

LET ME PARTICIPATE

Using shared decision-making
to involve persons with dementia
in care planning in long-term care



Elena Mariani

LET ME PARTICIPATE

Using shared decision-making to involve
persons with dementia in care planning in
long-term care

Elena Mariani

The research presented in this thesis was conducted at the Scientific Institute for Quality of Healthcare (IQ healthcare) in Nijmegen and at the Department of Psychology in Bologna. The first department is part of the Radboud Institute for Health Sciences (RIHS), one of the research institutes of the Radboud university medical center, Nijmegen, the Netherlands. The second department is part of the Alma Mater Studiorum, University of Bologna, Italy.

This study has received funding from the EU 7th Framework Programme FP7/2011-2015 under Grant Agreement n°258883.

Financial support by the Scientific Institute for Quality of Healthcare (IQ healthcare) for the publications of this thesis is gratefully acknowledged.

ISBN: 978-90-827383-8-4

Cover illustration: Keith Haring, Untitled No. 3, 1988
© Keith Haring Foundation
<http://www.haring.com/>

Lay-out: Stefano Naldi & Mijn Proefschrift | www.mijn-proefschrift.nl

Printed by: ProefschriftMaken | www.proefschriftmaken.nl

© 2019 Mariani Elena

All rights reserved. No part of this thesis may be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopy, recording or otherwise, without prior written permission of copyright owners or the author.

LET ME PARTICIPATE

Using shared decision-making to involve
persons with dementia in care planning in
long-term care

Proefschrift

ter verkrijging van de graad van doctor
aan de Radboud Universiteit Nijmegen
op gezag van de rector magnificus prof. dr. J.H.J.M. van Krieken,
volgens besluit van het college van decanen
in het openbaar te verdedigen
op dinsdag 12 november 2019
om 11:00 uur precies

door

Elena Mariani

geboren op 23 februari 1984
te Faenza, Italië

Promotoren:

Prof. dr. M.J.F.J. Vernooij-Dassen

Prof. dr. R.T.C.M. Koopmans

Copromotoren:

Prof. dr. Y.M.P. Engels

Dr. R. Chattat (Universiteit van Bologna, Italië)

Manuscriptcommissie:

Prof. dr. J.B.A.M. Schilderman

Dr. M.H.J. van de Pol

Prof. dr. L. Van den Block (Vrije Universiteit Brussel, België)

LET ME PARTICIPATE

Using shared decision-making to involve
persons with dementia in care planning in
long-term care

Doctoral Thesis

to obtain the degree of doctor
from Radboud University Nijmegen
on the authority of the Rector Magnificus prof. dr. J.H.J.M. van Krieken,
according to the decision of the Council of Deans
to be defended in public
on Tuesday, November 12, 2019
at 11:00 hours

by

Elena Mariani

born on February 23, 1984
in Faenza, Italy

Supervisors:

Prof. dr. M.J.F.J. Vernooij-Dassen

Prof. dr. R.T.C.M. Koopmans

Co-supervisors:

Prof. dr. Y.M.P. Engels

Dr. R. Chattat (University of Bologna, Italy)

Doctoral Thesis Committee:

Prof. dr. J.B.A.M. Schilderman

Dr. M.H.J. van de Pol

Prof. dr. L. Van den Block (Vrije Universiteit Brussel, Belgium)

Table of contents

Chapter	Title	Page
Chapter 1	GENERAL INTRODUCTION	9
Chapter 2	IDENTIFICATION OF THE PALLIATIVE PHASE IN PEOPLE WITH DEMENTIA: A VARIETY OF OPINIONS BETWEEN HEALTHCARE PROFESSIONALS <i>BMC Palliative Care (2015) 14, 56-62</i>	27
Chapter 3	SHARED DECISION-MAKING ON A 'LIFE-AND-CARE PLAN' IN LONG-TERM CARE FACILITIES: RESEARCH PROTOCOL <i>Nursing Open (2016) 3, 179-187</i>	41
Chapter 4	CARE PLAN IMPROVEMENT IN NURSING HOMES: AN INTEGRATIVE REVIEW <i>Journal of Alzheimer's Disease (2017) 55, 1621-1638</i>	57
Chapter 5	SHARED DECISION-MAKING IN DEMENTIA CARE PLANNING: BARRIERS AND FACILITATORS IN TWO EUROPEAN COUNTRIES <i>Aging and Mental Health (2017) 21, 31-39</i> <i>Special issue on Social Health</i>	83
Chapter 6	THE IMPACT OF A SHARED DECISION-MAKING TRAINING PROGRAM ON DEMENTIA CARE PLANNING IN LONG-TERM CARE <i>Journal of Alzheimer's Disease (2018) 64, 1123-1135</i>	105
Chapter 7	GENERAL DISCUSSION	131
Chapter 8	Summary	149
	Sommario	153
	Samenvatting	159
	Data Management	165
	Acknowledgements	167
	Publication list	169
	PhD Portfolio	171
	Curriculum Vitae	173

GENERAL INTRODUCTION

1

I am a neuropsychologist and, as a professional, I have been involved in all the steps of the dementia care pathway, from the diagnosis to the end-of life phase. In fact, I worked in a nursing home, leading cognitive stimulation therapy with persons with dementia (PwDs) and providing staff training and consultation. Now I am working in a hospital-based memory clinic performing neuropsychological testing for the assessment and diagnosis of dementia and cognitive impairment in older adults, providing cognitive intervention programmes to the elderly affected by Mild Cognitive Impairment as well as psychological support to family caregivers. My clinical practice helped me to realize that, if we really want to set up an effective, appropriate and personalized dementia care pathway, the PwDs and their social context, that is all the persons who are around them, should be involved. Therefore, combining practice and research, I became interested in understanding how PwDs, their families and staff could be actively involved in the care planning process by developing and implementing a shared decision-making (SDM) framework in long-term care (LTC) settings.

Problem summary

Dementia affects the cognitive functioning of people who have it. This disease progressively impacts their memory, attention, verbal skills, executive functions and their ability to perform basic activities of daily living [1, 2]. However, literature shows that although the degeneration affects their cognitive functions, thanks to neuroplasticity, compensatory mechanisms and cognitive reserve, the brain adapts as long as possible to the changes caused by the disease [3]. Both a cognitive and a social stimulation impact PwDs cognitive abilities, well-being and sense of identity [3]. As the disease progresses, the demand of continuous support increases and families are challenged in providing adequate care and a stimulating context that meet the PwD's multiple and complex needs. Long Term Care (LTC) settings offer an opportunity to the PwDs and to their families to be supported and to receive specialized professional care. In particular, within LTC settings, a multidisciplinary approach together with specific psychosocial interventions are usually put in place to improve the residents' quality of care and quality of life [4]. However, once admitted, both the PwD and the family first need to adapt to the new environment [5, 6].

A principle that should be kept in mind is that each resident with dementia living in LTC facilities is not his disease, is not 'a dementia patient' but, first of all, is a person and as any other human being, has desires, wishes, preferences and feels positive or negative emotions. Thus, he needs to find a way to communicate about his psychological state and to make himself known within the new organization. At the same time, the family caregivers, who are usually the persons who have provided most care up to then and who have a good knowledge of the PwD's preferences, have to find a way to remain involved in the care of their loved ones and/or to reframe a new personal role. In fact, the LTC facilities' staff becomes the main care provider, and, similarly, needs to make efforts and develop methods to

involve, stimulate and communicate with the resident and his family. SDM in LTC settings is a method that enables professionals to focus on a resident's personal interests and values, collaborating with him and his family caregiver and allowing their involvement in the care process [7-9]. It has been shown that the participation of the resident and his family caregiver in the decision-making process brings benefits to that dyad as well as to professionals [10-12]. However, SDM is not common practice in nursing homes. Furthermore, despite the existence of international care planning policy and guidelines that recommend the involvement of residents and family representatives in the development of care plans [13, 14], they are not always fulfilled. Moreover, the guidelines do not always specify how to implement these requirements within the nursing homes, and how to adapt them to their inner organization. As a consequence, care plans often fail to be person-centered [15]. This is also the case in Italy and in the Netherlands, where the studies in this thesis took place: requirements of a personalized care planning existed and 'life-and-care plans' were introduced, but not in a systematic way. Thus, our intervention was developed to provide support to two Italian and Dutch nursing homes during the implementation of a more personalized care planning process and to evaluate it.

Dementia: cognitive abilities, social interaction and identity

Dementia is one of the major causes of disability and dependency among older people worldwide. Its impact on the persons who have it, on the families and on society can be psychological, physical, economic, spiritual and social [16]. Currently, over 47 million people live with dementia worldwide and this number is expected to increase up to 131 million in 2050 [17]. Wrongfully, dementia is often not considered a life-limiting condition [18], as PwDs frequently show other health comorbidities that contribute to their death [17] and most of them die before reaching the advanced stages of the disease [17, 19].

Dementia affects the brain and its cognitive functioning. As the disease advances, symptoms become more evident in multiple cognitive domains, such as disorientation, confusion, verbal deficits, planning problems and behavioral changes [2]. All these deficits impact the person's abilities to perform activities of daily living, both at a social and at a professional level [20].

However, despite cognitive decline, brain plasticity still enables PwDs of new learning [21] and evidence demonstrated that enriched environments and training may improve memory and cognitive functioning in persons with mild and moderate dementia [22, 23]. Particularly, the involvement of PwDs in meaningful activities that require the combination of cognitive stimulation, social interaction and leisure, may decrease the progression of the disease and increase the people's well-being and sense of identity [3, 21]. The more a PwD does not or does not want to be involved in meaningful activities due to his cognitive impairment, the more this hampers him to maintain his identity and tends him to withdraw. As a consequence, cognitive and social stimulation will be reduced, negatively affecting

his cognitive abilities, skills and social interactions in turn [3].

The involvement of persons with dementia: policy and regulations

Although many steps have been taken toward acceptance and inclusion of PwDs and national policies or dementia strategies have been developed by some governments, there still is a lack of awareness and understanding of dementia, resulting in stigmatization and exclusion from everyday life and decisions [16]. Particularly, inclusion in everyday life is one of the major ethical issues that are related to dementia: a PwD has the right to access health and social services and to live a meaningful life within society [16]. However, frequently, stigma and related feelings of shame or embarrassment lead to isolation and to exclusion from taking part in activities and communal life.

According to some of the ten quality statements that NICE (National Institute for Health and Care Excellence) developed for supporting people to live well with dementia, PwDs should be: involved with the support of their family caregivers in decisions regarding their care; enabled to take part in activities that meet their preferences; and enabled to maintain and develop relationships [24]. These statements refer to all PwDs, irrespective of their living conditions. In fact, the problem of social inclusion and involvement occurs both at the community level and at the LTC level, where many PwDs are admitted when families are no longer able to deal with the physical, emotional or financial consequences of the disease. For this purpose, NICE developed six quality statements for people living in care homes. Some of them specify that residents should: be offered to be involved in meaningful activities promoting their health and mental well-being; be enabled to maintain and develop their personal identity; and have care plans that accurately reflect their mental, sensory and physical needs [25].

It has been demonstrated that the presence and severity of cognitive impairment cannot be considered the determining factor that accounts for the exclusion from decision-making [26]. In fact, PwDs maintain for a longer period the ability to answer preference questions [27] and are able to reliably express their care values and preferences also at a moderate stage of the disease [28-30]. However, persons with cognitive impairment are often not involved in decision making regarding their care [31-33], demonstrating that high quality care as described in the international guidelines is often not provided.

The transition into LTC settings

It is estimated that between 34% and 54% of PwDs from high income countries live in care homes whereas only 6% from low and middle-income countries [34, 35]. Mainly, the reasons for moving into LTC settings are: cognitive impairment; need of assistance 24/7 hours; safety and/or hygiene issues; challenging behaviors; inability of family caregivers to cope with the increased level of dependency and demand of care [36]. Particularly, when family caregivers experience psychological distress or need to cope with their own health issues and when both the family caregiver

and care recipient are older, it is more likely that the transition into nursing homes occurs [37]. Nursing home care enhances the delivery of kin care, providing mental and physical comfort to both the resident and the caregiver [38]. However, the transition into nursing homes can be difficult for PwDs as their lifestyle, habits and social environment change [37] and they are surrounded by new people who they see for the first time. As a consequence, there might be a risk of depersonalization, particularly when residents have cognitive decline that affects their communication abilities, impeding the expression of their habits, emotions and wishes. Similarly, family caregivers need to adapt to the new situation and have different expectations and attitudes that guide the choice of the nursing home, affect the trust in the LTC facility and impact their level of satisfaction [39]. Literature shows that after admission, mental health of family caregivers usually improves, with a decrease of their burden or strain [40]. It also emerged that they feel less frequently anger and tension [41-43] and sometimes experience mixed feelings, such as satisfaction together with sadness, guilt or loneliness [41, 44]. Furthermore, it appears that those family members who were caregivers prior to institutionalization want to remain involved in the care process, to continue their caregiver roles and do have more realistic expectations towards care provision, which results in higher levels of satisfaction [39, 40].

Residents' quality of life and need for involvement in LTC settings

Quality of Life (QoL) of PwDs living in LTC facilities is higher when many of their needs are met [45]. In fact, unmet needs lead to a higher level of anxiety, depression and challenging behavior [46]. Furthermore, the residents' QoL is related to social involvement: being engaged in occupational, social and meaningful activities enhances the residents' well-being in LTC settings [47], particularly when these activities are tailored to their skills and interests [48]. All these data show that psychosocial care is fundamental for the well-being of persons with dementia. However, symptoms such as depression are often underestimated in nursing homes [49] and psychosocial and spiritual needs are less reported in the resident's care plans in contrast to medical and nursing needs [15]. Furthermore, occupation and involvement remain unmet needs in many LTC settings [47] and lack of activities for residents is one of the major causes of dissatisfaction among family caregivers [39]. Since PwDs are rarely involved in care planning, there is often inadequate knowledge of their views, values and preferences and a consequent lack of personalization of both care provision and nursing documentation [50, 51],[15]. In particular, preferences and decisions about psychosocial, emotional and spiritual aspects are rarely discussed, neither with the residents nor with their family members [52]. The lack of involvement in needs discussions can lead to discrepancies in identifying and evaluating the residents' needs: in fact, professional caregivers tend to perceive more frequently the residents' needs as met as compared to the persons with dementia themselves [50].

