{ years})$ | .55 | .13 | .77 | 2vs3:33 | t(68) = -2.15 | | | |
| | | | | | (p = .035) | | | |
| | | | | | t(68) = -2.21 | | | |
| | | | | | (p = .031) | | | |
| Education level | | | | | , | | | |
| 1 (0–4 years) | .23 | .07 | .68 | 39 | t(47) = -2.47 | | | |
| $2 (\geq 5 \text{ years})$ | .62 | .14 | .71 | | (p = .017) | | | |
| Setting | | | | | | | | |
| Day Center | .39 | .08 | .70 | .18 | t(83) = 1.30 | | | |
| Nursing Home | .21 | .11 | .72 | | (p = .198) | | | |
| Cognitive status | | | | | | | | |
| With decline | .31 | .09 | .72 | 03 | t(119) = -0.26 | | | |
| Without decline | .35 | .09 | .69 | | (p = .793) | | | |
| Depression | Depression | | | | | | | |
| With depression | .12 | .08 | .71 | 62 | t(93) = -5.16 | | | |
| Without depression | .74 | .09 | .49 | | (p < .001) | | | |

Table 4. The analysis of group differences on the 8-item WHOQOL-OLD score.

4 Discussion

The internal consistency of the 8-item version of the WHOQOL-OLD, extracted from the 18-item experimental version of the instrument, was shown to be satisfactory (.756). Other studies, performed at an international level, have obtained less acceptable results, identifying the internal consistency values of .681, .678 or .649 [3]. Comparatively, in one study examining the properties of the EUROHIS-QOL-8 in the Portuguese population, the Cronbach's alpha of .83 was obtained [22], while other studies, conducted in several European countries, the Middle East and Brazil, obtained the internal consistency values for the EUROHIS-QOL-8 between .74 and .85 [23, 24]. A second application of the scale in a larger sample from day centers and nursing homes was conducted. Based on the TRI analyses, it was found that the unidimensionality of the 8-item WHOQOL-OLD is only moderately robust. However, the analysis of other indicators (the unexplained variance of the first factor and items with moderate and severe misfits) supported the flexible consideration of the scale's unidimensionality and, therefore, the use of the Rasch analysis. Non-achievement of the robust unidimensionality can be justified by the

^{*}Bonferroni correction: p = .05/8 = .00625

comprehensive and multidimensional nature of the QoL construct used by the WHOQOL Group. Similar findings were reported in relation to the 28-item European Portuguese version of the scale [5]. The reduced number of scale items usually has a significant impact on the robustness of its psychometric properties. The fit indexes for persons obtained in this study for the 8-item WHOQOL-OLD reflect this impact quite well. However, the analysis of the item statistics revealed that the selection of the items for the WHOQOL-OLD short version was adequate since none of the items included shows moderate to severe misfit.

TRI analysis evidenced the geriatric care setting as a source of DIF. There were two items that functioned differently in day centers and nursing homes. In day centers, the item less quoted in comparison to nursing homes was the one asking about the satisfaction with the way the older person uses her/his time. This finding can be justified by the fact that the moment in which the older persons start attending day center can be considered as a moment of transition. According to Schlossberg [25], a person faces a transitional situation when an event causes changes in her/his relationships, routines and/or roles, which affect the person's perception of the world around. A change from an earlier, more active period of life is often associated with an experience of a loss of self-control and decision-making [26]. The "sense of worth within the family" corresponds to the item less quoted by the nursing homes residents, as compared to day center attendees, which may reflect the perception that the family is more absent. In fact, admission to nursing homes often happens as a consequence of the loss of a partner, children or other relatives. It also emerges as an alternative to home care, when informal caregivers are not able to respond to the needs of their elderly familiars. In Portugal, institutionalization associated with aging arises as an alternative in the expansion. According to the Portuguese Ministry of Labor and Social Solidarity [27], about 10% of the nursing homes residents stayed for 10 or more years. Given the two items with DIF counterbalanced each other, it can be concluded that the geriatric care setting did not introduce the bias in the scale functioning. Thus, the 8-item WHOQOL-OLD meet criteria that allow its use in both day centers and nursing homes.

The 8-item WHOQOL-OLD showed to be able to differentiate between older adults with and without clinically significant depressive symptoms. In this study, as in the study centered on the 28-item WHOQOL-OLD by Vilar and associates [5], the older adults with depressive symptomatology had worse scores in QoL indicators. The impact of depressive symptoms on the reduction of QoL measured through the WHOQOL scales was also documented [28]. Similar results were also obtained by Pereira and associates in relation to the EUROHIS-QOL-8 [22]. Cognitive status, sociodemographic variables, and recruitment setting, did not influence the distribution of the 8-item WHOQOL-OLD results; therefore, the WHOQOL-OLD is suitable for use in the older adults without cognitive decline, but also in the older adults who have mild to moderate changes in cognitive functioning, regardless of gender, age, formal education level or geriatric care setting. The sample included in the different phases of the study was not representative of the entire Portuguese aged population that resort to geriatric care facilities. The samples recruited in both phases of the study included older adults with mild to severe changes in cognitive functioning, which could influence the results obtained. According to Lucas-Carrasco and associates [29], some instruments proposed by the WHOQOL Group are suitable for use in the assessment of QoL in the older adults in the early stages of neurocognitive disorders. However, the suitability of the WHOQOL instruments has not been confirmed for more advanced stages. Secondly, the regional (central area of Portugal) location of participating geriatric care settings may have conditioned the development of the 8-item WHOQOL-OLD scale. This is noteworthy since QoL is influenced by various systems, including the community (mesosystem) and culture, the country and its general organization (macro-system) in which the older adults are comprised [30]. Thirdly, the non-use of an additional short QoL assessment measure did not allow the analysis of convergent validity with the scale developed.

5 Conclusions

The 8-item WHOQOL-OLD has acceptable psychometric properties, being an interesting alternative for the assessment of the QoL in Portuguese older adults who resort to geriatric care facilities. Given its short format, the 8-item WHOQOL-OLD is suitable for use in epidemiological studies and in clinical care practice, allowing the evaluation of the impact of intervention programs in the health area. However, since the validation of an instrument is a continuous process, further studies are needed to examine the performance of the 8-item WHOQOL-OLD in older adults with different sociodemographic and clinical profiles, including community-dwelling older adults.

Acknowledgements. The authors would like to acknowledge the support provided by the Health Sciences Research Unit: Nursing (UICISA: E), hosted by the Nursing School of Coimbra (ESEnfC).

References

- Power, M., Quinn, K., Schmidt, S., WHOQOL-OLD Group: Development of the WHOQOL-old module. Qual. Life Res. 14, 2197–2214 (2005). https://doi.org/10.1007/s11136-005-7380-9
- Vilar, M., Simões, M., Lima, M., Cruz, C., Sousa, L., Sousa, A.R., Pires, L.: Adaptação e validação do WHOQOL-OLD para a população portuguesa: Resultados da implementação de grupos focais. Revista Iberoamericana de Diagnóstico y Evaluación - e Avaliação Psicológica 1, 73–97 (2014)
- Fang, J., Power, M., Lin, Y., Zhang, J., Hao, Y., Chatterji, S.: Development of short versions for the WHOQOL-OLD module. Gerontologist 52, 66–78 (2012). https://doi.org/10.1093/ geront/gnr085
- Urzúa, M.A., Navarrete, M.: Calidad de vida en adultos mayores: análisis factoriales de las versiones abreviadas del WHOQoL-Old en población chilena. Rev méd Chile 141, 28–33 (2013). https://doi.org/10.4067/S0034-98872013000100004
- Vilar, M., Sousa, L.B., Simões, M.R.: The European Portuguese WHOQOL-OLD module and the new facet Family/Family life: reliability and validity studies. Qual. Life Res. 25, 2367–2372 (2016). https://doi.org/10.1007/s11136-016-1275-9
- Folstein, M.F., Folstein, S.E., McHugh, P.R.: Mini-mental state. J. Psychiatr. Res. 12, 189–198 (1975). https://doi.org/10.1016/0022-3956(75)90026-6