The social context in LTC settings: impact on residents' personhood and quality of life

Personhood is maintained and defined within a social context, and for the persons with advanced dementia the caregiving relationship 'is their most relevant social context' [53]. Thus, despite challenging, informal and formal caregivers should support the PwD in maintaining his personhood and sense of self in spite of the changes and losses caused by the disease [53]. Indeed, the resident's well-being in LTC settings is a multidimensional concept that mainly depends on the involvement and engagement of the persons who are around him. In fact, the QoL of PwDs seems to be related to some characteristics of professional caregivers. Specifically, a positive outcome such as job satisfaction may affect the quality of care provided [54] that in turn affects the QoL of residents. Equally, the involvement of family caregivers in the care of the PwDs admitted to the nursing home can enhance their QoL and quality of care [55]. Particularly, family visits to nursing home residents' may positively affect the psychosocial well-being of residents [56] and the informal care provided to residents after admission impacts the quality of care provided in the LTC environment [57]. Furthermore, the more family caregivers are involved in the resident's needs discussion, the higher is the level of satisfaction as perceived by both the resident and the family caregivers [58]. Despite this, little evidence exists on family caregivers being engaged with staff in the care of relatives living in LTC settings [59]. As described by LeNavenec in her book chapter [60], only by understanding the unique social context of a PwD and his family it is possible to understand his perceptions, definitions of the situation and constructions of the reality that define the meaning of life. Thus, it is fundamental to contextualize care of nursing home residents. Many tools have been proposed to address this issue, for example, the use of life histories, interviews or journal/diary keeping. Irrespective of the method chosen, the feature they have in common is that they imply an interactive process in which the staff, the family caregivers and/or the residents are engaged, demonstrating that only by involving them in the care process, the provision of care really becomes individualized and meaningful.

Nursing homes' organization and the care planning process in Italy and the Netherlands

Overall, according to the report on LTC quality assurance policies in European countries [61], both Italy and the Netherlands have quality policies, indicators and guidelines on formal LTC. However, Italy shows a lack of policies on responsiveness to patient needs, whereas in the Netherlands outcome-related policies and indicators are in place [61].

With regard to the organization of nursing homes for older people, the two countries are similar. In fact, they are staffed by multidisciplinary care teams that provide medical and nursing care and high levels of personal care. Moreover, within nursing homes, often dementia special care units for the provision of specialist care for those with advanced dementia exist [37]. Yet, the Netherlands is the only

country that has a three-year specialist training program for elderly care physicians [62, 63].

Care planning represents a fundamental activity in the provision of care. It supports services directed to nursing home residents and international guidelines and regulations regarding interdisciplinary care planning are in place [13, 14, 64]. Care planning is the process in which the resident's needs, abilities and preferences are identified, assessed and care goals are set, whereas the care plan is the document that describes the actions and measures taken to assess them and to evaluate whether they have been reached or not [65]. Both the care planning process and care plans are similar in the two countries. In fact, the needs' assessment process starts within two weeks after residents' admission. The main outcome of the care planning process is the 'life-and-care plan', that should be compulsory signed by the professional who is responsible for it, together with the family caregiver and the resident if possible and that has to be updated at least once a year, but earlier when significant changes in the residents' condition occur. The document consists of four main sections: Problems (that primarily cover mental and physical well-being; activities of daily living; cognitive and social functioning); Goals; Actions; Evaluation.

Decision-making in LTC settings

Due to their cognitive deficits, it becomes increasingly difficult for PwDs to make decisions [66] as their decisional capacities decrease over time [67]. Decisions are often made on their behalf, but such decision-making process is frequently problematic and distressing for their caregivers [68]. However, cognitive impairment is not uniform [69] and several studies demonstrated that it is possible to enhance the involvement of a PwD in decision-making, even in advanced stages of dementia [12, 70-72]. In fact, the ability of a PwD to make choices remains quite stable over time [27, 73] and many PwDs want to participate in decisions regarding their treatment and care [12, 74]. Despite this evidence, involvement of PwDs in decision-making is often ignored [75].

With regards to decision-making in LTC settings, literature mainly focuses on interventions and approaches developed to facilitate the involvement of family caregivers in the decision-making process and/or to improve the communication between staff and families. From this body of research, it emerges that family caregivers often would like to have more frequent meetings with the care team and more opportunities to share with them the resident's information and preferences [76-78]. Furthermore, it appears that the type of family-nurse relationship [79], the attitudes and level of trust of family members [76, 77, 80] together with their values and beliefs [81], impact the family involvement in decision-making and the decisions taken. Particularly, family caregivers report incomplete or inadequate information to take decisions regarding end-of-life care [82, 83] and difficulties in conceptualizing the PwD's dying trajectory or the health conditions in which end-of-life decisions should be taken [81]. Similarly, if staff do not consider the

expertise of the family members, they tend to exclude them from the decision-making process. In contrast, when staff members adopt a person-centered approach, they facilitate the family's involvement [79]. Furthermore, it appears that if staff members feel supported by the organization in which they work, they more frequently build positive relationships with families [79].

Few studies focused on how PwDs living in LTC settings participate in the decision-making process and how nursing home professionals, with their attitudes, behaviors, communication style and specific strategies, may support the PwD involvement [12, 72, 84, 85].

Shared decision-making in LTC settings

Originally, the concept of SDM was used to indicate the process that develops during medical encounters between the healthcare professional and the patient making decisions together [86-88]. The use of SDM in the dementia context is quite new. Its use results in increased autonomy and improved well-being of both the PwD and family caregivers [10-12]. However, it seems that the research studies on SDM in dementia do not explicitly provide a specific and clear definition of SDM, specifying only the amount or type of involvement of the PwD in the process [26]. Furthermore, the majority of studies are conducted at the community level, exploring the practice of SDM within the family care dyad. In particular, everyday care, medical treatment and long-term care placements are the main types of decisions investigated within the dyad [26]. Another important type of decisions explored concerns end of life care. In fact, SDM is considered the best way to engage PwDs and their family caregivers in end of life decision-making [89, 90] and the European Association for Palliative Care (EACP) recommends its use to provide optimal palliative care in dementia [91].

A growing number of studies explores the use of SDM in LTC settings. They mainly regard end-of-life care and advance care planning [92-98] and to a lesser extent the PwDs' health, daily care or preferences for the near future [12, 72, 85]. It emerges that if staff and family caregivers use specific strategies to support nursing home residents, e.g. reducing the range of available choices, using SDM tools such as aids or props and communicating in a simple way, it is possible to make shared decisions [72, 99]. Furthermore, it appears fundamental to observe, investigate and document what it really matters to a PwD living in LTC settings, as it will improve both everyday and end of life care [94].

Researches demonstrated that cognitive stimulation seem to be effective in improving and maintaining PwDs' cognitive functions [100] and such interventions have a stronger value in the light of emerging evidence supporting existence of the brain' compensatory and plasticity mechanisms which delay the progressions of dementia [101]. At the same time, social engagement is important as cognitive stimulation in dementia, considering that dementia is a 'socially ostracizing condition' [102]. Thus, based on their remaining capacities and abilities, SDM might represent the way to involve PwDs, acknowledging their identity and self-worth.

Rationale

Neuroplastic processes are present in the ageing brain and it seems that enriched environments may increase cognitive functioning or decrease its deterioration [23]. In fact, many PwDs are still capable of new learning when errorless learning interventions are implemented to teach daily tasks and skills [103] and when cognitive support is provided in a stimulating context [21]. This is particularly true in the context of LTC. In fact, when the LTC facility does not stimulate the residents and meet their needs, it may contribute to an additional impairment of their functional skills and abilities [104]. Indeed, studies demonstrated that activities' involvement in LTC facilities contribute to improving residents with dementia' quality of life and wellbeing [105]. However, nursing homes often fail in involving residents in leisure activities and occupation [46, 50]. When it comes to involving PwD in their own care decisions, the situation gets even worse: their engagement is not considered important nor it is not adequately supported. Too often the voice of people with dementia is not heard or not addressed, assuming that they are not given the opportunity to make any decisions regarding their own care [72, 106].

In the projects described in this thesis, we aimed to develop an approach that could allow, at least to a minimum extent, the involvement of people with moderate to advanced dementia living in LTC facilities in care-related decisions, supporting professionals in enabling and valuing their participation. Thus, this thesis describes the development and implementation of an SDM framework in care planning for long-term care residents with dementia.

The idea to develop an SDM framework in Italy and the Netherlands originates from two main reasons. The first one is that both countries were involved in the IMPACT project (IMplementation of quality indicators in PAlliative Care sTudy), an FP7 EU-funded research project that aimed to develop optimal strategies to improve the organization of palliative cancer and dementia care in Europe. From a study carried out during the project that explored the opinions of professionals working in nursing homes based in six European countries concerning when they considered residents with dementia in need of palliative care, discrepancies in opinions even between staff members working in the same LTC setting emerged. This indicated that it was very challenging for professionals to identify the time point when palliative care and proactive care planning should start. However, international guidelines consider the use of SDM as the unique way to provide optimal palliative care, stating that only by involving the PwDs and their family caregivers before the terminal stages, professionals can become aware of their preferences and provide care in line with their values [91]. Usually LTC settings provide care to residents for a longer period, from admission to death. In fact, nursing homes mainly offer professional everyday care in addition to end of life care and knowing the residents' preferences and values is the only way to really provide personalized care.

The second reason is that in both countries, requirements of a personalized care planning in LTC existed, such as the involvement of the family caregivers and/or of the residents in the planning process and the development of person-centered

care plans. However, they were not always implemented in a standardized way. That is, they were not embedded into the nursing home's daily practice schedule. Following the international guidelines, we considered SDM the optimal method to improve these care aspects. Consequently, we decided to develop the SDM framework and implement it in Dutch and Italian nursing homes to support them during the implementation of a more personalized care planning process, fulfilling in this way the recommended care requirements. In our research, SDM is considered an opportunity for PwDs and their family caregivers to be involved in the care planning process, being allowed to express their opinion and wishes, and for professionals to record the residents' care preferences in their care plans. In fact, the SDM process we implemented consisted in involving a triad composed of the resident with dementia, the family caregiver and a professional caregiver who usually takes care of the resident.

Objectives

In the present thesis, involvement is considered a fundamental principle that should be acted along the whole long-term care journey, from admission to the end-of-life phase. Thus, the objective of the thesis is to develop and implement an SDM framework that

1) can be used to assess, meet and document in the care plan the residents' needs taking into account their perspective in order to make the care planning process more personalized; 2) standardizes the involvement of residents and their relatives in care planning; 3) is embedded into the clinical practice of the nursing homes' staff.

Therefore, the main research questions of this thesis are:

1. When do professionals working in LTC settings consider a person with dementia in need of palliative care?
2. What are the core elements of the implementation of changes in nursing homes' care plans?
3. What are the main barriers and facilitators regarding the implementation of an SDM framework in nursing homes?
4. Is it feasible for professionals to implement the SDM framework during their daily practice and what are the main factors that allow nursing homes' residents with dementia and their families to be involved in the care planning process?
5. How do the care plan's contents change by involving the residents with dementia and their family caregivers?

Outline of this thesis

This thesis, aiming to improve care planning in LTC settings, starts by investigating among professionals working in these settings when persons with dementia are considered to be in need for palliative care (Chapter 2). These opinions provided important background information to be considered in the development of a

framework to timely and better engage residents and their families in decisions on daily care provision. Therefore, a SDM framework was developed to be used in nursing home following international guidelines, which advocate the involvement of residents and families in care decisions. The study protocol provides details on this framework, the subjects and LTC settings involved in Italy and the Netherlands, on the implementation process and on the instruments used (Chapter 3).

Since the main aim of our study is to make care planning more personalized, we have conducted an integrative review to find core elements of the implementation of changes in nursing homes' care plans (Chapter 4). Chapter 5 describes a qualitative study that provided an overview of barriers and facilitators perceived by professionals when implementing the SDM framework during their daily practice and the main factors that allowed the involvement of the residents with dementia and their families in the care planning process. Focus group interviews were analyzed using content analysis and the professionals' feedback were explored to address research question 3 and 4.

Chapter 6 reports on the impact of the involvement of the residents and of their family caregivers on the care plans, answering research question 5. It elaborates on the results of a mixed-method study that explored the impact of the SDM framework on the residents' care plans and on the family caregivers' sense of competence and quality of life and on the professionals' job satisfaction.

Chapter 7 contains the general discussion that reports and discusses the main findings of this thesis and the implications of the study.

References

- [1] Giebel CM, Sutcliffe C, Stolt M, Karlsson S, Renom-Guiteras A, Soto M, Verbeek H, Zabalegui A, Challis D (2014) Deterioration of basic activities of daily living and their impact on quality of life across different cognitive stages of dementia: a European study. *Int Psychogeriatr* **26**, 1283-1293.
- [2] Winblad B, Commission TLN (2016) Defeating Alzheimer's disease and other dementias: a priority for European science and society. *Lancet Neurol* **15**, 77.
- [3] Ashworth, R., Punch, S., Small C (2016) A Review of Possible Interventions into Healthy Ageing and Cognitive Stimulation: Exploring the Links between Bridge and Dementia In *English Bridge Education & Development (EBED)*, Aylesbury, ed.
- [4] Vernooij-Dassen M, Vasse E, Zuidema S, Cohen-Mansfield J, Moyle W (2010) Psychosocial interventions for dementia patients in long-term care. *Int Psychogeriatr* **22**, 1121-1128.
- [5] Gaugler JE, Pot AM, Zarit SH (2007) Long-term adaptation to institutionalization in dementia caregivers. *Gerontologist* **47**, 730-740.
- [6] Chao SY, Lan YH, Tso HC, Chung CM, Neim YM, Clark MJ (2008) Predictors of psychosocial adaptation among elderly residents in long-term care settings. *J Nurs Res* **16**, 149-159.
- [7] Joosten EA, DeFuentes-Merillas L, de Weert GH, Sensky T, van der Staak CP, de Jong CA (2008) Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status. *Psychother Psychosom* **77**, 219-226.
- [8] Fried TR, Tinetti M, Agostini J, Iannone L, Towle V (2011) Health outcome prioritization to elicit preferences of older persons with multiple health conditions. *Patient Educ Couns* **83**, 278-282.
- [9] Boyle G (2008) The Mental Capacity Act 2005: promoting the citizenship of people with dementia? *Health Soc Care Community* **16**, 529-537.
- [10] Dupuis, SL, Gilies, J, Carson, J, White, C (2011) Moving beyond patient and client approaches: mobilizing 'authentic partnership' in dementia care, support and services. *Dementia* **11**, 15.
- [11] Menne HL, Tucke SS, Whitlatch CJ, Feinberg LF (2008) Decision-making involvement scale for individuals with dementia and family caregivers. *Am J Alzheimers Dis Other Dement* **23**, 23-29.
- [12] Fetherstonhaugh D, Tarzia L, Nay R (2013) Being central to decision making means I am still here!: the essence of decision making for people with dementia. *J Aging Stud* **27**, 143-150.
- [13] American Healthcare Association (2005), Appendix PP: Guidance to surveyors for long-term care facilities part II. Washington, DC.
- [14] European Commission (2008), Long Term Care in the European Union ed. DG for Employment SAaEO, Brussels.
- [15] Broderick MC, Coffey A (2013) Person-centred care in nursing documentation. *Int J Older People Nurs* **8**, 309-318.
- [16] International AsD (2012), ed. 2012 WHO, UK.
- [17] Prince M, Comas-Herrera A, Knapp M, Guerchet M, Karagiannidou M (2016), ed. (ADI) AsDI, London, UK.
- [18] Harris D (2007) Forget me not: palliative care for people with dementia. *Postgrad Med J*. **83**, 4.
- [19] Koopmans RT, Ekkerink JL, van Weel C (2003) Survival to late dementia in Dutch nursing home patients. *J Am Geriatr Soc* **51**, 184-187.
- [20] American Psychiatric Association (1987) Diagnostic and statistical manual of mental disorders, 3rd edn, revised. *American Psychiatric Association*, Washington, DC.
- [21] van Paasschen J, Clare L, Yuen KS, Woods RT, Evans SJ, Parkinson CH, Rugg MD, Linden DE (2013) Cognitive rehabilitation changes memory-related brain activity in people with Alzheimer disease. *Neurorehabil Neural Repair* **27**, 448-459.
- [22] Zanetti O, Binetti G, Magni E, Rozzini L, Bianchetti A, Trabucchi M (1997) Procedural memory stimulation in Alzheimer's disease: impact of a training programme. *Acta Neurol Scand* **95**, 152-157.
- [23] Rabipour S, Raz A (2012) Training the brain: fact and fad in cognitive and behavioral remediation. *Brain Cogn* **79**, 159-179.
- [24] NICE (2013). Quality standard for supporting people to live well with dementia
- [25] NICE (2013). Mental wellbeing of older people in care homes. Quality standard
- [26] Miller LM, Whitlatch CJ, Lyons KS (2016) Shared decision-making in dementia: A review of patient and family carer involvement. *Dementia (London)* **15**, 1141-1157.
- [27] Whitlatch CJ (2010) Assessing the personal preferences of persons with dementia. In *Handbook*

- of Assessment in Clinical Gerontology*, P.A L, ed. Academic Press, London, pp. 557 – 578.
- [28] Feinberg LF, Whitlatch CJ (2002) Decision-making for persons with cognitive impairment and their family caregivers. *Am J Alzheimers Dis Other Demen* **17**, 237-244.
- [29] Karel MJ, Gurrera RJ, Hicken B, Moye J (2010) Reasoning in the capacity to make medical decisions: the consideration of values. *J Clin Ethics* **21**, 58-71.
- [30] Mak W (2011) Self-reported goal pursuit and purpose in life among people with dementia. *J Gerontol B Psychol Sci Soc Sci* **66**, 177-184.
- [31] Karlawish JH, Casarett D, Propert KJ, James BD, Clark CM (2002) Relationship between Alzheimer's disease severity and patient participation in decisions about their medical care. *J Geriatr Psychiatry Neurol* **15**, 68-72.
- [32] Hirschman KB, Xie SX, Feudtner C, Karlawish JH (2004) How does an Alzheimer's disease patient's role in medical decision making change over time? *J Geriatr Psychiatry Neurol* **17**, 55-60.
- [33] Menne HL, Whitlatch CJ (2007) Decision-making involvement of individuals with dementia. *Gerontologist* **47**, 810-819.
- [34] Wimo A, M. P (2010) in *World Alzheimer Report 2010*, London.
- [35] Macdonald A, Cooper B (2007) Long-term care and dementia services: an impending crisis. *Age Ageing* **36**, 16-22.
- [36] Kane M, Cook L (2013), ed. report AsS.
- [37] Prince M, Prina M, Guerchet M (2013) in *World Alzheimer's report London*.
- [38] Groger L (1997) Miami University, Scripps Gerontology Center Publications.
- [39] Tornatore JB, Grant LA (2004) Family caregiver satisfaction with the nursing home after placement of a relative with dementia. *J Gerontol B Psychol Sci Soc Sci* **59**, S80-88.
- [40] Kong EH (2008) Family caregivers of older people in nursing homes. *Asian Nurs Res (Korean Soc Nurs Sci)* **2**, 195-207.
- [41] Rosenthal CJ, Dawson P (1991) Wives of Institutionalized Elderly Men: The First Stage of the Transition to Quasi-Widowhood. *Journal of Aging and Health* **3**, 19.
- [42] Zarit SH, Whitlatch CJ (1993) The effects of placement in nursing homes on family caregivers: Short and long term consequences. *The Irish Journal of Psychology* **14**, 12.
- [43] Donald E. Stull, Janet Cosbey, Karen Bowman, al. e (1997) Institutionalization: A Continuation of Family Care. *Journal of Applied Gerontology* **16**, 23.
- [44] Riddick CC, Cohen-Mansfield J, Fleshner E, Kraft G (1992) Caregiver adaptations to having a relative with dementia admitted to a nursing home. *Journal of Gerontological Social Work* **19**, 25.
- [45] Hoe J, Hancock G, Livingston G, Orrell M (2006) Quality of life of people with dementia in residential care homes. *Br J Psychiatry* **188**, 460-464.
- [46] Hancock GA, Woods B, Challis D, Orrell M (2006) The needs of older people with dementia in residential care. *Int J Geriatr Psychiatry* **21**, 43-49.
- [47] Smit D, Willemse B, de Lange J, Pot AM (2014) Wellbeing-enhancing occupation and organizational and environmental contributors in long-term dementia care facilities: an explorative study. *Int Psychogeriatr* **26**, 69-80.
- [48] Schreiner AS, Yamamoto E, Shiotani H (2005) Positive affect among nursing home residents with Alzheimer's dementia: the effect of recreational activity. *Aging Ment Health* **9**, 129-134.
- [49] Leontjevas R, Gerritsen DL, Smalbrugge M, Teerenstra S, Vernooij-Dassen MJ, Koopmans RT (2013) A structural multidisciplinary approach to depression management in nursing-home residents: a multicentre, stepped-wedge cluster-randomised trial. *Lancet* **381**, 2255-2264.
- [50] Orrell M, Hancock GA, Liyanage KC, Woods B, Challis D, Hoe J (2008) The needs of people with dementia in care homes: the perspectives of users, staff and family caregivers. *Int Psychogeriatr* **20**, 941-951.
- [51] Popham C, Orrell M (2012) What matters for people with dementia in care homes? *Aging Ment Health* **16**, 181-188.
- [52] Petriwskyj A, Gibson A, Parker D, Banks S, Andrews S, Robinson A (2014) A qualitative metasynthesis: family involvement in decision making for people with dementia in residential aged care. *Int J Evid Based Healthc* **12**, 87-104.
- [53] Long VJ (2010) *Palliative Care for Advanced Alzheimer's and Dementia: Guidelines and Standards for Evidence-Based Care*, Springer Publishing Company.

- [54] Jenkins H, Allen C (1998) The relationship between staff burnout/distress and interactions with residents in two residential homes for older people. *Int J Geriatr Psychiatry* **13**, 466-472.
- [55] Maas ML, Reed D, Park M, Specht JP, Schutte D, Kelley LS, Swanson EA, Trip-Reimer T, Buckwalter KC (2004) Outcomes of family involvement in care intervention for caregivers of individuals with dementia. *Nurs Res* **53**, 76-86.
- [56] Gaugler JE (2005) Family involvement in residential long-term care: a synthesis and critical review. *Aging Ment Health* **9**, 105-118.
- [57] Penrod JD, Kane RL, Finch MD, Kane RA (1998) Effects of post-hospital Medicare home health and informal care on patient functional status. *Health Serv Res* **33**, 513-529.
- [58] de Geest G (2003) The relation between the perceived role of family and the behavior of the person with dementia. *Am J Alzheimers Dis Other Demen* **18**, 181-187.
- [59] Bauer M (2006) Collaboration and control: nurses' constructions of the role of family in nursing home care. *J Adv Nurs* **54**, 45-52.
- [60] Jones GMM, Miesen BML (1997) *Care-giving in Dementia: Research and Applications, Volume 2*, Routledge London.
- [61] Dandi R, Casanova G, Lillini R, Volpe M, De Belvis AG, Avolio M, Pelone F (2012), Long-term care quality assurance policies in European countries eds. ENEPRI, www.ceps.eu).
- [62] Schols JM, Crebolder HF, van Weel C (2004) Nursing home and nursing home physician: the Dutch experience. *J Am Med Dir Assoc* **5**, 207-212.
- [63] Koopmans RT, Lavrijsen JC, Hoek JF, Went PB, Schols JM (2010) Dutch elderly care physician: a new generation of nursing home physician specialists. *J Am Geriatr Soc* **58**, 1807-1809.
- [64] Dellefield ME (2006) Interdisciplinary care planning and the written care plan in nursing homes: a critical review. *Gerontologist* **46**, 128-133.
- [65] Burt J, Roland M, Paddison C, Reeves D, Campbell J, Abel G, Bower P (2012) Prevalence and benefits of care plans and care planning for people with long-term conditions in England. *J Health Serv Res Policy* **17 Suppl 1**, 64-71.
- [66] Samsi K, Manthorpe J (2013) Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers. *Int Psychogeriatr* **25**, 949-961.
- [67] Livingston G, Leavey G, Manela M, Livingston D, Rait G, Sampson E, Bavishi S, Shahriyarmolki K, Cooper C (2010) Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK. *BMJ* **341**, c4184.
- [68] Légaré F, Moumjid-Ferdjaoui N, Drolet R, Stacey D, Härter M, Bastian H, Beaulieu MD, Borduas F, Charles C, Coulter A, Desroches S, Friedrich G, Gafni A, Graham ID, Labrecque M, LeBlanc A, Légaré J, Politi M, Sargeant J, Thomson R (2013) Core competencies for shared decision making training programs: insights from an international, interdisciplinary working group. *J Contin Educ Health Prof* **33**, 267-273.
- [69] Kapp, M. B., Mossman D (1996) Measuring decisional capacity: Cautions on the construction of a capacitor. *Psychology, Public Health and the Law* **2**.
- [70] Feinberg LF, Whitlatch CJ (2001) Are persons with cognitive impairment able to state consistent choices? *Gerontologist* **41**, 374-382.
- [71] Whitlatch, J, H M (2009) Don't forget about me. Decision making by people with dementia. *Journal of the American Society on Aging* **33**, 5.
- [72] Smebye KL, Kirkevold M, Engedal K (2012) How do persons with dementia participate in decision making related to health and daily care? a multi-case study. *BMC Health Serv Res* **12**, 241.
- [73] Kim SY, Karlawish JH, Caine ED (2002) Current state of research on decision-making competence of cognitively impaired elderly persons. *Am J Geriatr Psychiatry* **10**, 151-165.
- [74] Hirschman KB, Joyce CM, James BD, Xie SX, Karlawish JH (2005) Do Alzheimer's disease patients want to participate in a treatment decision, and would their caregivers let them? *Gerontologist* **45**, 381-388.
- [75] Davies S, Nolan M (2004) 'Making the move': relatives' experiences of the transition to a care home. *Health Soc Care Community* **12**, 517-526.
- [76] Caron C, Griffith J, Arcand M (2005) Decision making at the end of life in dementia: how family caregivers perceive their interactions with health care providers in long-term-care settings. *J Appl Gerontol* **24**, 16.
- [77] Hertzberg A, Ekman SL (2000) 'We, not them and us?' Views on the relationships and interactions