- 7. Guerreiro, M., Silva, A., Botelho, M., Leitão, O., Castro-Caldas, A., Garcia, C.: Adaptação à população portuguesa da tradução do Mini Mental State Examination. Revista Portuguesa de Neurologia 1, 9–10 (1994)
- 8. Freitas, S., Simões, M.R., Alves, L., Santana, I.: Mini Mental State Examination (MMSE): normative study for the Portuguese population in a community stratified sample. Appl. Neuropsychol. Adult **22**, 311–319 (2015)
- 9. Pestana, M.H., Gageiro, J.N.: Análise de dados para ciências sociais. A complementaridade do SPSS, 4th edn. Edições Sílabo, Lisboa (2005)
- 10. Brooke, P., Bullock, R.: Validation of a 6 item cognitive impairment test with a view to primary care usage. Int. J. Geriatr. Psychiatry **14**, 936–940 (1999)
- Apóstolo, J.L.A., Paiva, D.D.S., da Silva, R.C.G., Santos, E.J.F.D., Schultz, T.J.: Adaptation and validation into Portuguese language of the six-item cognitive impairment test (6CIT). Aging Ment. Health 22, 1184–1189 (2018). https://doi.org/10.1080/13607863.2017.1348473
- Yesavage, J.A., Brink, T.L., Rose, T.L., Lum, O., Huang, V., Adey, M., Leirer, V.O.: Development and validation of a geriatric depression screening scale: a preliminary report. J. Psychiatr. Res. 17, 37–49 (1982). https://doi.org/10.1016/0022-3956(82)90033-4
- Apóstolo, J., Loureiro, L., Reis, I., Silva, I., Cardoso, D., Sfetcu, R.: Contribution to the adaptation of the Geriatric Depression Scale -15 into Portuguese. Rev. Enf. Ref. 4, 65–73 (2014). https://doi.org/10.12707/RIV14033
- Alves Apóstolo, J.L., Bobrowicz-Campos, E.M., Carvalho dos Reis, I.A., Henriques, S.J., Veiga Correia, C.A.: Exploring a capacity to screen of the European Portuguese version of the 15-item Geriatric Depression Scale. RPPC 23, 99 (2018). https://doi.org/10.5944/rppc. vol.23.num.2.2018.21050
- 15. Linacre, J.M.: A User's Guide to WINSTEPS & MINISTEP. Rash-Model Computer Programs. Program Manual 4.5.4. Winsteps® (2012)
- 16. Andrich, D.: A rating formulation for ordered response categories. Psychometrika **43**, 561–573 (1978). https://doi.org/10.1007/BF02293814
- 17. Wright, B.D.: Model selection: rating scale or partial credit? Rasch Measur. Trans. **12**, 641–642 (1999)
- 18. Tennant, A., Pallant, J.F.: Unidimensionality matters. Rasch Measur. Trans. **20**, 1048–1051 (2006)
- 19. Andrich, D.: Rasch Models for Measurement. SAGE Publications Inc., Thousand Oaks (1988)
- 20. Benjamini, Y., Hochberg, Y.: Controlling the false discovery rate: a practical and powerful approach to multiple testing. J. Roy. Stat. Soc. Ser. B (Methodol.) **57**, 289–300 (1995)
- Zwick, R., Ercikan, K.: Analysis of differential item functioning in the NAEP history assessment. J. Educ. Measur. 26, 55–66 (1989). https://doi.org/10.1111/j.1745-3984.1989. tb00318.x
- 22. Pereira, M., Melo, C., Gameiro, S., Canavarro, M.C.: Estudos psicométricos da versão em Português Europeu do índice de qualidade de vida EUROHIS-QOL-8. LP 9, 109–123 (2011). https://doi.org/10.14417/lp.627
- 23. Pires, A.C., Fleck, M.P., Power, M., da Rocha, N.S.: Psychometric properties of the EUROHIS-QOL 8-item index (WHOQOL-8) in a Brazilian sample. Rev. Bras. Psiquiatr. 40, 249–255 (2018). https://doi.org/10.1590/1516-4446-2017-2297
- Schmidt, S., Mühlan, H., Power, M.: The EUROHIS-QOL 8-item index: psychometric results of a cross-cultural field study. Eur. J. Pub. Health 16, 420–428 (2006). https://doi.org/10.1093/ eurpub/cki155
- Schlossberg, N.K.: A Model For Analyzing Human Adaptation To Transition. Couns. Psychol. 9, 2–18 (1981). https://doi.org/10.1177/001100008100900202
- Yamada, Y., Siersma, V., Avlund, K., Vass, M.: Formal home help services and institutionalization. Arch. Gerontol. Geriatr. 54, e52–e56 (2012). https://doi.org/10.1016/j.archger.2011. 05.023

- 27. Gabinete de Estratégia e Planeamento (GEP): Carta social. Rede de serviços e equipamentos. Ministério do Trabalho, Solidariedade e Segurança Social, Lisboa (2015)
- Chachamovich, E., Fleck, M., Laidlaw, K., Power, M.: Impact of major depression and subsyndromal symptoms on quality of life and attitudes toward aging in an international sample of older adults. Gerontologist 48, 593–602 (2008). https://doi.org/10.1093/geront/48.5.593
- Lucas-Carrasco, R., Skevington, S.M., Gómez-Benito, J., Rejas, J., March, J.: Using the WHOQOL-BREF in persons with dementia: a validation study. Alzheimer Dis. Assoc. Disord. 25, 345–351 (2011). https://doi.org/10.1097/WAD.0b013e31820bc98b
- 30. Canavarro, M.C.: Qualidade de vida: Significados e níveis de análise. In: Qualidade de vida e saúde: Uma abordagem na perspectiva da Organização Mun-dial de Saúde, M.C. Canavarro&A. Vaz Serra. F. C. Gulbenkian, Lisboa, pp. 3–21 (2010)



Management of the Pandemic in the Elderly. The Case of Pescueza

Alfonso Vázquez Atochero^(⊠) , Jesús Seco González , and Santiago Cambero Rivero .

Universidad de Extremadura, Badajoz, Spain {alfonso, jseco, scamriv}@unex.es

Abstract. In this paper we will try to analyze the impact of COVID-19 on the elderly. This age group has been the most attacked by the virus, with the highest death rates. A double biological and cultural dimension has characterized the problem. First, the age factor makes the body less resistant to disease. Second, the concentration of the population at risk in residences means that once the virus enters, its action is catastrophic. The models of reception of the population of this group, based on massive gatherings (residences) have given rise to a deadly double dimension: on the one hand we concentrate and facilitate the possibility of the virus spreading and on the other, we group the population at risk in a place that does not meet the basic sanitary conditions (ventilation, housing density...). Pescueza constitutes an alternative model to nursing homes that under normal conditions presents better levels of user satisfaction. But in times of health crisis like the current one, it stands out much more compared to conventional models and is shown to be a safer environment.

Keywords: Elderly · Care home · Dependency · Active ageing · Pandemia

1 From Virus to Pandemic

The following day, no one died, the fact, being absolutely contrary the life's rules, provoked enormous and, in the circumstances, perfectly justifiable anxiety in people's minds, for we have only to consider that in the entire forty volumes of universal history there is no mention, not even one exemplary case, of such a phenomenon ever having occurred, for a whole day to go by, with its generous allowance of twenty-four hours, diurnal and nocturnal, matutinal and vespertine, without one death from an illness, as fatal fall, or a successful suicide, not one not a single one (Saramago 2009).