- between staff and relatives of older people permanently living in nursing homes. *J Adv Nurs* **31**, 614-622.
- [78] Givens JL, Lopez RP, Mazor KM, Mitchell SL (2012) Sources of stress for family members of nursing home residents with advanced dementia. *Alzheimer Dis Assoc Disord* **26**, 254-259.
- [79] Ward-Griffin C, Bol N, Hay K, Dashnaw I (2003) Relationships between families and registered nurses in long-term-care facilities: a critical analysis. *Can J Nurs Res* **35**, 150-174.
- [80] Legault A, Ducharme F (2009) Advocating for a parent with dementia in a long-term care facility: the process experienced by daughters. *J Fam Nurs* **15**, 198-219.
- [81] Forbes S, Bern-Klug M, Gessert C (2000) End-of-life decision making for nursing home residents with dementia. *J Nurs Scholarsh* **32**, 251-258.
- [82] Robinson EM (2000) Wives' struggle in living through treatment decisions for husbands with advanced Alzheimer's disease. *J Nurs Law* **7**, 21-39.
- [83] Gessert CE, Elliott BA, Peden-McAlpine C (2006) Family decision-making for nursing home residents with dementia: rural-urban differences. *J Rural Health* **22**, 1-8.
- [84] Ripich DN, Wykle M, Niles S (1995) Alzheimer's disease caregivers: the focused program. A communication skills training program helps nursing assistants to give better care to patients with disease. *Geriatr Nurs* **16**, 15-19.
- [85] Vogelpohl TS, Beck CK, Heacock P, Mercer SO (1996) "I can do it!" Dressing: promoting independence through individualized strategies. *J Gerontol Nurs* **22**, 39-42; quiz 48.
- [86] Charles C, Gafni A, Whelan T (1999) Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Soc Sci Med* **49**, 651-661.
- [87] Charles C, Gafni A, Whelan T (1997) Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med* **44**, 681-692.
- [88] Elwyn G, Laitner S, Coulter A, Walker E, Watson P, Thomson R (2010) Implementing shared decision making in the NHS. *BMJ* **341**, c5146.
- [89] van der Steen JT (2010) Dying with dementia: what we know after more than a decade of research. *J Alzheimers Dis* **22**, 37-55.
- [90] Mitchell G (2015) Palliative and end-of-life decision-making in dementia care. *Int J Palliat Nurs* **21**, 536-541.
- [91] van der Steen JT, Radbruch L, Hertogh CM, de Boer ME, Hughes JC, Larkin P, Francke AL, Jünger S, Gove D, Firth P, Koopmans RT, Volicer L, (EAPC) (2014) White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med* **28**, 197-209.
- [92] Morrison RS, Chichin E, Carter J, Burack O, Lantz M, Meier DE (2005) The effect of a social work intervention to enhance advance care planning documentation in the nursing home. *J Am Geriatr Soc* **53**, 290-294.
- [93] Stewart F, Goddard C, Schiff R, Hall S (2011) Advanced care planning in care homes for older people: a qualitative study of the views of care staff and families. *Age Ageing* **40**, 330-335.
- [94] Goodman C, Amador S, Elmore N, Machen I, Mathie E (2013) Preferences and priorities for ongoing and end-of-life care: a qualitative study of older people with dementia resident in care homes. *Int J Nurs Stud* **50**, 1639-1647.
- [95] Stone L, Kinley J, Hockley J (2013) Advance care planning in care homes: the experience of staff, residents, and family members. *Int J Palliat Nurs* **19**, 550-557.
- [96] Fosse A, Schaufel MA, Ruths S, Malterud K (2014) End-of-life expectations and experiences among nursing home patients and their relatives--a synthesis of qualitative studies. *Patient Educ Couns* **97**, 3-9.
- [97] van Soest-Poortvliet MC, van der Steen JT, Gutschow G, Deliens L, Onwuteaka-Philipsen BD, de Vet HC, Hertogh CM (2015) Advance Care Planning in Nursing Home Patients With Dementia: A Qualitative Interview Study Among Family and Professional Caregivers. *J Am Med Dir Assoc* **16**, 979-989.
- [98] Gjerberg E, Lillemoen L, Førde R, Pedersen R (2015) End-of-life care communications and shared decision-making in Norwegian nursing homes--experiences and perspectives of patients and relatives. *BMC Geriatr* **15**, 103.
- [99] Fetherstonhaugh D, Tarzia L, Bauer M, Nay R, Beattie E (2016) "The Red Dress or the Blue?": How Do Staff Perceive That They Support Decision Making for People With Dementia Living in

- Residential Aged Care Facilities? *J Appl Gerontol* **35**, 209-226.
- [100] Woods B, Aguirre E, Spector AE, Orrell M (2012) Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database Syst Rev*, CD005562.
- [101] Hill NL, Kolanowski AM, Gill DJ (2011) Plasticity in Early Alzheimer's Disease: An Opportunity for Intervention. *Top Geriatr Rehabil* **27**, 257-267.
- [102] Thacker SP (2012) Social engagement may be as important as cognitive stimulation therapy in dementia. *BMJ* **6**.
- [103] de Werd MM, Boelen D, Rikkert MG, Kessels RP (2013) Errorless learning of everyday tasks in people with dementia. *Clin Interv Aging* **8**, 1177-1190.
- [104] Wells DL, Dawson P (2000) Description of retained abilities in older persons with dementia. *Res Nurs Health* **23**, 158-166.
- [105] Smit D, de Lange J, Willemse B, Twisk J, Pot AM (2016) Activity involvement and quality of life of people at different stages of dementia in long term care facilities. *Aging Ment Health* **20**, 100-109.
- [106] Adams T, Manthorpe J (2003) *Dementia Care: An Evidence Based Textbook*, Arnold, London.

IDENTIFICATION OF THE
PALLIATIVE PHASE IN PEOPLE
WITH DEMENTIA: A VARIETY OF
OPINIONS BETWEEN
HEALTHCARE PROFESSIONALS

BMC Palliative Care (2015) 14, 56-62

Elena Mariani,
Jasper van Riet Paap (shared first author),
Rabih Chattat,
Raymond Koopmans,
Hélène Kerhervé,
Wojciech Leppert,
Maria Forycka,
Lukas Radbruch,
Birgit Jaspers,
Kris Vissers,
Myrra Vernooij-Dassen,
Yvonne Engels
on behalf of the IMPACT research team

ABSTRACT

BACKGROUND: People with dementia can benefit from a palliative care approach. Recommendations, such as those of the EAPC have been proposed to strengthen the provision of palliative care for this group of patients. Yet, it remains challenging for professionals to identify when a person with dementia is in need of palliative care.

OBJECTIVE: To explore when professionals in long-term care settings consider a person with dementia in need of palliative care.

METHODS: Teams with in total 85 professionals working in 13 long-term care settings from 6 countries (France, Germany, Italy, Norway, Poland and the Netherlands) received a case-vignette concerning a person with dementia recently admitted to a nursing home. Teams were asked to discuss when they considered people with dementia eligible for palliative care. The constant comparative method was used to analyse their answers.

RESULTS: Three different time points in the disease trajectory when people with dementia were considered to be eligible for palliative care were extracted: (1) early in the disease trajectory; (2) when signs and symptoms of advanced dementia are present; and (3) from the time point that curative treatment of co-morbidities is futile. Yet, none of these time points was uniformly considered by the professional teams across Europe. In some cases, professionals working in the same nursing home didn't even reach consensus when considering persons with dementia eligible for palliative care.

CONCLUSION: The results of the study identified that professionals across Europe have different opinions regarding the time point when to consider a person with dementia in need of palliative care.

Background

Worldwide, about 36 million persons have dementia [1]. People with advanced stages of dementia have complex physical and psychological needs [2, 3]. Many suffer from symptoms such as pain, agitation, dyspnea, neuropsychiatric symptoms and depression [4], which threatens the quality of their lives as well as that of their relatives. Appropriate palliative care can deal with the needs and preferences of people with dementia and their families [2]. However, access to palliative care services for people with dementia is less defined than for patients with cancer [5]. Professionals in dementia care often lack the necessary skills to anticipate the changing palliative care needs of a person with dementia [5-7]. Therefore, people with dementia are more frequently hospitalized and too often receive burdensome interventions [8]. Moreover, compared to patients with other life-threatening diseases, they are less likely to receive advance care planning [6], are less frequently referred to palliative care teams or hospice care [6] and more often experience symptoms for a longer period of time [9].

Dementia is more and more acknowledged as a life-threatening disease [5]. Time from diagnosis until death varies from two to 20 years [2, 10]. This protracted course of dementia makes it difficult for persons with dementia and their families, as well as for professionals to discuss end-of-life issues, such as advance treatment decisions, preferred place of care and death or lasting power of attorney [2, 4, 5]. Consequently, people with dementia are often not involved in discussions about preferences and needs early in the disease [11], when their cognitive impairment does not yet impede their participation in the decision-making process.

Recently, the European Association for Palliative Care published a white paper on defining palliative care in dementia [12]. One of the recommendations is to consider the time point of the diagnosis of dementia as the starting point of palliative care [12]. However, there is still an ongoing discussion on the identification of the palliative phase in dementia. Besides, people with dementia have unequal access to palliative care services compared to patients with cancer [13]. Therefore, the aim of this study was to explore when professionals in long-term care (LTC) facilities across Europe consider a person with dementia in need of palliative care.

Methods

The EU-funded Seventh Framework IMPACT project (**IM**plementation of quality indicators in **P**alliative **C**are **s**Tudy) aims to develop and tailor national and setting-specific strategies to improve the organisation of palliative care in several European countries. As part of this study, a pre-post test was conducted in 40 services across Europe to assess the organisation of palliative care of long-term care settings, in which also a case-vignette was used. Case-vignettes have been used in a variety of settings [14-18], and they offer a promising alternative for the assessment of the performance of healthcare professionals. Case-vignettes consist of 'text, images or other stimuli to which research participants are asked to respond'

[16]. In this study, the case-vignette was created in a way that it explicitly excluded clinical details of the depicted subject (e.g. about the prognosis, symptoms, etc.) in order to stimulate discussion. The present paper presents the results of the case-vignette about identifying the palliative phase in people with dementia.

Case-vignette

Specific characteristics of a person with dementia were drafted by a general practitioner (Professor of Primary Care for Older People, SI), and used to develop a case-vignette in English. The case-vignette was presented to the IMPACT project team (consisting of 14 clinicians and researchers). After having fine-tuned the concept case-vignette with their feedback (see box one), the English case-vignette was translated into the local languages of the participating countries involved in the project, using a forward-backwards translation. Subsequently, researchers were asked to pilot test the translated case-vignette with at least two professionals in their country. These professionals were asked to evaluate the comprehensiveness and clarity of the vignettes.

Box 1 Case-vignette of a person with dementia

Mrs. White is 83 years old. She has been married for 56 years to Charles. They have one child, Lucy, who is 47, and who keeps in regular contact with them.

Mrs. White was diagnosed with dementia about 9 years ago. Until recently, she lived with her husband in a house in the country. Because Mrs. White can get quite aggressive when she does not understand what is going on, her husband can no longer deal with her at home. Therefore Mrs. White recently moved to a nursing home.

Question: Please explain if and when you would consider Mrs. White as a person in need of palliative care?

Setting and participants

At least two LTC settings for people with dementia were purposefully selected per country. These LTC settings had to have at least one year of experience in the provision of palliative care. Each of the selected LTC settings recruited members from their multidisciplinary team (table 1). Selection criteria for these team members were being involved in direct patient care or, at least, having knowledge of direct patient care. In each setting, one professional was appointed by the researchers as contact person.

Data collection

The multidisciplinary teams participated in a meeting in which the case vignette was presented. In each setting, the contact person chaired this meeting. This person was instructed about the purpose of the meeting. The participants did not receive a definition of palliative care as this would have biased the results. In this study, participants were stimulated to share their own definitions and clinical perceptions about palliative care. Participants were also instructed to consider the depicted person as one of their own residents and were asked: *'Please, could you explain if and when you would consider Mrs. White as a person in need of palliative*

care?. Instructions also stated that consensus within the multidisciplinary team was not important; different opinions could exist. Within each multidisciplinary group, the chairperson summarized and documented the answer(s) according to a predefined template divided into three main sections: job titles of participants; outcomes of the discussion; observational analysis of the discussion process. The chair person was asked to translate the answers into English and to provide detailed information about the process how they came to their answers (e.g. specifying if there was immediate consensus, whether there was a long discussion, if requests of clarifications occurred and reactions of the participants). Subsequently, the chair persons submitted their answer(s) as open text into an online data-registration tool (a web-based data registration tool based on LimeSurvey). If any of the information was unclear, the chair person was contacted to provide further explanations.

Analysis

In each non-English country, the researcher translated the answers of the vignette into English. Two researchers (JvRP and EM) independently coded the data by using a constant comparative method [19]. First, each researcher conducted the comparison within single interviews, developing and labeling categories with appropriate codes in order to outline the core concepts of the interviews. Second, a comparison between interviews was conducted, combining the codes in clusters, in order to define the concepts and identify similarities and differences between interviews [20]. The two researchers discussed their codings until consensus was reached. Regular contact (face-to-face, by Skype and by email) was used during the analysis to refine codes and to group the codes into unique categories. When no consensus could be reached, a third researcher was consulted (YE). Themes and categories were regularly fed back and discussed with two other authors (MVD and YE).

Ethical considerations

The Medical Ethics Committee of the district Arnhem-Nijmegen has declared that this study doesn't fall within the remit of the Medical Research Involving Human Subjects Act (WMO) (registration number 2012/075). This means that this study can be carried out without an approval by an accredited medical ethics committee.

Results

Thirteen nursing homes in six European countries (France, Germany, Italy, Norway, Poland and the Netherlands) participated in the vignette study. In all nursing homes, the staff were responsible for the provision of palliative care. In Germany, Poland and one Dutch nursing home, staff had 24/7 accessibility to specialist services, whereas in the other nursing homes this fluctuated between working hours only to none at all. In one German, the Italian and Dutch nursing homes, an end-of-life care pathway was commonly used for the last three days of life of a person in need of palliative care.

Table 1 Participating professionals per nursing home

	DE -1	DE -2	FR -1	FR -2	IT -1	IT -2	IT -3	NO -1	NO -2	NL -1	NL -2	PL -1	PL -2
Physician	-	-	1	1	1	1	1	-	-	-	-	1	1
Nurse	3	2	1	1	1	1	1	2	6	3	5	2	3
Healthcare assistant	4	2	1	3	1	1	-	3	1	3	-	-	-
Psychologist	-	-	-	1	1	2	-	-	-	-	-	1	1
Social worker	-	-	-	-	-	-	-	-	-	-	-	1	-
Other	-	-	2	5	3	2	4	-	-	1	-	1	3
Total	7	4	5	11	7	7	6	5	7	7	5	6	8

DE: Germany, FR: France, IT: Italy, NO: Norway, PL: Poland, NL: the Netherlands

In total, 85 professionals took part in the multidisciplinary team discussions (Table 1). Professionals in nine nursing homes considered Mrs. White in need of palliative care. In four nursing homes, professionals stated that Mrs. White was not in need of palliative care. The multidisciplinary team reached consensus on their view when to consider Mrs. White in need of palliative care in ten nursing homes. The opinions of the multidisciplinary teams varied so much in the remaining three nursing homes, that they were not able to reach consensus during the discussion of the vignette. The reasons why the multidisciplinary teams did or did not consider Mrs. White in need of palliative care varied and could be grouped into three categories representing different attitudes of staff members on the entry point for palliative care: (1) palliative care starts early in the disease trajectory, (2) palliative care starts when signs and symptoms of advanced dementia are present, and (3) palliative care starts when curative treatment for co-morbidities is no longer possible.

Palliative care should start early in the disease trajectory

Professionals in a German nursing home (DE-2) unambiguously agreed that Mrs. White was a person in need of palliative care from the day she moved in. A similar answer came from an Italian nursing home (IT-2), whereby some professionals stated that dementia is a terminal disease and consequently all their residents, including Mrs. White, should be treated as people in need of palliative care. In the Netherlands, the vignette generated a debate between professionals in a nursing home (NL-1): participating health care assistants first had the impression that palliative care only involved the last three days of life. Two nurses, however, persuaded the health care assistants that they should consider people like Mrs. White, with a diagnosis of dementia, as in need of palliative care. In the end, the multidisciplinary team agreed that Mrs. White was in need of palliative care. Similarly, some professionals of a Norwegian (NO-2) and of a Polish (PL-2) nursing home argued that people with early-stage dementia should be considered in need of palliative care.

Palliative care should start when clinical symptoms of advanced dementia are present

A German nursing home (DE-1) used a self-developed assessment tool to identify palliative care needs and symptoms of their own residents. For that reason, the members of this team agreed that if Mrs. White would meet the criteria of this assessment tool, they would consider her in need of palliative care. Similarly, staff in an Italian nursing home (IT-1) unanimously considered Mrs. White in need of palliative care if she suffered from serious communication deficits, physical disorders, pain and severe agitation. Yet, in a second Italian nursing home (IT-2), staff were not able to reach consensus whether to consider Mrs. White in need of palliative care. Some professionals did mention that palliative care is exclusively applicable for people with advanced dementia. In a third Italian nursing home (IT-3), team members agreed that a person with advanced dementia would be considered in need of palliative care. However, they considered that Mrs. White, as depicted in the vignette, did not show symptoms of advanced dementia. An analogous concept was expressed by professionals in two French nursing homes (FR-1 and FR-2). They unanimously agreed that Mrs. White was not in an advanced stage of dementia and therefore not in need of palliative care. Professionals in a Norwegian nursing home (NO-1) also shared this opinion. However, in another Norwegian nursing home (NO-2), staff were not able to reach consensus. Some stated that palliative care is applicable for people with dementia with a short life expectancy. Lastly, Polish professionals (PL-1 and PL-2) referred to the time point in the disease trajectory in which dementia symptoms seriously hamper a person's autonomy and demand intensive medical and nursing care.

Palliative care should start when curative treatment for co-morbidities has no longer a beneficial effect

Professionals from a Dutch nursing home (NL-2) agreed that at the time Mrs. White is experiencing physical diseases and the doctors decide not to treat these anymore, she should be considered in need of palliative care. In a Norwegian nursing home (NO-2) professionals did not reach consensus, and only some of them considered Mrs. White in need of palliative care when she would no longer benefit from medical or surgical treatment.

Table 3: Professionals' consideration if and when a person with dementia is in need of palliative care

	DE-1	DE-2	FR-1	FR-2	IT-1	IT-2	IT-3	NO-1	NO-2*	NL-1	NL-2	PL-1	PL-2*
Do you consider the person in the case vignette to be in need of palliative care?	Yes	Yes	No	No	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes
When she is in the early stage of dementia	-	+	-	-	-	+	-	-	+	+	-	-	+
When she has signs and symptoms of advanced dementia	+	-	+	+	+	+	+	+	+	-	-	+	+
When she has no more beneficial effect of curative treatment for co-morbidities	-	-	-	-	-	-	-	-	+	-	+	-	-

DE: Germany, FR: France, IT: Italy, NO: Norway, PL: The Netherlands
 * Services where there was no consensus between professionals

Discussion

This study highlights the challenges faced by professionals working in long-term care settings with people with advanced dementia in defining the time point when palliative care should start. With the help of a case-vignette, we identified three time points in the disease trajectory of a person with dementia that teams of nursing home professionals considered as the moment to start palliative care: (1) from the early stages of dementia, (2) when signs and symptoms of advanced dementia are present, and (3) from the time point that curative treatment for co-morbidities is futile. Discrepancies were found not only between European countries, but also between staff members working in the same LTC setting. In some nursing homes, for example, professionals disagreed about the time point a person with dementia is in need of palliative care. Also between countries, different time points when a person becomes eligible for palliative care were mentioned.

However, most professionals described that palliative care should be provided when a person with dementia shows symptoms indicating the advanced stage of dementia is approaching the end-of-life phase, such as swallowing disorders, pain, or when the body does not respond to food or liquids anymore.

Birch et al described that professionals often find it difficult to recognize unmet palliative care needs of people with dementia because the progression of dementia differs in each person [2]. The progression towards the advanced stages of dementia, for example, remains unpredictable [2, 10]. Prognostic indicators to identify end-stage dementia may increase the availability of palliative care options for people with dementia and their families [8], but they are often used too late and seem unreliable to predict a person's death [21]. Some of the professional teams in our study responded that the early stages of dementia can be considered as the time point palliative care starts. Black et al [22] described that recognizing the needs and preferences of people with dementia early in the disease trajectory facilitates the involvement in the decision-making process and advance care planning.

Professionals in two nursing homes considered the time point that curative treatment for co-morbidities is futile and does not improve the person's quality of life as the starting point for palliative care. However, similarly to using prognostic indicators, considering the time point when co-morbidities cannot be treated might be too late in the disease trajectory to provide proactive palliative care as the cognitive abilities of a person with dementia have declined too much so that the person is no longer able to participate in the decision making process and advance care planning.

Before group discussion, some professionals even considered the last days of life as the starting point for palliative care, meaning when the patient is about to die. Although we only reported about the final considerations of the professionals, it is important to note that this could potentially be a fourth time-point.

Differences between countries in identifying the time point of the palliative phase were expected, because of different cultures and national regulations for palliative care [23]. However, even within countries, different opinions about the time point

of the palliative phase were identified. Thereby, there appeared to be differences in definition about palliative care between services. Although important consensus statement reports such as the EAPC's White Paper, defining optimal palliative care in older people with dementia [12], have been developed and disseminated, they are not sufficient to overcome these barriers. Access to palliative care therefore depends on the perceptions of palliative care professionals about when palliative care becomes appropriate for people with dementia. There is a need for further research into the differences palliative care makes to quality of life and end of life care for people with dementia, and the perceptions of palliative care professionals about the value of engaging in the care of people with dementia. Knowledge about and experience in palliative care of professionals working in dementia care therefore need to be improved [24]. Teaching professionals to lead their caregiving by needs probably might be the most important step in providing timely palliative care in each phase of the disease. Reaching consensus about the definition of palliative care and subsequently about the time point of the palliative phase is therefore necessary [25].

This study can contribute to the ongoing discussion on this topic by showing that there are three time points when nursing home professionals consider a person with dementia in need of palliative care: early in the disease trajectory, advanced dementia or when curative treatment for co-morbidities has no more beneficial effect. Even within services, it appeared that sometimes there were different opinions regarding the starting point of the palliative phase. Future attempts to define the optimal time point of the palliative phase in dementia should acknowledge these differences.

Strengths and limitations

This study contributes to our knowledge about the challenges that professionals working in LTC settings experience during their daily work with people suffering from dementia, particularly regarding their palliative care needs. However, some limitations have to be taken into account. Because no definition of palliative care was provided to the participants prior to their discussion about the starting point of palliative care, their opinion may have been influenced by the type of palliative care intervention available in their service. Secondly, because the answers were anonymized, it was not possible to identify differences in the personal perspectives of the healthcare professionals. Thirdly, although data was collected in nursing homes in six European countries and can therefore be considered an international finding, the data may not be representative for all services at the regional or national healthcare system in the respective countries. Thereby, it was not the aim of this study to reach consensus about the time point that the palliative phase starts in people with dementia. Future research can therefore use the three time points identified in this paper, to further explore the possibilities of reaching consensus about the time point of the palliative phase in people with dementia within and between services.

Conclusion

The findings from this study show that professionals across Europe have different opinions regarding the time point when to consider a person with dementia in need of palliative care. The range of opinions described in this study lead to the recommendation that multiple methods for information and education of staff members should be pursued to improve palliative care policy and service delivery for people with dementia.

References

- [1] World Health Organization (2012) World Health Organization, Geneva.
- [2] Birch D, Stokoe D (2010) Caring for people with end-stage dementia. *Nurs Older People* **22**, 31-36.
- [3] Hendriks SA, Smalbrugge M, Hertogh CM, van der Steen JT (2014) Dying with dementia: symptoms, treatment, and quality of life in the last week of life. *J Pain Symptom Manage* **47**, 710-720.
- [4] Sachs GA, Shega JW, Cox-Hayley D (2004) Barriers to excellent end-of-life care for patients with dementia. *J Gen Intern Med* **19**, 1057-1063.
- [5] Ouldred E, Bryant C (2008) Dementia care. Part 3: end-of-life care for people with advanced dementia. *Br J Nurs* **17**, 308-314.
- [6] Harris D (2007) Forget me not: palliative care for people with dementia. *Postgrad Med J* **83**, 362-366.
- [7] Bekkema N, de Veer AJE, Albers G, Hertogh CMPM, Onwuteaka-Philipsen BD, Francke AL (2014) Training needs of nurses and social workers in the end-of-life care for people with intellectual disabilities: A national survey. *Nurse Education Today* **34**, 494-500.
- [8] Brown MA, Sampson EL, Jones L, Barron AM (2013) Prognostic indicators of 6-month mortality in elderly people with advanced dementia: a systematic review. *Palliat Med* **27**, 389-400.
- [9] McCarthy M, Addington-Hall J, Altmann D (1997) The experience of dying with dementia: a retrospective study. *Int J Geriatr Psychiatry* **12**, 404-409.
- [10] Volicer L, Seltzer B, Rheaume Y, Fabiszewski K, Herz L, Shapiro R, Innis P (1987) Progression of Alzheimer-Type Dementia in Institutionalized Patients: A Cross-Sectional Study. *Journal of Applied Gerontology* **6**, 83-94.
- [11] Birch D, Draper J (2008) A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia. *J Clin Nurs* **17**, 1144-1163.
- [12] van der Steen JT, Radbruch L, Hertogh CM, de Boer ME, Hughes JC, Larkin P, Francke AL, Junger S, Gove D, Firth P, Koopmans RT, Volicer L (2013) White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med* **28**, 197-209.
- [13] Piers R, Pautex S, Curiale V, Pfisterer M, Van Nes MC, Rexach L, Ribbe M, Van Den Noortgate N (2010) Palliative care for the geriatric patient in Europe. Survey describing the services, policies, legislation, and associations. *Z Gerontol Geriatr* **43**, 381-385.
- [14] Sandvik H (1995) Criterion validity of responses to patient vignettes: an analysis based on management of female urinary incontinence. *Fam Med* **27**, 388-392.
- [15] Leucht CA, Bjorck JP, Klewicki LL, Goodman M (1999) Patient Impairment Lexicon: a validation study. *J Clin Psychol* **55**, 1567-1582.
- [16] Hughes R, Huby M (2002) The application of vignettes in social and nursing research. *J Adv Nurs* **37**, 382-386.
- [17] Tiemeier H, de Vries WJ, van het Loo M, Kahan JP, Klazinga N, Grol R, Rigter H (2002) Guideline adherence rates and interprofessional variation in a vignette study of depression. *Qual Saf Health Care* **11**, 214-218.
- [18] Rutten GM, Harting J, Rutten ST, Bekkering GE, Kremers SP (2006) Measuring physiotherapists' guideline adherence by means of clinical vignettes: a validation study. *J Eval Clin Pract* **12**, 491-500.
- [19] Johnson JK, Barach P, Vernooij-Dassen M (2012) Conducting a multicentre and multinational qualitative study on patient transitions. *BMJ Qual Saf* **21 Suppl 1**, i22-28.
- [20] Boeije H (2002) A Purposeful Approach to the Constant Comparative Method in the Analysis of Qualitative Interviews. *Quality and Quantity* **36**, 391-409.
- [21] Mitchell SL, Teno JM, Kiely DK, Shaffer ML, Jones RN, Prigerson HG, Volicer L, Givens JL, Hamel MB (2009) The clinical course of advanced dementia. *N Engl J Med* **361**, 1529-1538.
- [22] Black BS, Fogarty LA, Phillips H, Finucane T, Loreck DJ, Baker A, Blass DM, Rabins PV (2009) Surrogate decision makers' understanding of dementia patients' prior wishes for end-of-life care. *J Aging Health* **21**, 627-650.
- [23] Centeno C, José Pons J, Lynch T, Donea O, Rocafort J, Clark D (2013), Milan.
- [24] Quill TE, Abernethy AP (2013) Generalist plus specialist palliative care--creating a more

- sustainable model. *N Engl J Med* **368**, 1173-1175.
- [25] Pastrana T, Junger S, Ostgathe C, Elsner F, Radbruch L (2008) A matter of definition--key elements identified in a discourse analysis of definitions of palliative care. *Palliat Med* **22**, 222-232.

SHARED DECISION-MAKING ON
A 'LIFE-AND-CARE PLAN' IN
LONG-TERM CARE FACILITIES:
RESEARCH PROTOCOL

Nursing Open (2016) **3**, 179-187

Elena Mariani,
Yvonne Engels,
Raymond Koopmans,
Rabih Chattat,
Myrra Vernooij-Dassen

ABSTRACT

BACKGROUND: Shared Decision Making (SDM) is defined as a process where healthcare professionals and patients make decisions together, using the best available evidence.