In December 2019, an outbreak of pneumonia appeared in the city of Wuhan. In January 2020, the Chinese authorities identified a new virus as the causative agent that was called SARS-CoV-2 (RENAVE 2020). On January 31, the National Center for Microbiology confirmed the first case in Spain: A German citizen in La Gomera. The disease caused by this virus was called COVID-19 and on May 11 the global pandemic was declared (WHO 2020). The mutation of the coronavirus that we agree to call COVID-19 and the subsequent global pandemic that it has created has led us to perceive a different

social model. We have accepted that the pandemic was a possible reality. But not a very hopeful reality for the human being. It has forced us to accept the fragility of our bodies in the face of uncontrolled viral infections (Marcos 2020). And it has forced us to accept our weakness in certain situations. Not surprisingly, Spain has been one of the most affected countries by the pandemic (Mora-Rodrígues 2020).

1.1 The Data War

In crisis situations, information is essential to coordinate preventive and palliative treatment. At critical moments, it is necessary to report and try to reduce false information (Mora-Rodrígues 2020). It is a governmental responsibility to transmit this information through official channels. The media also need to maintain a constant stream of headlines. Barraza Macias (2020) talks about informational stress and Manfredi-Sánchez (2020) highlights the influence of fake news and its ability to misinform. Statistics have become an all-out war amongst the government (Flores-Vivar 2020). The partisan press does not hesitate to publish biased headlines to confuse public opinion.

Sample Heading (Third Level). Only two levels of headings should be numbered. Lower level headings remain unnumbered; they are formatted as run-in headings (Fig. 1).



Fig. 1. Infographic of Libertad Digital about the pandemic data.

This situation makes it difficult to understand the scope of the problem. Furthermore, the lack of access to complete and reliable data hinders the investigation process itself. However, official data and those offered by the "rebel" media agree that the population over 70 years of age is the most affected by the virus.

2 The Most Sensitive Populations

The coldness of the data confirms that from the age of 60, the risk group begins to emerge. From the 1980s on, risk is consolidated, as shown by the image of RENAVE (2020). The Spanish Society of Cardiology analyzes various scenarios that influence the mortality rate (demographic, social) and specifies the impact of COVID in the elderly population. Other authors are especially concerned about the rate of population aging in modern countries, which opens a first-level health emergency (Bonanad 2020) (Fig. 2).

As we know from different information sources and close testimonies, the elderly as a social group have been severely attacked by COVID-19 in their homes and in geriatric residences. In Spain, more than 17,000 deaths of the elderly are registered in the more than 5,500 residences, both public, private or state-subsidised, which represents around 70% of the total number of deaths from coronavirus. Figures that express personal and

Defunción entre los casos hospitalizados

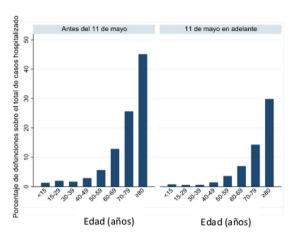


Fig. 2. Percentage of deaths out of the total number of hospitalized cases (RENAVE).

family dramas of great social significance, since anyone is frightened by the viral lethality spread by the media among our longest-lived relatives.

Undoubtedly, the protection and defense of the good treatment of the elderly is a constant that underlies this text, thus demonstrating that each and every one of us wants to be cared for until the end of our days in the best possible conditions. Hence, we hope that this analysis of the pandemic reality and the post-COVID-19 era, from the micro and macro-sociological perspective, moves us in such a way that we are cautious as a society, and thus avoid making the same fatal mistakes.

What are verifiable facts is that Spain is one of the countries with the most cases detected at the end of June, behind The United States, Brazil, Russia, India, The United Kingdom and Peru, among others. More than 10 million infected and 500,000 deaths from COVID-19 are the data at the moment, although those affected are multiplying rapidly in countries of the Southern Hemisphere. In our country, there are about 250,000 confirmed cases, so that the proportion is 5,200 cases per million inhabitants in Spain. Fortunately, the figure of more than 150,000 cured was reached compared to the more than 28,000 deceased, of which 70% are people over 80 years of age. The most symptomatic data about the failures in the residential system for the elderly is that 72% died in some of the 5,500 residences in Spain, that is, almost 20,000 deaths with COVID-19 or compatible symptoms.

It is worth noting the complication of the equation when the elderly person resides in residences. This scenario makes the safety of the elderly more unstable, since the spread of the virus occurs quickly and generates many cases in a short time. In addition, the configuration of the facilities makes it impossible to meet basic safety conditions, such as social distance (Haddinni 2020).

3 Elderly and COVID in Extremadura

In Extremadura, the month of past October opens with 519 deaths of which 431 are elderly residents, which would represent 85% of deaths from COVID-19. In the social and political debate, there are signs of concern and responsibility given the seriousness of the events, the impact that the entry of this virus has had in residences, mainly in the province of Cáceres, which could not be contained as would have been intended by public officials. Nevertheless, the Junta de Extremadura has recently announced a plan to reconvert the residential model centered on the person with home care to avoid family and community uprooting of senior citizens.

These fateful figures in a globalized and interdependent world would reflect the degree of ignorance and uncertainty about this new coronavirus, which activated the international scientific community in the search for vaccines for the upcoming autumnwinter months.

Undoubtedly, an urgent change of view towards old age is needed in all orders of society, moving on from the over-guardianship or the infantilization of old age or the abandonment of institutionalized old age towards non-ageist social practices that allows identifying those who represent more than nine million people over 60 years of age in Spain, 19.3% of the total population, from the perspective of gender, ethnic or functional diversity of these people.

Person-centered care and attention systems should be one more pillar of the so-called welfare state, which emerged after World War II in Europe and continues to this day as a fundamental axis of our systems and social rights. That will be one of the challenges of the post-COVID-19 society.

3.1 Towards a New Healthcare Model

The presence of this pandemic has changed the way we view aging and death, especially in how we walk towards it. Where and with whom will our last years be afflicted with pain, crammed into spaces surrounded by strangers, in situations where sometimes people trade with dependent elderly people, or surrounded only by our memories, or if on the contrary, we will spend these las years in a friendly environment with our loved ones.

One of the obvious signs of developed and modern societies is the increase in life expectancy, to the extent that science is capable of solving the diseases that appear over time, therefore in these societies is worth mentioning that people live longer than before on average and there has been a significant growth in the number of people in advanced ages (Chackiel et al. 2001). In short, they are many more than before and demand greater services.

Industrialized countries have seen their life expectancy increase in recent years, consequently increasing the number of elderly people with respect to the total population. However, as Riley (1987) indicates, the social position of the elderly in modern societies is much more insecure than it was in other cultures, prior to the current one. In the past, old age meant prestige, wealth, power, wisdom, and old people constituted committees of wise men or similar structures. This situation with the passage of time was disappearing.

The pandemic has shown that this society of fatigue, accelerated and volatile, does not respect the elderly, but rather abandons them surrounded by peers with mobility and memory problems until their death. However, the significant volume of elderly people who died from Covid 19 has made us reflect on the paradigm shift in the model of transit towards the death of our elders in their last years of life. A pandemic has been necessary to think about the treatment we confer on all those thousands of grandparents and grandmothers who fought in the Spanish Civil War, who raised numerous children during the famine years and who at the end of their lives paid with their pensions the supermarket tickets for their children in the worst moments of the last crisis, to realize that the model implemented is not the best.

Covid-19 has taught us that there may be another care model and that it is probably located in the same towns, where our elders lived and were happy, surrounded by their memories and their loved ones. Such a place could never be living cemetery but rather a warm, personalized space closely connected with care services, doctors and health professionals and that allows the elder to be monitored.