The aims of the present research project are to assess the feasibility and acceptability of an SDM framework for care planning in long-term care facilities and its potential effectiveness on the proportion of dementia residents whose own preferences and needs, and the related actions, are known, satisfied and documented in their 'life-and-care plans'.

METHODS/DESIGN: The current project is a feasibility trial and it has been approved in November 2013. Research subjects are triads composed of the resident with dementia, his family caregiver and the professional usually taking care for the resident. Professional caregivers of two nursing homes, one located in Italy and one in the Netherlands, will receive a specific training in SDM principles and will guide the SDM interview within the triad. Primary outcome will be the proportion of residents whose preferences and needs, together with the related actions to meet them, are known, documented and satisfied in their 'life-and-care plans'.

DISCUSSION: We want to determine whether the number of residents' preferences and needs together with the actions taken to satisfy them recorded into their 'life-and-care plans' will increase and the process of SDM will improve the residents' psychosocial well-being. The key element of this study is that it will contribute to our knowledge about the efficacy and feasibility of an SDM framework in care planning in long-term care facilities with persons with moderate to severe dementia.

Background

Long-term care (LTC) residents with dementia have complex needs and can have difficulties in articulating them, since the ability to express their wishes is impaired [1]. This does not mean that they do not have their own preferences, that they are completely unable to articulate preferences and feelings [2], or that they are unable to answer simple questions about needs and preferences [3]. While the abilities to answer fact-based questions deteriorate after the early stages of dementia, the abilities to answer preference questions remain more stable over time [3]. Some studies have underlined that it is possible to assess individuals with dementia's personal preferences and to enhance their decision-making involvement [3]. Such studies have shown a positive link between the involvement of people suffering from dementia in decision-making and their quality of life [4].

Shared Decision Making (SDM) is defined as a process where the healthcare professional and the patient make decisions together, using the best available evidence [5-7]. It requires sharing of information and agreement by both parties upon the decisions taken [8]. The SDM process entails the patient's and family's expression of their preferences and their discussion with the healthcare professional, who on his side elicits the patient's thoughts about pro and cons of the available treatments or options, aiming to reach agreement about healthcare decisions to be made [9]. SDM is a component of a person-centred care approach, a recognized theoretical framework that can guide the provision of high quality dementia care. Its aim is to acknowledge the identity and personhood of people with dementia. According to Edvardsson's review, the two key elements of a person-centred care approach for people with severe Alzheimer disease are to take into account the person with dementia's point of view and to offer SDM [10].

Reciprocity, by the contribution of the patient in the decision-making process, is an important element that can improve health and well-being in frail elderly people and that indirectly has an impact on the effectiveness of psychosocial interventions [11]. Moreover, SDM seems to be the most typical pattern that occurs in decision-making situations where the person with dementia, a family member and a professional caregiver are involved [12].

Despite this potential, SDM is not often used in LTC settings with persons with dementia or even with their family caregivers, whose views are frequently not included and documented in care planning [13, 14].

Context

The study runs within the IMPACT project (Implementation of quality indicators in Palliative Care sTudy) funded by the EU 7th Framework Programme that involves five European countries, among which the Netherlands and Italy. Life-and-care plans, as tools for goal planning and for care and registration of treatment actions, are compulsory in both Dutch and Italian LTC facilities. In these settings, a multidisciplinary team assesses residents during the first two weeks following admission. When assessment is completed, a 'life-and-care plan' is developed and compulsorily signed by the professional responsible for the plan, the family caregiver and if

possible the resident. In the Dutch LTC facility usually a nurse is responsible for the plan and in the Italian setting a nurse or any available and qualified member of the multidisciplinary team. The structure of the plans adopted in both countries is similar and consists of four main sections: Problems; Goals; Actions; Evaluation. Problem areas primarily cover: mental and physical well-being; activities of daily living; and cognitive and social functioning. Plans are updated as changes in the resident's condition occur and at least once a year. The choice to develop and implement an SDM framework in care planning in the Netherlands and in Italy was primarily based on the existing collaboration between the University of Bologna and the University of Nijmegen. Secondly, SDM is an issue that is receiving growing attention in both countries. In the Netherlands, a policy called 'family participation' has been developed in the '90s to promote the participation of family members in the care planning of their relatives admitted into nursing homes [15]. Yet, a structured involvement of both family carers and dementia residents by using SDM in LTC settings has not become common practice. In Italy the National Health Plan developed in 2011 underlines the importance of involving citizens and patients in the healthcare decision-making process. However, there are only few studies on SDM carried out in this country [26] (Goss Claudia 2011) (Goss Claudia, 2011) [26] [26] and none of them was conducted in the dementia care area [16].

Aim and objectives

The present study has the following primary objectives: (1) to assess the feasibility and acceptability of an SDM framework in care planning to be used both to assess the preferences and (un)met needs of the LTC resident with dementia and his family caregiver, and to plan tailored and shared actions based on the assessment outcomes; (2) to investigate how the process of SDM evolves between the resident, professional caregiver and family caregiver; (3) to investigate whether it is acceptable to professionals, residents and families becoming, embedded into the clinical practice of the involved LTC settings in Italy and the Netherlands.

The secondary objectives intend to explore the impact of the SDM framework on:

- the dementia residents' quality of life
- the family carers' quality of life and sense of competence
- the professional caregivers' job satisfaction
- the caregivers' satisfaction with the SDM intervention
- the organizational context where it takes place, i.e barriers and facilitators, as perceived by the professionals.

In particular, we want to determine whether the SDM framework is likely to increase the number of residents' preferences and needs together with the actions taken to satisfy them recorded into their 'life-and-care plans' and whether it improves the residents' psychosocial well-being.

Methods/Design

Study design

The current project is a feasibility study. The research population consists of dementia residents living in the selected LTC settings, their main family carers and the professional caregivers usually taking care for the residents. The subjects are organized in triads: each triad is composed by the resident with dementia, the family and the professional caregiver. A multi-method approach [17] will be adopted to provide an in-depth description of the SDM process developed within the triad. Quantitative data based on residents' personal files and on the screening and evaluation measures collected from professionals and family caregivers will be used.

Subjects and settings

Two nursing home wards in the Netherlands and two nursing home wards in Italy are involved. In each country, one ward will randomly be assigned to the intervention group and the other to the control group. The same number of residents, family caregivers and healthcare professionals will be assessed in both groups, and the same tools will be used. In the Netherlands two Dementia Special Care (DSC) units within the same nursing home will be recruited, whereas in Italy two different nursing homes will be enlisted, being similar in numbers of residents admitted, staffing patterns and level of medical and psychosocial care provided, as described in their charters of services. In order to avoid contamination, in the Netherlands the professionals working in the experimental DSC unit will not be the same as the ones working in the control DSC unit.

In each experimental and control nursing home ward, 20 dementia residents will be included, based on the following inclusion criteria: (1) having a diagnosis of dementia based on DSM IV [18], (2) being able to give informed consent or, if legally incapable, having a family caregiver who can give informed consent for them and (3) being supported by one primary family caregiver who agrees to participate and to be involved in the study too.

Inclusion criteria for the principal professional caregivers are: (1) being a member of the multidisciplinary team who is used to being directly involved in the care planning process and (2) being a key staff member in the provision of residents' care and consequently to know the identified residents well. In both countries, at least eight healthcare professionals will be recruited to attend the training provided for the project and will later conduct the SDM interviews with 20 residents and their family caregivers.

Thus, the entire experimental group is composed by a total of 40 dementia residents, 40 family carers and about 16 healthcare professionals. These participants will be compared to the two other control nursing home wards, that will be asked to involve the same number of subjects. After the selection is completed, a researcher will check the accuracy of the choices based on the requested inclusion criteria.

Intervention

As shown in Figure 1, the present project is a multifaceted intervention consisting of four phases to implement an SDM framework in (long-term) care planning, in order to obtain a constantly developing plan that focuses not only on the medical, physical, psychosocial and spiritual needs of the residents, but that considers and documents their preferences and the actions taken by caregivers to meet them.

a) Pre-intervention assessment - Dementia residents' (un)met needs assessment

At baseline (for a complete overview of measures see Table 1), a trained researcher will administer an adapted version of the Camberwell Assessment of Needs in the Elderly (CANE) [19,20] to the dementia residents and to the formal and informal caregivers. The CANE is a comprehensive, person-centred needs assessment tool that has been designed for use in the elderly: the instrument is based on the principle that identifying a need means identifying a problem plus an appropriate intervention which will help or meet the need. It assesses the elderly's needs from various perspectives: to reach this goal, CANE is to be administered not only to the elderly person, but also to a key staff member and to an informal caregiver. The CANE has shown a good validity and reliability [21]. In the present study, only those items of the Dutch [22] and Italian [23] version of the CANE will be used to assess specific psychosocial needs of dementia persons who live in LTC settings. This was decided after discussion with the involved professionals as they declined the use of the full CANE questionnaire because of its length and relevance for nursing homes. They considered the need to manage behavioural problems, the need for tailored activities and the emotional and social needs as most important for residents with dementia in LTC settings [24]. Starting from this data, we tried to improve the study protocol by discussing it with professionals to be involved. The items' relevance for nursing homes was related to a model for nursing home care, the Eden Alternative that aims to provide a person-centered care environment for elderly residents [25]. Based on its principles, we have selected the CANE items that cover the following psychosocial issues: self-care; daytime activities; psychological distress; information; behaviour; company; intimate relationship. The outcome of the selected CANE items will be a summary of met and unmet needs. The trained researcher who administers the CANE will share and discuss the information gained with the LTC professionals involved in the study before they will conduct the SDM interviews with the dementia resident and his family caregiver, so that they can use this information as a guidance for the interview. This will facilitate the selection and prioritization of their needs and the identification of possible interventions to meet them.

b) Phase 1 - Training for professionals

Dementia experts with an expertise in teaching communication skills in the context of clinical care have developed a training for professionals, teaching them how to appropriately stimulate the residents with dementia during the SDM interview to facilitate the expression of their wishes and needs. This training will be provided

to the professionals in the intervention wards of both LTC settings. The training programme will focus on SDM principles in dementia care and active listening [26], in order to enhance the healthcare professionals' verbal and non-verbal communication skills to be used to assess, meet and record the residents' needs and preferences during the SDM interview. Participants will receive a 2-hour weekly training for 5 weeks. Each lesson will be guided by clearly defined learning goals and will be divided into three sessions: theory, role-playing and feedback sessions.

I. Theory sessions

During these sessions the healthcare professionals will learn the SDM model, active listening and self-management principles as a guide to 1) identify residents' problems or needs, 2) prioritize them, choosing the main needs or problems that will become the goals of the intervention, 3) identify alternatives to meet them, 4) decide and plan the intervention, 5) execute plans, 6) and evaluate the outcomes.

II. Role-playing sessions

During these sessions professionals will practice skills and knowledge acquired in the theoretical part of the lesson. In some cases, the trainer will provide case-vignettes that will be used as cues to set up role-play exercises; in others professionals will be asked to report difficult situations they face during their daily work. Moreover, professionals will be invited to bring real care plans, in order to understand whether SDM is applied, and to practice the learning objectives of the training programme in daily care situations.

III. Feedback sessions

The trainer will support and supervise the professionals during the role-playing sessions, guide the discussion and provide feedbacks in order to stimulate reflection on their own professional attitude.

One additional lesson, three months after the end of the training, will be organized in order to discuss the problems professionals faced so far and to refresh some of the core issues of the training.

c) Phase 2 - SDM conversation

The SDM conversation will take place between a triad, composed of the resident with dementia, the family caregiver and the LTC professional as facilitator. The professional will be taught to tell the resident and the family caregiver that the aim of the consultation is to tailor the 'life-and-care plan' to the resident's actual needs and preferences. Using the unmet needs as collected with the CANE, as starting point, the main steps of the SDM process that will be applied during the conversation are (a) identification of problems and needs, (b) prioritization of the most important problems or needs to set the intervention's goals, (c) discussion of options and preferences and (d) identification of actions. The role of the family caregiver is to support and facilitate the resident's expression: if communication is limited, the family caregiver is stimulated to intervene, to add information and to

stimulate the person with dementia. Together, the participants in the consultation will make plans to comply with the prioritized needs and will develop actions to meet them.

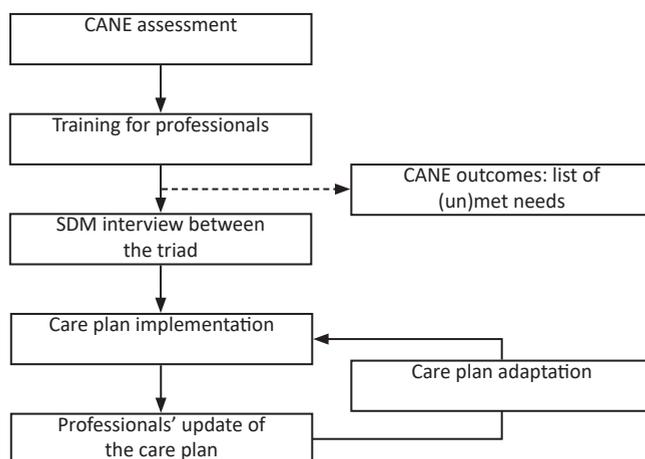
d) Phase 3 - Implementation of plans

Immediately after the interview, the professional caregiver is asked to update the resident 'life-and-care plan' with the outcomes of the SDM interview reporting: I. the goals of the intervention based on the resident's problems and needs identified and preferences expressed, II. the planned actions based on the agreed decisions taken, and III. the monitoring of the SDM intervention (i.e. the planned actions have been effectively implemented and/or the agreed decisions satisfied).

e) Phase 4 - Update

The 'life-and-care plan' is then updated regularly by the professional caregiver, who will report if all aspects of the intervention are (not) going according to plan.

Figure 1 Graphical representation of the intervention



Measures

Participants' details and LTC settings description

Demographics of the participants will be collected together with data on the inner organization and management of the involved LTC settings, considered potential influencing factors regarding the implementation process.