3.2 Pescueza: The Search for a New Model of Accompaniment for the Elderly

In Extremadura, solutions are being sought after so that there are fewer elderly people in residences, avoiding saturation and promoting telecare for those who want or can live the last years of their life at home. This model has been in operation for years in the small town of Pescueza, where the elderly is cared for in their own homes from a coordinating center. It is about a change in the way of managing old age based on support, active aging and the quality of services in a friendly rural environment. It is a model that is also self-sustaining and that serves as a catalyst for the rural environment, since jobs of different kinds are generated, such as nursing, home help, physiotherapy or psychology, among others.

We must not forget that it is difficult to undertake the investment of a nursing home for the smallest localities, that it is difficult to sustain with the elderly in a region like Extremadura where meager pensions abound, the public administration having to assume a large part of the expenses, for a population with an increasing number of elderly people.

For the implementation of this model known as housing in the European context and which has been spreading among those pensioners who charge higher pensions, it is necessary to improve home care, the development of proximity services, support for caregivers and the family, improve the accessibility of homes and invest in the development of home automation and advanced remote assistance (Rodríguez 2011).

To date, there are a diverse variety of housing examples, as Croucher (2006) points out, enunciating different models in different areas of the world designed for frail or dependent older people, such as supported housing, integrated care: Extra care housing, close care, flexi-care, assisted living, retirement village, retirement community and continuing care retirement community, etc.

Obviously, it is a model that is not available to all pensions, which, as has been indicated, in the case of Extremadura, due to the importance of the primary sector, are low. However, in the case of the town of Pescueza, the secret lies in the process of participation and social dynamization, through which the entire population is part of the project and they are themselves the managers of the entire system, through the creation of an association of which all the residents of the town are part, contributing with their fees to co-finance expenses together with the public administration. Today the entire population is involved in a process that aims to change the traditional model of the healthcare center.

As an example, in Pescueza there is already a remote surveillance system in the houses, an electric car transports the elderly, handrails have been placed on the facades of the houses to prevent falls and recently, a walking lane has been created, similar to the bicycle lane of cities, in this case designed for those elderly who have mobility problems and are forced to use a walker.

Pescueza is adapted for the daily needs of the elderly population. This project called "Quédate con nosotros" ("Stay with us") has been echoed by different media around the world. The project dates back to 2009, by an idea José Vicente Granado (mayor), and the current president of the Friends of Pescueza Association, Constancio Rodríguez. Raquel García, manager of the association, affirms that "We do not like it to be said that we have transformed the town into a nursing home. What we do is provide the service in their homes, in the Day Center, and adapt the streets to their situation (Manzano et al. 2019).

Regional (Manzano 2019; Rubio et al. 2020), state (Montañés 2019; RTVE 2019; Viejo et al. 2019) and international media have echoed the experience (BBC 2019; BBC News 2019) highlighting their benefits.

3.3 COVID in Pescueza

Despite the high average age of the municipality, there have been no deaths due to COVID (crossing data from Extremadura Health, Bando Pescueza reports, Diario Hoy). In addition to being a more user-friendly assistance service, it becomes a stable and safe environment. The structure itself and the accommodation in individual houses facilitate the maintenance of social distance. The decision to increase the home service made it possible for social contacts to be reduced. Pescueza is a friendly town for the elderly.

4 The Project "Quédate Con Nosotros" ("Stay with US"). An Ethnographic Approach

Ethnography opens an epistemological path to knowledge. The primary source is one of the great neglected of the social sciences and is almost absent in scientific journals. Except if it is ethnography, of course. However, direct contact with the informant allows building a more accurate and complete account of the social phenomenon. The fact studied is multidisciplinary and the interview, the survey and the quantitative forms acquire their own weight in this epistemology (Peralta Matínez 2009). Getting closer to

the protagonist or participant of the experience makes it easier to understand their reason for being.

Jose Vicente Granado, one of the promoters of the project, considers that one of the pillars of the project is the impulse of the citizens when making self-government decisions. He calls it open government, and it is based on assemblies and consultations. In this case studied, he promoted the project "Stay with us" for a very specific purpose. To provide services to the elderly so that they never have to go to any residence and that they can spend the rest of their lives in their own homes. It highlights the importance of changing the residence model. This model also generates an economic fabric, since workers from various sectors are hired to provide care for the elderly. The elderly remain in their homes and receive care there. It is beneficial in all aspects: health, self-esteem, economic. The model is built on a non-profit undertaking, not deficient but not designed to generate profits. For the correct development of the project, the public and private sectors collaborate closely. As it is not speculative, private management is developed by an association (Amigos de Pescueza) as it is not profitable for an external company. This mechanism generates an affection of the citizen towards politics. Despite the effectiveness of the project, there are still many steps to take that are awaiting funding. Raquel García, manager of the Amigos de Pescueza Association, as has been mentioned before, "does not consider the town to have been transformed into a nursing home". Constancio Rodríguez, president of the Association emphasizes the importance of empathy and reciprocity, "it is something as simple as taking care of the people who have taken care of you, that they feel comfortable in the locality." (Manzano et al. 2019).

Users highlight the advantage of being able to continue enjoying their life independently, as collected by Manzano (2019). Informant 1 (female, 89 years-old) is satisfied to have returned to the town where she was born: "I've come here, this is my place." She values her independence positively as well as the security of feeling protected: "My husband and I sleep at home, but we go in and out of the center, we watch TV, we go to mass, yesterday we thought there was a rosary but in the end it was not celebrated." On the contrary, Informants 2 and 3 use the health center to sleep, but during the day they live at home "We are very well here, very happy. We stay at night but we go back and forth to our homes, there is no problem. ", Informant 4 (man, 76 years-old) refers to the tranquility of living independently but with services "My routine is to walk, to be at home, come to eat. Here we talk a lot, there is harmony".

5 Pictures from Pescueza

```
(Fig. 3, Fig. 4 and Fig. 5).
```





Fig. 3. Accessible streets. Elder-friendly town (Jesús Seco).



Fig. 4. Walkways with handrails as well as non-slip surface (Jesús Seco).



Fig. 5. Day center. Meeting point (Jesús Seco).

References

Barraza Macías, A.: The informative stress in time of pandemic (COVID 19). Praxis Investigativa ReDIE 12(23) (2020)

BBC redacción: Cómo este pueblo de España se transformó para cuidar a sus ancianos, 14 de agosto de 2019. https://cutt.ly/BgjDjm7

BBC News. The village adapted for its ageing population, 25 de agosto de 2019. https://www.youtube.com/watch?v=aEXWUnE4OZE

Bonanad, C., García-Blas, S., Tarazona-Santabalbina, F.J., Díez-Villanueva, P., Ayesta, A., Sanchis Forés, J., et al.: Coronavirus: la emergencia geriátrica de 2020. Revista Española de Cardiología **73**(7) (2020). https://doi.org/10.1016/j.recesp.2020.03.027

Chakiel, J.: El envejecimiento de la población latinoamericana. En Sociología del desarrollo, políticas sociales y democracia. VV.AA. Siglo XXI Editores (2001)

Croucher, K.: Housing with Care for Later Life: A Literature Review. Editorial Joseph Rowntree Foundation, York (2006)

Flores-Vivar, J.M.: Datos masivos, algoritmización y nuevos medios frente a desinformación y fake news. Bots para minimizar el impacto en las organizaciones. Comunicación y Hombre **16**, 101–114 (2020). https://doi.org/10.26441/rc17.2-2018-a12

Haddinni, J., Hernández-Cardón, M.: La tercera edad y el COVID. Acción Soc. **4**(7) (2020). https://cutt.ly/Vgh03uJ

Manfredi-Sánchez, J., Amado-Suárez, A., Waisbord, S.: Presidential Twitter in the face of COVID-19: between populism and pop politics. [Twitter presidencial ante la COVID-19: Entre el populismo y la política pop]. Comunicar **39** (66) (2021). https://doi.org/10.3916/C66-2021-07

Manzano, A.: Pescueza, el pueblo donde los mayores no son invisibles. El Periódico Extremadura, 17 de noviembre de 2019. https://cutt.ly/Cgh2l9p

Marcos, A.: Con COVID y sin COVID: La vulnerabilidad humana. Cuadernos de Bioética **31**(102), 139–149 (2020). https://doi.org/10.30444/CB.58

Montañes, E.: Pescueza, el pueblo que nunca morirá. Abc, 6 de noviembre de 2019. https://cutt.ly/egjDtt3

Mora-Rodríguez, A., Melero-López, I.: News consumption and risk perception of Covid-19 in Spain. [Seguimiento informativo y percepción del riesgo ante la Covid-19 en España]. Comunicar **39**(66) (2021). https://doi.org/10.3916/C66-2021-06

Peralta Martínez, C.: Etnografía y métodos etnográficos. Revista Análisis (74), 33–52 (2009). https://cutt.ly/AgjzKCS

RENAVE: Red Nacional de Vigilancia Epidemiológica. Informe nº 48. Situación de COVID-19 en España. Casos diagnosticados a partir 10 de mayo (2020). https://cutt.ly/kgh1Hyn

Riley, M.V.: On the significance of age in sociology. Am. Sociol. Rev. 52 (1987)

Rodríguez Rodríguez, P., et al.: Servicios de Ayuda a Domicilio. Manual de planificación y formación. Editorial Panamericana (2011)

RTVE España directo, Pescueza, un pueblo para mayores, 1 de julio de 2019. https://cutt.ly/mgj DYXJ

Rubio, A.: Pescueza resiste a la pandemia al lado de sus mayores. Diario Hoy, 22 de junio de 2020. https://cutt.ly/igh28Or

Saramago, J.: Death at Intervals. Vintage (2009)

Sociedad Española de Cardiología. Coronavirus en el paciente mayor: una emergencia geriátrica. Sección de de Cardiología Geriátrica (2020). https://cutt.ly/Wgh0FUn

Viejo, M.: El pueblo de España que se transformó en una residencia de mayores. El País, 23 de mayo de 2019. https://cutt.ly/KgjDAFI

WHO: Coronavirus (2020). https://cutt.ly/Wgr9XMe



Sociodemographic Profile of People Aged 65 or Over in Long-Term Care in Portugal: Analysis of a Big Data

Ana Ramos^{1(⊠)}, Manuel Lopes², César Fonseca¹, and Adriana Henriques¹

 Lisbon Nursing School, Lisbon, Portugal
 Comprehensive Health Research Center, Universidade de Évora, POCTEP 0499 4IE PLUS 4 E, Évora, Portugal

Abstract. Aim: To know the sociodemographic profile of people aged 65 or over who use the Continuing Care Network in Portugal, between 2010 and 2017, of the Convalescence Units, Medium Duration and Rehabilitation Unit and Long Term and Convalescence Unit.

Methods: Retrospective and cross-sectional study, based the analysis on the big data, produced by the National Network of Integrated Continuing Care in Portugal. Were analyze electronic health records of the status of older people.

Results: Most people dominant characteristics are: age group of 75 and 84 years old, female, married, with low level of education and professional level. Social isolation is greater in women, they are the ones who most live alone and spend the most time without company. In both sexes, it is people aged 85 and over who live most alone.

Conclusions: Knowing the sociodemographic characteristics of the elderly, with dependence on self-care, will allow in the next stages of the study to outline bundles of health interventions more adjusted to their needs

Keywords: Elderly · Long-term care · Sociodemographic profile

1 Introdution

The aging of the population is a global challenge, which require a better knowledge of the needs of older people, particularly in health care. In 2050 the elderly will amount to two billion (20% of the world's population), thus the number of people over 60 will exceed the population of young people under 15 years. Parallel to aging, unhealthy lifestyles have contributed to the prevalence of chronic diseases [1]. Multimorbidity rises significantly the risk of dependence when combined with conditions that affect cognitive and mental status. This association that appears frequently, being composed mainly by dementia, depression and anxiety [2]. Elderly people with multimorbidity are generally excluded from clinical studies, due to their complexity, which converged for the recommendations in how to provide care to this population are still small or insufficient[3, 4]. Old people who suffer from three or more diseases have a complex morbidity profile, which over

the years are propense to develop severe inability to perform activities of daily living and have a moderate risk of mortality [5].

Based on the demographic changes that tend to increase and alteration of the professional roles, caused by the absence of the woman in the home - traditional caregiver, and the gradual number of situations of dependence on self-care, emerged the need to create a new typology of financially and sustainable service, called long-term care. Long-term care takes different designations and organizational models in several countries, in Portugal is classified as Integrated Continuous Care [6, 7]. For the Organization for Economic Co-operation and Development [7], long-term care is a set of interprofessional services, which is required when there is a reduction in functional, physical or cognitive capacity, which consequently leads to a situation of dependence, which it requires help over a period of time in performing basic daily and instrumental life activities. In Portugal, the National Network of Integrated Continuing Care (NNICC) was created in 2006, consisting of a set of public and private institutions. There are several types of care in the NNICC, which include inpatient units (Convalescence, Medium Duration and Rehabilitation and Long Duration and Maintenance). These units aim is clinical and functional stabilization, as the promotion of rehabilitation, autonomy and control of the acute or chronic process, with the purpose of preventing and/or delaying the exacerbation of the condition of dependence [8].

Self-care is present in nursing interventions in the diagnosis, planning, intervention and evaluation of results, in order to promote the independence of the elderly and their families, in order to assume their needs for self-care. Nurses ensure essential life-sustaining care, which can be described as a complex set of interventions that ensure the person's physical comfort, such as keeping himself clean, warm, nourished, hydrated, adequately dressed, functional and safe. As well as include psychosocial aspects such as feeling calm, adapted, respected, involved and dignified [9, 10]. This type of care has been associated with improved health service security, reduction of mortality rate and hospital readmission [11]. For the World Health Organization [12] self-care can be understood as an ability for individuals, families and communities to promote and maintain health, prevent disease and deal with dependency and disability with or without the support of health professionals. Self-care deficit emerges when individual capacity is not enough to perform activities, fundamentals to health maintenance [13].

The assessment of a person's criteria for integrating long-term care is based primarily on the evaluation of the degree of dependency. So, if knowing their individual and collective characteristic is the first step to planning and modeling interventions more appropriated to their health needs in long-term care. The purpose of this study is draw sociodemographic profile of people with 65 years or over institutionalized in National Network of Integrated Continuing Care.

2 Methodology

To trace the sociodemographic profile, information related to the first assessment of each hospitalization episode between 2010 and 2017 was selected. Data for the year 2017 is until February 27, once the use of the Integrated Assessment Instrument has ended, succeeding it the implementation of the International Classification of Functionality, Disability and Health.

The analysis of the variables introduced in the Network's big data, based on the Biopsychosocial Assessment Model were obtained in responses: 36.1% of cases by the elderly person and in 63.9% by the care provider. This information is collected using the variable: Who responds to Biopsychosocial Assessment Model.

Population

This is a retrospective and cross-sectional study based on the Big Data analysis, targeting people aged 65 or older, users of the National Network of Integrated Continuing Care in Continental Portugal. The typologies of the Network included are: Convalescence Units, Medium Duration and Rehabilitation and Long-Term Units and Maintenance, with a total of 171414 persons, between 2010 and 2017.