Besides, several valid instruments will be used. For a full description of the data collected and of the tools used, see Table 1.

Residents' characteristics

Katz index of independence in Activities of Daily Living (ADL)

The Katz ADL [27] measures the clients' ability to independently perform activities of daily living. The Index ranks adequacy of performance in the six functions bathing, dressing, toileting, transferring, continence, and feeding. Lower scores indicate a higher level of dependency. If the Katz index is not reported in the residents' medical record, the information will be gained by asking the units' key nurses or healthcare professionals to complete it. These data will be used as additional information to make a profile of the residents, in order to better identify and prioritize their main needs to be satisfied.

Outcome measures

Primary outcome measure

The primary outcome measure is the proportion of dementia residents whose preferences, needs and related actions are known, satisfied and documented in their 'life-and-care plan' [28]. Six months after the SDM interviews, a researcher will determine the compliance with residents' needs and wishes accomplished. The researcher will check the residents 'life-and-care plan' updated after the SDM interviews by professional caregivers, identifying any documentation of the resident's needs and preferences, goal set by the triad, actions taken to satisfy it and goal satisfaction (see Phase 3 of the intervention).

Secondary outcome measures for the residents

Dementia quality of life Instrument (DQoL)

The DQoL is a reliable instrument to assess dementia patients' quality of life [29]. It is administered in the present study to measure the effects of applying the SDM framework on residents' quality of life. It is a 29-items scale and one global item on overall quality of life. It directly assesses five domains of quality of life: positive affects, negative affects, feelings of belonging, self-esteem and sense of aesthetics. Items are rated on 5-point visual scales to facilitate the person with dementia' answers. In the present study, given the impaired cognitive functioning of residents, the rating scale will be recoded and patients will answer yes or no to each question.

Secondary outcome measures for the family caregivers

EuroQOL

The EuroQOL [30] is used to assess family caregivers' quality of life. EuroQOL is a generic health-related quality of life measure composed of five domains: mobility, self-care, usual activities, pain/discomfort, anxiety/depression. It is valid and can be applied in the general population [31].

Short Sense of Competence Questionnaire (SSCQ)

SSCQ [32] is used to assess the sense of competence of the family caregivers of dementia residents. It is a scale to be used for informal caregivers of older adults diagnosed with dementia. It consists of three domains: satisfaction with the

demented person as a recipient of care, satisfaction with one own's performance and consequences of involvement in care for the personal life of the caregiver. It comprises 7 items to be rated on a 5 point scale (from very strongly agree to very strongly disagree). In the present study, answers will be dichotomized [33].

Secondary outcome measures for the professional caregivers

Job Satisfaction Questionnaire (JSQ)

The JSQ consists of 20 items, scored on a four-point scale, from mostly negative to mostly positive and it consists of five factors: autonomy, competence, emotion, initiative and relation. High scores indicate high levels of job satisfaction [34]. The factors have Cronbach's alpha coefficients between 0.74 and 0.92 [35].

Process measures

SDM interview process questionnaire

A questionnaire has been developed to measure how residents with dementia have been involved in the SDM process from the formal and informal caregivers point of views. The questions have been developed by combining and adapting the items of two validated tools used to measure SDM in clinical encounters in order to be applicable in the nursing home situation [36, 37]. Selection has been made based on the principles that will guide the SDM process with persons with dementia in LTC settings and that focus on: needs identification; options provision; advantages and disadvantages explanation; support to the clients in understanding the information given and in expressing their preferences and wishes; agreement about the final plans to satisfy them. Immediately after the SDM interviews, formal and informal caregivers will be asked to complete it.

Process evaluation measures

To explore caregivers' satisfaction with the SDM intervention, questionnaires with closed and open questions will be used. Moreover, data on the adherence rate (operationalized as the proportion of caregivers that actually adopt the intervention in the study), relevance, feasibility and maintenance of the intervention (operationalized as the extent to which the intervention is sustained over time) will be collected.

Focus group interviews

Focus group interviews with the involved professional caregivers will take place at the end of the project in order to collect suggestions, observations and opinions on barriers and facilitators to this practice in LTC settings, also considering and discussing national and setting-related factors that could have affected the intervention's results, such as the organization of the National Health System, the national attention to the SDM attitude in healthcare settings or the nursing home's inner organisation.

Measurements related to LTC residents, professional and family caregivers will be performed at baseline and six months after the intervention, as shown in Table 1.

Table 1 Overview of outcomes measure

<u>Variable</u>	<u>Instrument</u>	<u>Time of assessment</u>	
		<u>B</u>	<u>F1</u>
Baseline measurements			
Demographic data of participants	Age, gender, educational status, marital status, employment	I	I
Descriptive data of LTC settings	Type of hierarchical organization, care models adopted, family carers involvement, National Health System information, staff members' roles and education	I	I
Patient			
Needs assessment	Camberwell Assessment of Needs in the Elderly (CANE)	R/FC/C	R/FC/C
Level of dependency	Katz Activities of Daily Living index (ADL)	P/C	P/C
Primary outcome measure			
Documentation of residents' preferences and of the actions taken to satisfy them	Proportion of residents whose preferences and needs' satisfaction is documented	DR	DR
Secondary outcome measure			
Quality of life	Dementia quality of life Instrument (DQoL)	R	R
Family caregivers			
Secondary outcome measure			
Quality of life	EuroQOL	FC	FC
Sense of competence	Sense of Competence Questionnaire (SCQ)	FC	FC
Professional caregivers			
Secondary outcome measure			
Job satisfaction	Job Satisfaction Questionnaire	C	C
Assessment of the SDM professional attitude	Structured interviews	C	C
Process measures			
Assessment of the SDM interview process	Self-report questionnaire	-	C/FC
Satisfaction with the SDM process; relevance, feasibility and maintenance of the intervention	Self-report questionnaires	-	R/FC
Barriers/facilitators and influencing factors	Focus group interview	-	C/FC

B (baseline); F1 (6 months after the first SDM interview); P (patient file); C (professional caregiver as informant); I (structured interviews with participants); DR (documentation review); R (residents as informant); FC (family caregiver as informant).

Data analysis

Quantitative data will be analyzed using the Statistical Package for Social Science (SPSS). The proportion of residents whose SDM documentation on needs satisfaction has been fulfilled, will be analyzed using the Fischer exact test. Secondary outcomes, at the level of residents, professional and informal caregivers, will be calculated using parametric and non-parametric tests, making comparison between and within groups. Descriptive statistics will be used to compare the experimental and control nursing home wards for socio-demographic characteristics and baseline variables. In each country, the focus group discussions' content will be translated into English. Two independent researchers will code the data by using a constant comparative method [38]. Each researcher will develop and label categories with appropriate codes outlining the core concepts of the focus group interviews. Then, the codes will be combined in clusters to define the concepts and identify similarities and differences between the interviews [39]. Codings will be discussed until consensus will be reached.

Ethical approval

In November 2013 the study has been approved by the ethics committee of both universities involved in the project in Italy and The Netherlands.

Discussion

The present paper presents the study protocol of a study to assess feasibility, acceptability and potential effectiveness of an SDM framework in care planning for long-term care residents with dementia. The aim of the study is to explore whether it is effective and feasible to take the dementia residents' personal perspective into account regarding assessing and meeting their own needs through an SDM process with the professional and family caregivers. Thus, SDM is here considered an opportunity for persons with dementia to express their opinion and wishes, and care planning a comprehensive and constantly developing process that should be based on the residents' preferences, not only on the professionals' or family carers' perspective.

Strengths and limitations

The key element of this study is that it will contribute to our knowledge about the efficacy and of SDM interviews in nursing homes with persons with moderate to severe dementia, and will consider the barriers and facilitators to this practice in LTC settings. Besides, it will make an important contribution to test the feasibility for a full trial, as recommended by the United Kingdom Medical Research Council guidance on the development and evaluation of complex intervention [40]. Moreover, the study will take place in nursing homes located in two different countries, Italy and the Netherlands: these data represent a source of interesting information on the application and feasibility of this study in countries characterized by different cultures and healthcare systems organization.

At the same time, cultural differences may affect the primary and secondary outcomes: this data is therefore collected and considered during data analysis. Furthermore, only a few nursing homes are recruited in this study: their organization and residents population may not be representative of these parameters in both countries. In addition, the supportive presence of the family caregivers during the SDM interview may influence the resident's behaviour and attitude. Therefore, this co-variable will be taken into account.

References

- [1] Hancock GA, Woods B, Challis DA, Orrell M (2006) The needs of older people with dementia in residential care. *International Journal of Geriatric Psychiatry* **21**, 43-49.
- [2] Carpenter BD, Kissel EC, Lee MM (2007) Preferences and Life Evaluations of Older Adults With and Without Dementia: Reliability, Stability, and Proxy Knowledge. *Psychology and Aging* **22**(3), 650–655.
- [3] Whitlatch CJ (2010) Assessing the personal preferences of persons with dementia. In *Handbook of assessment in clinical gerontology* (Lichtenberg P.A. ed.), Academic Press, London, pp. 557-578.
- [4] Fetherstonhaugh D, Tarzi L, Nay R (2013) Being central to decision making means I am still here!: The essence of decision making for people with dementia. *Journal of Aging Studies* **27**, 143–150.
- [5] Charles C, Gafni A, Whelan T (1997) Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango) *Soc Sci Med* **44**(5), 681-92.
- [6] Charles C, Gafni A, Whelan T (1999) Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Soc Sci Med* **49**(5), 651-61.
- [7] Elwyn G, Edwards A, Mowle S, Wensing M, Wilkinson C, Kinnersley P, Grol R (2010) Implementing shared decision making in the NHS. *BMJ* **341**, 971-973.
- [8] Elwyn G., Edwards A. & Kinnersley P. (1999) Shared decision-making in primary care: the neglected second half of the consultation. *British Journal of General Practice* **49**, 477-482.
- [9] Elwyn G, Koelewijn-van Loon M, Sepucha K, Elwyn G, Legare F, Harter M, Dirmaire J (2001) Measuring the involvement of patients in shared decision making: a systematic review of instruments. *Patient and education counselling* **43**, 5-22.
- [10] Edvardsson D, Winblad B, Sandman PO (2008) Person-centered care of people with severe Alzheimer's disease: current status and ways forward. *Lancet Neurol* **7**, 362-367.
- [11] Vernooij-Dassen M, Leatherman S, Olde Rikkert M (2001) Quality of care in frail older people: the balance between receiving and giving. *BMJ Analysis* **342**, 1062-1063.
- [12] Smebye KL, Kirkevold M, Engedal K (2012) How do persons with dementia participate in decision making related to health and daily care? A multi-case study. *BMC Health Services Research* **12**, 241-253.
- [13] Cohen D (1991) The subjective experience of Alzheimer's disease: the anatomy of an illness as perceived by patients and families. *American Journal of Alzheimers Disease and Other Dementias* **6**(6), 6-11.
- [14] Broderick MC, Coffey A (2013) Person-centred care in nursing documentation. *International Journal of Older People Nursing* **8**, 309-318.
- [15] Dijkstra A (2007) Family participation in care plan meetings: promoting a collaborative organizational culture in nursing homes. *Journal of Gerontological Nursing* **33**(4), 22-9.
- [16] Goss C, Mosconi P, Renzi C, Deledda G (2011) Participation of patients and citizens in healthcare decisions in Italy. *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen* **105**, 277-282
- [17] Morse, JM (2003) Principles of mixed methods and multimethod research design. In Tashakkori, A. & Teddlie, C., eds, *Handbook of mixed methods in social & behavioural research*. Thousand Oaks, CA: Sage, pp. 189-209.
- [18] American Psychiatric Association (2000) Diagnostic and Statistical manual of mental disorders (4th ed., text rev.). Author, Washington DC.
- [19] Orrell M, Hancock G, Hoe J, Woods B, Livingstone G, Challis D (2007) A cluster randomized controlled trial to reduce the unmet needs of people with dementia living in residential care. *International Journal of Geriatric Psychiatry* **21**, 1127-1134.
- [20] Orrell M, Hancock G (2004) *Camberwell Assessment of Need for the Elderly*. Gaskell: London.
- [21] Reynolds T, Thronicroft G, Abas M, Woods B, Hoe J, Leese M, Orrell M (2000) Camberwell Assessment of Need for the Elderly (CANE): Development, validity and reliability. *British Journal of Psychiatry* **176**, 444-452.
- [22] Van der Roest HG, Meiland FJ, van Hout HP, Jonker C, Droes RM (2008) Validity and reliability of the Dutch version of the Camberwell Assessment of Need for the Elderly in community dwelling people with dementia. *International Psychogeriatrics* **20**, 1273-1290.
- [23] Chattat R, Celeste C (2008) Assessment of needs in elderly Italian version of the 'can elderly'. *Ricerche di psicologia* **31**(12), 121-131.