3 Material

To assess and monitor the sociodemographic profile of people, it was used the Network the Integrated Assessment Instrument, in addition to other variables present in a computer platform called GestCare [14]. The Integrated Assessment Instrument is divided into the bio, psycho and social areas, and the domains of its components are: sex, age, health complaints, nutritional status, falls, locomotion, physical autonomy [15], instrumental autonomy [16], emotional complaints, cognitive state (based on the Mini-Mental State) [17], social state, and habits [14]. Statistical analysis was performed using statistical software IBM SPSS Statistics® (version 25.0). In this article we will present the first stage of data analysis, that included a descriptive analysis (sociodemographic profile) and inferential.

Ethical Considerations

This study was approved by on Ethics Committee of a University and for the National Data Protection Commission (Portugal). Participants' anonymity and individual data confidentiality were preserved, for ethical reasons. The clinical dates of individuals, presents in big data, were identified by a code specifically created for this study.

4 Results

Between 2010 and 2017, the National Network of Integrated Continuous Care had institutionalized 305447, particularly 67.4% in the Units under study (Convalescence, Medium Term and Rehabilitation and Long Term and Maintenance Units) and all other typologies had 32.6% (N = 99519), as reveals Table 1.

The most persons who were admitted to the Convalescence, Medium Duration and Rehabilitation and Long-Term and Maintenance Units were aged 65 or over (83.5%). With regard to people aged 65 or over, the Long-Term Care and Maintenance Unit was the one with the highest occupancy rate (34.7%; N=59516), followed by the Medium Duration and Rehabilitation Units (34, 4%; N=59013) and, finally, the Convalescence Units. At the same time, the age group from 75 to 85 years old was the largest user of inpatient units (46.6%; N=52885).

Regarding age, it fluctuated between 65 and 109 years old (range = 44). The mean age is 80.17; the most frequent ages are 80, 81, 82 and 83 years. The dispersion relative

| Typologies of network | N | % |
|--|--------|-------|
| Integrated continuous care teams - home care | 72818 | 23,8 |
| Palliative care unit | 23776 | 7,8 |
| Convalescence unit | 65691 | 21,5 |
| Medium duration and rehabilitation unit | 71750 | 23,5 |
| Long term maintenance unit | 68510 | 22,4 |
| Others | 2902 | 1,0 |
| Total | 305447 | 100,0 |

Table 1. Distribution of individuals by typologies of the Network, Portugal, 2010–2017

to the average is 7,383 years (std. Deviation). To facilitate its analysis, we recode it in age groups (1. from 65 to 74 years old; 2. from 75 to 84 years old; 3. 85 and more years old). Most people are positioned in the age group from 75 to 84 years old (46.6%) and are female (59.0%). Regarding marital status, persons are predominantly married (45.6%) and widowed (37.2%).

In terms of education, the low level of education (less than 6 years) is the most frequent (56.4%), followed by individuals who have never attended school (36.5%). About the professional level, the largest percentage is unskilled (71.4%), followed by the qualified (22.8%), intermediate (4.3%) and specialists (1.6%).

Social condition of the elderly, the majority lived with one or more individuals (78.6%) and 21.4% lived alone. In the 24 h/day, most people spent less than 8 h alone (75.4%). Most elderly people have a confidant or someone close to them (85.1%), to talk about personal matters. The social isolation, based on the previous variables, the majority are non-isolated (38.5%); 30.2% is classified as little isolated; 17.8% as very isolated and 13.5% as isolated. Which means, 64.5% of people experience isolation, in different intensity gradients. It appears that the majority of people hospitalized were in the North of Portugal (30.5%). Table 2 summarizes the general characterization of the elderly population.

From the bivariate analysis between the sex and age variables, it is possible to verify that people over the age of 75 are mostly female (58.4%), with an increasing feminization as age evolves, reaching 66,4% after 85 years of age. About marital status, there is a great predominance of widowed (78.6%) and single women (70.6%), with a greater number of married men (59.2%). The highest level of education is more frequent in males. The highest percentage of people with no education is female (70,6%) (x2 = 2977,038 p < .001; Coefficient V de Cramer = ,180, p < .001).

Men are the most qualified, the reverse of women being the least qualified, with a percentage rate of 66.3% (x2 = 4282,068 p < .001; Coefficient V de Cramer = .216, p < .001). When recoding at two levels the professional level: 1. Without qualification; 2. With qualification (qualified, intermediate and specialist) it is noticeable that it is men aged between 65 and 74 who have the greatest differentiation. In the female sex, "unskilled" predominates, which gradually increases with age.

Table 2. Sociodemographic variables of the convalescence units, medium duration and rehabilitation units and long-term units and maintenance of the network (2010–2017)

| Sociodemographic variables | N (%) |
|----------------------------|---------------|
| Age (years-old) | |
| 65–74 | 40409 (23.6) |
| 75–84 | 79899 (46.6) |
| >85 | 51106 (29.6) |
| Sex | |
| Female | 101150 (59.0) |
| Male | 70264 (41.0) |
| Marital status | |
| Single | 19945 (13.0) |
| Married | 70037 (45.6) |
| Cohabiting | 454 (0.3) |
| Divorced | 5782 (3,8) |
| Widower | 57076 (37.2) |
| Unknown | 18120 (0,2) |
| Education (years) | |
| Illiterate | 33596 (36,5) |
| 1 a 6 | 51879 (56.4) |
| 7 a 12 | 3395 (3.7) |
| >13 | 3164 (3.4) |
| Profession level | |
| Unqualified | 65634 (71.4) |
| Qualified | 20993 (22.8) |
| Iintermediate | 3930 (4.3) |
| Expert | 1430 (1.6) |
| No. of cohabitants | |
| Lives alone | 19692 (21.4) |
| Lives with 1 or more | 72395 (78.6) |
| Time alone per day (hours) | |
| <8 | 69384 (75.6) |
| ≥8 | 22685 (24.6) |
| | (continued) |

(continued)

| Sociodemographic variables | N (%) |
|----------------------------|--------------|
| Confident person | |
| Yes | 78330 (85.1) |
| No | 13739 (14.9) |
| Social isolation | |
| Very isolated | 16365 (17.8) |
| Isolated | 12443 (13.5) |
| Slightly isolated | 27814 (30.2) |
| Not isolated | 35465 (38.5) |
| Region of Portugal | |
| Alentejo | 15165 (9.3) |
| Algarve | 8937 (5.5) |
| Center | 42802 (26.4) |
| Lisbon and Vale do Tejo | 45872 (28.3) |
| North | 49565 (30.5) |

 Table 2. (continued)

They are the women who most live alone (x2 = 1114,150 p < .001; Coefficient V de Cramer = ,110, p < .001). In both sexes, it is people aged 85 and over who most live alone.

Women spend the most time without company, for a period of 8 h or more (x2 = 899,783 p < .001; Coefficient V de Cramer = ,099, p < .001). The relationship between time only in the 24 h and the different age groups are not statistically significant with each other (p = .302).

They are the men who have the more individuals who talk about persons problems (x2 = 15,033 p < .001; Coefficient V de Cramer = .014, p < .001). In both sexes, people between the ages of 75 and 84 are who have more people to share personal matters.

Men are the ones who feel less isolated, with the majority standing in non-isolated ones (59.7%) (x2 = 8939,505 p < .001; Coefficient V de Cramer = ,312, p < .001), In women there is a greater tendency for the feeling of social isolation to increase with age. However, it is in the age group of 85 or more that the feeling of social isolation is most expressive, for both sexes.

5 Discussion

Among the results of this study, the highest percentage rate of women (59%) stands out, which may be related to their greater longevity compared to men in Portugal [18]. Worldwide, women survive 4.8 years longer than men [19]. Regarding marital status, there was a predominance of widowed in women, which may also be associated with their higher average life expectancy. In Europe (EU-28) in 2013, average life expectancy

at birth was estimated at 80.6 years, more particularly 83.3 years for women and 77.8 years for men [20].

The regions with the highest number of hospitalizations, it is not correlated with the highest dependency rate for the elderly, but with the highest population density. In 2013, the date show that the Alentejo the dependency rate was 38.4% and in the North region 26% [21].

The low level of education and low professional level, present in most elderly people hospitalized in the Network, were identified in previous studies [22, 23]. as factors of greater risk for the needs of long-term care. While, they can constitute a disadvantage in access to information and health care. The evidence also highlights that, the socioe-conomic level leads to a negative appreciation of the perception of health and increases the probability of decline in functional capacity [24, 25].

Regarding the social condition of the elderly, it is women who live more alone, spend more time without company, have fewer people to share their personal concerns and, consecutively, feel more isolated. These findings are similar to the panorama of Europe, where 4 in 10 elderly women live alone (40%), when compared to men (19%) [26]. It should also be noted that, in both sexes, it is people aged 85 and over who most live alone. There are several studies that identify social isolation and/or loneliness are risk factors for the deterioration of physical and mental health, such as dementia, cardiovascular disease and, consequently, can increase the mortality rate [27–29].

6 Conclusion

Considering the network's inpatient units in Portugal, between 2010 and 2017, we concluded that older people were the largest users. From their sociodemographic profile, it is noteworthy that most of them were included in the age group from 75 to 84 years old, they are women, with married marital status, low education and professional level. Most older people live with others, spend less than 8 h a day without company and have someone to share personal matters with. However, most elderly people experience the feeling of social isolation, which fluctuates from the gradient of little to very isolated.

From the bivariate analysis it is possible to verify that it is women who have less education and qualification, as well as feeling more isolated, they spend more hours alone and without company. Another worrying fact, in both sexes, is the older people, with 85 or more years, who live more without others.

References

- United Nations Organization (UNO/ ONU): World population ageing 2013. United Nations, New York (2013)
- Bao, J., Chua, K., Prina, M., et al.: Multimorbidity and care dependence in older adults: a longitudinal analysis of findings from the 10/66 study. BMC Public Health 19, 585 (2019). https://doi.org/10.1186/s12889-019-6961-4
- Vetrano, D.L., Roso-Llorach, A., Fernández, S., et al.: Twelve-year clinical trajectories of multimorbidity in a population of older adults. Nat. Commun. 11, 3223 (2020). https://doi. org/10.1038/s41467-020-16780-x

- 4. Muth, C., et al.: Evidence supporting the best clinical management of patients with multimorbidity and polypharmacy: a systematic guideline review and expert consensus. J. Int. Med. **285**, 272–288 (2019)
- Storeng, S.H., Vinjerui, K.H., Sund, E.R., et al.: Associations between complex multimorbidity, activities of daily living and mortality among older Norwegians. A prospective cohort study: the HUNT study, Norway. BMC Geriatr. 20, 21 (2020). https://doi.org/10.1186/s12877-020-1425-3
- 6. Rodrigues, R., Huber, M., Lamura, G.: Facts and Figures on Healthy Ageing and Long-Term Care. European Centre for Social Welfare Policy and Research, Vienna (2012)
- Organization for Economic Co-operation and Development (OECD). Conceptual Framework and Methods for Analysis of Data Sources for Long-Term Care Expenditure. OCDE Health Division, Paris (2008)
- 8. Feo, R., Kitson, A.: Promoting patient-centred fundamental care in acute healthcare systems. Int. J. Nurs. Stud. **57**, 1–11 (2016)
- 9. Kitson, A., Conroy, T., Wegstrom, Y., Profetto-McGrath, J., Robertson-Malt, S.: Defining the fundamentals of care. Int. J. Nurs. Pract. 16, 423–434 (2010)
- Needleman, J.: The economic case for fundamental nursing care. Nurs. Leadersh. (1910-622X) 29(1), 26–36 (2016)
- 11. World Health Organization (WHO): Self care for health: a handbook for community health workers & volunteers. WHO, Geneve (2013)
- 12. Orem, D.: Nursing: Concepts of Pratice, 6th edn. Mosby, St Louis (2001)
- Botelho, M.: Autonomia Funcional em Idosos: Caracterização multidimensional em idosos utentes de um centro de saúde urbano. Universidade Nova de Lisboa, Faculdade de Ciências Médicas, Lisboa (1999)
- Katz, S., et al.: Studies of illness in the aged: the index of ADL; a standardized measure of biological and psychosocial function. JAMA 185(12), 914–919 (1963)
- 15. Lawton, M., Brody, E.: Assessment of older people: self-maintaining and instrumental activities of daily living. Gerontologist **9**(3), 179–186 (1969)
- Folstein, M., Folstein, S., Mchugh, P.: Mini-mental state: a practical method for grading the cognitive state of patients for the clinician. J. Psychiatr. Res. 12(3), 189–198 (1975)
- 17. United Nations: World Population Ageing 2019: Highlights. Department of Economic and Social Affairs Population Division, New York (2019)
- Instituto Nacional de Estatística. Índice de dependência total de idosos. Acedido a 30. 11. 20110 (2020). https://www.pordata.pt/DB/Municipios/Ambiente+de+Consulta/Tabela
- 19. Gratão, A., Costa, A., Diniz, A., Neri, K., Melo, B.: The health conditions of elderly individuals and caregivers in a long-term care facility. Rev. Enferm UFPE 9(3), 7562–7571 (2015)
- 20. Yun, L., Young, E., Eunhee, C.: Factors impacting the physical function of older adults in Korean long-term care hospitals. J. Korean Acad. Nur. **41**(6), 760–787 (2011)
- 21. European Commission. Report on the impact of demographic change. Publications Office of the European Union, Luxembourg (2020)
- Solé-Auró, A., Alcañiz, M.: Educational attainment, gender and health inequalities among older adults in Catalonia (Spain). Int. J. Equity Health 15, 126 (2016). https://doi.org/10.1186/ s12939-016-0414-9
- Finlay, J.M., Kobayashi, L.C.: Social isolation and loneliness in later life: a parallel convergent mixed-methods case study of older adults and their residential contexts in the Minneapolis metropolitan area, USA. Soc. Sci. Med. 208, 25–33 (2018). https://doi.org/10.1016/j.socsci med.2018.05.010. Epub 2018 May 4 PMID: 29758475
- Valtorta, N.K., Kanaan, M., Gilbody, S., Hanratty, B.: Loneliness, social isolation and risk of cardiovascular disease in the English longitudinal study of ageing. Eur. J. Prev. Cardiol. 25(13), 1387–1396 (2018). https://doi.org/10.1177/2047487318792696. Epub 2018 Aug 2 PMID: 30068233

- Holwerda, T.J., Beekman, A.T., Deeg, D.J., Stek, M.L., van Tilburg, T.G., Visser, P.J., Schmand, B., Jonker, C., Schoevers, R.A.: Increased risk of mortality associated with social isolation in older men: only when feeling lonely? Results from the Amsterdam Study of the Elderly (AMSTEL). Psychol. Med. 42(4), 843–853 (2012). https://doi.org/10.1017/S00332 91711001772. Epub 2011 Sep 6 PMID: 21896239
- Vieira, J.V., Fonseca, C.: Rehabilitation nursing in the elderly with mobility deficit due to fracture of the femur. In: Gerontechnology: Second International Workshop, IWoG 2019, Cáceres, Revised Selected Papers, vol. 1185, p. 292. Springer Nature (2020)
- Goes, M., Lopes, M.J., Oliveira, H., Fonseca, C., Marôco, J.: A nursing care intervention model for elderly people to ascertain general profiles of functionality and self care needs. Sci. Rep. 10(1), 1–11 (2020)
- Porto Gautério, D., Zortea, B., Costa Santos, S.S., da Silva Tarouco, B., Lo-pes, M.J., João Fonseca, C.: Risk factors for new accidental falls in elderly patients at traumatology ambulatory center. Investigación y educación en enfermería 33(1), 35–43 (2015)
- Moguel, E., Berrocal, J., Murillo, J.M., García-Alonso, J., Mendes, D., Fonseca, C., Lopes, M.: Enriched elderly virtual profiles by means of a multidimensional integrated assessment platform. Procedia Comput. Sci. (2018). https://doi.org/10.1016/j.procs.2018.10.009

Author Index

| A | Cipriano Crespo, Carmen, 371 | |
|--------------------------------------|---|--|
| Advinha, Ana Margarida, 184 | Conde Caballero, David, 43 | |
| Aguiar, José, 357 | Conde-Caballero, David, 99 | |
| Apóstolo, João, 414 | Cordovilla-Guardia, Sergio, 168, 235 | |
| Arco, Helena, 253 | Cortes, Rui, 357 | |
| Arroyo Chacón, S., 315 | Costa, Pedro, 217 | |
| Arroyo Chacón, Sara, 371 | Curaj, Aurelia, 133, 177 | |
| Atochero, Alfonso Vázquez, 428 | | |
| - | D | |
| | Dankbar, Ruth, 139 | |
| B | de Fátima Moreira, Maria, 391 | |
| Baixinho, Cristina Lavareda, 336 | de Pinho, Lara Guedes, 69, 87, 149, 161, 202, | |
| Barbas, Liliana, 69, 161 | 291, 303 | |
| Basílio, Carla, 217 | Diaz, Daniel, 81 | |
| Bernardes, Rafael A., 245 | do Céu Marques, Maria, 357, 391 | |
| Berrocal, Javier, 3, 111 | Drago, Susana, 277 | |
| Berrocal-Olmeda, Javier, 57 | Duarte, Andreia, 303 | |
| Blas Pagador, J., 133, 177 | Dulce, Edgar, 23 | |
| Bobrowicz-Campos, Elzbieta, 414 | | |
| Bonilla Bermejo, J., 315 | ${f E}$ | |
| Bonilla-Bermejo, Jara, 43, 99 | Esteves, Nelson, 217 | |
| Branco, Juliano, 303 | | |
| Brandão, Ana, 161 | F | |
| | Faustino, Sara, 184 | |
| _ | Fernandes, Manuel Agostinho, 217 | |
| C | Ferreira, Óscar Ramos, 336 | |
| Cadena, Steban, 81 | Ferreira, Paulo Alexandre, 245 | |
| Cardoso, Inês, 69, 87, 149, 291, 303 | Ferreira, Rogério, 217, 262, 277 | |
| Caro Anzola, Edward Wilder, 121 | Ferrinho, Rogério, 69, 87 | |
| Castanheira, Rosa, 202 | Flores-Martin, Daniel, 3, 111 | |
| Chaves, Deisy, 81 | Fonseca, César, 11, 69, 87, 149, 161, 202, 217, | |
| Chimento-Díaz, Sara, 168, 235 | 277, 291, 303, 324, 402, 438 | |
| Cipriano Crespo, C., 315 | Franco-Antonio, Cristina, 168, 235 | |
| | | |
| | | |

© The Editor(s) (if applicable) and The Author(s), under exclusive license to Springer Nature Switzerland AG 2021

J. García-Alonso and C. Fonseca (Eds.): IWoG 2020, LNBE, pp. 447–449, 2021. https://doi.org/10.1007/978-3-030-72567-9

448 Author Index

| G Galán-Jiménez, Jaime, 57 | Morgado, Bruno, 324 Mourão, Sara, 277 |
|---|--|
| García-Alonso, José, 11, 57, 69, 149, 161, 291, | Mróz, Anna, 380 |
| 303 | Muñoz González, Beatriz, 315, 371 |
| García-Cuevas, José Luis Moyano, 133, 177 | Murillo, Juan M., 3, 111 |
| García-Pérez, Daniel, 35 | 77477710, 74447777, 75, 777 |
| Gil, Isabel, 414 | N |
| Gil, Juan, 81 | Nevelsteen, Dorine, 245 |
| Goes, Maria M., 262 | Nicolau, Célia, 217 |
| Gogova, Tina, 245 | Nobre, Sara, 277 |
| Gomes, Idalina, 345 | - · · · · · · · · · · · · · · · · · · · |
| Gomes, Sandra, 402 | 0 |
| Gómez, Francisco Manuel Esteban, 133, 177 | Oliveira, Henrique, 262 |
| | Oliveira-Martins, Sofia, 184 |
| Gonçalves, Helena, 202 | , , |
| González, Jesús Seco, 428 | P |
| Graveto, João, 245 | Parreira, Pedro, 245 |
| TT | Pedro, Adriano, 253 |
| H | Pereira, Iromisa, 262 |
| Henriques, Adriana, 438 | Pinho, Lara, 253, 324 |
| Hernández Encuentra, Eulàlia, 139 | Plexa, Andreia, 202 |
| Hernandez, Juan, 11 | Potyrała, Katarzyna, 380 |
| Hurtado, Julio, 23 | Proença, Adelaide, 253 |
| J | D. |
| Jesús-Azabal, J., 43 | R |
| Jesús-Azabal, Manuel, 57 | Ramalho, Jorge, 391 |
| , | Ramos, Ana, 438 |
| K | Rebola, Ermelinda, 357 |
| Kapun, Marija Milavec, 245 | Reis, Inês, 391 |
| Kokko, Raija, 245 | Rivero Jiménez, Borja, 43, 99 |
| Koumanakos, Georgios, 139 | Rivero, Santiago Cambero, 428 |
| Roumanaxos, Georgios, 139 | Rojo, Javier, 11 |
| L | S |
| Laso, Sergio, 3 | Salgueiro-Oliveira, Anabela, 245 |
| Lopes, Elisabete, 161 | Sánchez Margallo, Francisco M., 133, 177 |
| Lopes, Manuel, 11, 87, 149, 161, 291, 324, 402, | Sánchez-García, Pablo, 168, 235 |
| 438 | Santano-Mogena, Esperanza, 168, 235 |
| Lopes, Mauro, 217 | Santos-Costa, Paulo, 245, 414 |
| López-Lago Ortiz, Luis, 315, 371 | Serambeque, Beatriz, 245 |
| Lozano-Pinilla, José Ramón, 35 | Serra, Nuno, 133, 177 |
| Luengo Polo, Jerónimo, 371 | Silva, Anabela, 87, 149, 291 |
| Luengo-Polo, Jerónimo, 43, 99 | Silva, Helena, 391 |
| | |
| M | Silva, Liliana, 357 |
| Mäkitalo, Niko, 111 | Silva, Susana, 87, 149, 291 |
| Marçal, Sofia, 202 | Sousa, Liliana B., 245, 414 |
| Mariano Juárez, Lorenzo, 43, 99 | Sousa, Luís, 87, 336, 357 |
| Martins, Patrícia, 69 | Т |
| Mendoza Moreno, Miguel Ángel, 121 | _ |
| Mestre, Teresa, 262 | Tomczyk, Łukasz, 380 |
| Mikkonen, Tommi, 111 | Trujillo, Maria, 81 |
| | V |
| Moguel, Enrique, 11 | |
| Mónico, Lisete, 245 | Valentim, Olga, 202 |
| Morais, Filomena, 391 | Vandenhoudt, Hilde, 245 |
| Morán, Juan Francisco Ortega, 133, 177 | Vesa, Pirio, 245 |

Author Index 449

| Vicente-Chicote, Cristina, 35 Vieira, João, 262 | W Wnęk-Gozdek, Joanna, 380 |
|--|-------------------------------|
| Vila-Cha, Carolina, 133, 177 | Z |
| Vilar, Maria Manuela, 414 | Zamillo, Debora, 133, 177 |