- [24] Cadieux MA, Garcia LJ and Patrick J (2013) Needs of People With Dementia in Long-Term Care: A Systematic Review. *American Journal of Alzheimer's Disease and Other Dementias* **28**(8), 723-733.
- [25] Brownie S, Nancarrow S (2013) Effects of person-centered care on residents and staff in aged care facilities: a systematic review. *Clinical Interventions in Ageing* **8**, 1-10.
- [26] Gordon T (2000) *Parent effectiveness training*. Three Rivers Press, New York.
- [27] Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW (1963) Studies of illness in the aged. The index of ADL: a standardized measure of biological and psychosocial function. *JAMA* **185**, 914-919.
- [28] Detering KM, Hancock AD, Reade MC, Silvester W (2010) The impact of advanced care planning on end of life care in elderly patients: randomized controlled trial. *BMJ* **340**, c1345
- [29] Brod M, Stewart AL, Sands L, Walton P (1999) Conceptualization and measurement of quality of life in dementia: the dementia quality of life instrument (DQoL). *Gerontologist* **39**(1), 25-35.
- [30] The EuroQol Group (1990) EuroQol-a new facility for the measurement of health-related quality of life. *Health Policy* **16**(3), 199-208.
- [31] Brazier P, Jones N, Kind P (1993) Testing the validity of Euroqol and comparing it with the SF-36 health survey questionnaire. *Quality of Life Research* **2**, 169-180.
- [32] Vernooij-Dassen M (1993) *Dementie en thuiszorg (Dementia and home care)*. Swets and Zeitlinger, Amsterdam.
- [33] Vernooij-Dassen M, Felling AJ, Brummelkamp E, Dautzenberg MG, van den Bosch GA, Grol R (1999) Assessment of caregiver's competence in dealing with the burden of caregiving for a dementia patient: a Short Sense of Competence Questionnaire (SSCQ) suitable for clinical practice. *J Am Geriatr Soc* **47**(2), 256-257.
- [34] Orrung Walli A, Edbg AK, Beck I, Jakobsson U (2013) Psychometric properties concerning four instruments measuring job satisfaction, strain, and stress of conscience in a residential care context. *Archives Gerontology and Geriatrics* **57**(2), 162-171.
- [35] Sellgren SF, Ekvall G, Tomson G (2008) Leadership behaviour of nurse managers in relation to job satisfaction and work climate. *Leadership behaviour of nurse managers* **16**, 578-587.
- [36] Melbourne E, Sinclair K, Durand MA, Légaré F, Elwyn G (2010) Developing a Dyadic OPTION scale to measure perception of shared decision making. *Patient Education and Counseling* **78**, 177-183.
- [37] Kriston L, Scholl I, Holzel L, Simon D, Loh A, Harter M (2010) The 9-item Shared Decision-Making Questionnaire (SDM-Q-9) Development and psychometric properties in a primary care sample. *Patient Education and Counseling* **80**, 94-99.
- [38] Johnson JK, Barach P, Vernooij-Dassen M (2012) Conducting a multicentre and multinational qualitative study on patients' transition. *BMJ Quality Safety* **21**, 22-28.
- [39] Boeije HA (2002) Purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Quality and Quantity* **36**, 391-40.
- [40] Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M (2008) Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ* **337**:a1655.

CARE PLAN IMPROVEMENT IN NURSING HOMES: AN INTEGRATIVE REVIEW

Journal of Alzheimer's Disease (2017) 55,
1621-1638

Elena Mariani,
Rabih Chattat,
Myrra Vernooij-Dassen,
Raymond Koopmans,
Yvonne Engels

ABSTRACT

BACKGROUND: Care planning nowadays is a key activity in the provision of services to nursing home residents. A care plan describes the residents' needs and the actions to address them, providing both individualized and standardized interventions and should be updated as changes in the residents' condition occur.

OBJECTIVE: The aim of this review was to identify the core elements of the implementation of changes in nursing homes' care plans, by providing an overview of the type of stakeholders involved, describing the implementation strategies used and exploring how care plans changed.

METHODS: An integrative literature review was used to evaluate intervention studies taking place in nursing homes. Data were collected from PubMed, CINAHL-EBSCO and PsycINFO. English language articles published between 1995 and April 2015 were included. Data analysis followed the strategy of Knafl and Whitemore.

RESULTS: Twenty-six articles were included. The stakeholders involved were professionals, family caregivers, and patients. Only few studies directly involved residents and family caregivers in the quality improvement process. The implementation strategies used were technology implementation, audit, training, feedback and supervision. The majority of interventions changed the residents' care plans in terms of developing a more standardized care documentation that primarily focuses on its quality. Only some interventions developed more tailored care plans that focus on individualized needs.

CONCLUSION: Care plans generally failed in providing both standardized and personalized interventions. Efforts should be made to directly involve residents in care planning and provide professionals with efficient tools to report care goals and actions in care plans.

Background

Care planning is considered to be a key activity in the provision of services to nursing home residents [1]. Elderly residents are often frail and have multiple disabilities and comorbidities that require specific treatment [2, 3]. Nowadays, long-term care (LTC) settings attempt to provide interdisciplinary and tailored care, acknowledging residents with and without cognitive impairment as unique, autonomous persons and try to involve them in care planning and delivery [4, 5]. The satisfaction of the older residents' complex needs and the provision of both standardized and individualized support demands integrated care and a multidisciplinary approach. Thus, care planning becomes crucial to ensure a high level of quality in the care provided.

The goals of both the interdisciplinary care planning process and the written care plan include individualized care, continuity of care and team communication [6]. However, it is important to distinguish between care planning and the actual care plan [7]. The former reflects the assessment process, in which residents' needs and abilities are identified and care goals are set, whereas the latter describes how these needs will be met, indicating the actions required to reach the goals set and to evaluate their fulfilment. Ideally, a patient record delineates the patient's journey from admission to discharge or death [8], describing his or her medical, nursing, mental and psychosocial needs [9] and facilitating the information flow between healthcare professionals, ensuring the continuity, quality and safety of care [10]. Furthermore, care plans need to be flexible and should be updated as changes in the residents' condition occur [6]. However, nursing homes are not always effective at accomplishing such requirements. In fact, care plans often do not guide the delivery of daily care [11] and research suggests that there are discrepancies between the actions recorded in care plans and actual care delivery [12, 13]. Besides, residents' nursing documentation frequently lacks completeness: an accurate assessment of the patients' cognition is not always performed or documented despite it is essential in planning care, in order to make a reliable and individualized plan [14]. Moreover, albeit the person-centered approach is a recognized framework used to meet residents' needs and to provide high quality dementia care in nursing homes, little emphasis is usually put on psychosocial aspects, indicating a lack of person-centeredness in nursing documentation [15]. This might not only affect the quality of care provided to residents, but also the costs the facilities have to bear [16]: it has been shown that high quality care programs may even cost less than poor quality improvement programs, as the latter are ineffective in planning, communicating and coordinating care [17].

Quality improvement is stimulated in European and non-European countries by specific regulations and criteria to be met on care planning [6]. At policy level, many countries are promoting initiatives to improve care coordination and plans for common assessment schemes and evaluation by multidisciplinary teams to define care plans to be used in LCT settings [18]. Along with this, both clinical guidelines and regulations regarding comprehensive care plans [9, 19], as well as quality indicators that are used to measure nursing home residential care processes, have

been developed [20].

Given the relevance of cost-effectiveness issues related to care coordination and planning in nursing homes, and considering the role that care plans play in such processes, it becomes crucial to understand how care plans can be improved and efficiently implemented in daily routine. In fact, implementation of programs or innovations is never easy [21], especially when they involve complex processes such as care planning. Changes in healthcare are the result of different factors that interact at different levels such as patients, professionals and organizational and economic context [22]. The ideal model for change in healthcare includes both impact and process theories, which focus on the core elements that found the implementation of change. Impact theories describe how specific interventions facilitate the change as well as the factors and causes that contribute to it. Process theories, regard the organization, planning, schedule and use of the preferred implementation activities and how the target groups are influenced by them [22]. Therefore, in order to describe the implementation of changes in nursing homes' care plans, we focused on core elements such as the target groups involved, the implementation activities used and the resulting changes.

Thus, the aim of this integrative review was to provide an overview of the type of stakeholders included in intervention studies concerning elderly residents' care plans, to describe the implementation strategies used and to explore how care plans changed in terms of being more comprehensive, accurate or individualized.

Methods

Search strategy

The electronic databases PubMed, CINAHL-EBSCO and PsycINFO were searched for English literature published between 1995 and April 2015. Key words used in the search were terms that described elderly residents' care documentation (care plan elderly, nursing care plan, goals of care, health record, documentation) and the target settings (residential facility, nursing home). The search string is available in Appendix 1. Reference lists of the relevant journal articles were also reviewed.

Selection of studies

The review included studies of any design, involving care plans of older people living in nursing homes. Few papers used the term medical record instead of care plan: only when it was clear that the record was comprehensive and contained all aspects of residents' care and needs, they were included as well. Articles were included when they described the implementation of healthcare interventions that changed residents' nursing care plans (1) by modifying the care plans' framework, (2) by adding new tools to care plans (electronic and/or paper version), (3) by reporting the interventions' outcomes into residents' care plans. Articles were excluded when they described studies that (1) refer to a specific type of nursing documentation or care planning phase (e.g. falls care plans, medication monitoring

care plans, discharge plans, advance care planning etc.) with no indications that it was integrated into the residents' comprehensive care plans, (2) are not intervention studies but focus only on the analysis of the care plans' content, checking for accuracy or adherence, (3) do not take place in nursing homes for older people. We focused on care plans, regardless of type of residents' disease. However, given our interest in dementia research, when the selected interventions also involved residents with dementia, this was specified in the studies' description.

Data management and analysis

Based on the inclusion criteria just described, two authors (EM and RC) selected the relevant articles, independently screening titles and abstracts. When clear or sufficient information was not provided, the full text was reviewed. In particular, a data extraction form with Microsoft Excel was developed and filled with papers' relevant information: country, research methods, type and steps of the intervention, outcomes, implementation strategies used and description of the resulting changes on care plans. The methodological framework specific to the integrative review method proposed by Whitemore and Knafel was used to summarize past empirical literature and to provide a better comprehensive understanding of the implementation of changes in nursing homes' care plans [23]. Strategies for data analysis, as described by Whitemore and Knafel [23], were followed. Firstly, primary

Table 1 Codes and categories

<u>General definition</u>	<u>Category</u>	<u>Codes (n=number of studies)</u>
STAKEHOLDERS INVOLVEMENT INTERVENTIONS		
<i>Participation of care providers in the quality improvement process, by developing or improving new or existing care tools (i.e. care plans; care approaches; interventions)</i>	1. Staff involvement	
	1.1	Team meetings to develop a new care approach (n=1)
	1.2	Cooperation between nurses and a specific committee to modify care plans and identify new interventions (n=1)
	1.3	Team meetings to discuss and develop a new care plan (n=1)
<i>Participation of both care providers and family carers in the quality improvement process by cooperating to reach specific care goals</i>	2. Staff and family caregivers involvement	
	2.1	Family participation in professionals' care plans meetings (n=1)

	2.2	Nurses and relatives asked to assess patients' burden symptoms and communication (n=1)
<i>Residents directly involved in the care planning process by discussing care goals with them or observing their behaviours</i>	3. Patients involvement	
	3.1	Care plans' discussion between the resident, his/her family caregiver and family physician (n=1)
	3.2	Residents' observation and /or interviews (n=4)
PROFESSIONAL-ORIENTED INTERVENTIONS		
<i>Implementation of a completely new ICT system or embedment into an existing system</i>	4. ICT implementation	
	4.1	Implementation of a new electronic documentation system (n=3)
	4.2	ICT tools' incorporation into the existing documentation system (n=4)
<i>Audit to guide the quality improvement process and implement new care practice</i>	5. Audit	
	5.1	Staff training in the use of audit tools (n=1)
	5.2	Audit to assess best/current practice (n=2)
	5.3	Audits' outcomes provided to staff to change practice (n=1)
<i>Education that addresses aspect related to care (written) documentation</i>	6. Training on documenting	
	6.1	Education to implement a new documentation model (n=1)
	6.2	Education on the system of reporting, writing style and care contents (n=1)
<i>External educators/supervisors support care providers during the quality improvement process by supervising them or providing them with feedback</i>	7. External feedback and supervision	
	7.1	Corporate officers' supervision (n=1)
	7.2	Training and supervision provided by nurse educators (n=1)
	7.3	Feedback by visiting professionals (n=1)

sources were divided into subgroups according to a logical system that facilitates analysis (data reduction). In fact, based on the type of intervention, two subgroups were identified. Secondly, data tables were elaborated and, starting from the specific implementation strategy used in each intervention study, codes were generated (data display). Thirdly, links were determined (data comparison) and codes were combined in categories. Table 1 provides an overview of the codes and categories identified. Eventually findings were summarized into a new conceptualization of the topic (conclusion drawing and verification) describing the overall impact of the implementation strategies identified on the residents' care plans.

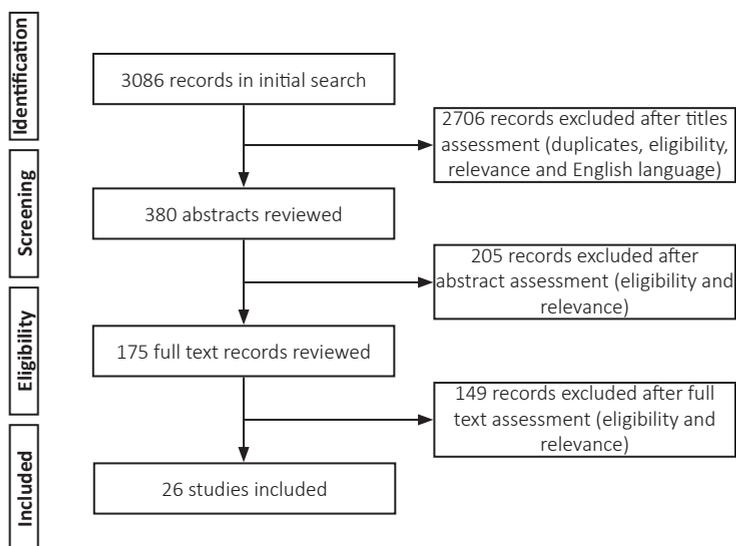
Methodological assessment quality

The quality of included publications was assessed using Mixed Method Appraisal Tool (MMAT) version 2011, designed for the appraisal stage of complex systematic literature reviews that include qualitative, quantitative and mixed methods studies [24]. The overall qualitative score of each retained study is presented using the MMAT descriptors, i.e. the number of stars obtained by applying the tool (Table 2). Scores can vary from 25% (*), when one methodological quality criterion is met, to 100% (****) when all criteria are met.

Results

Using the mentioned exclusion and inclusion criteria, 26 studies were identified and included in the present review (Figure 1). Two of these were qualitative, three mixed-methods and 21 quantitative. Table 2 provides an overview of the characteristics of included studies and the related MMAT scores. Studies were conducted in both non-European (USA, Australia, Taiwan, Japan, Brazil) as well as European countries (The Netherlands, Sweden, UK, Norway).

Applying the methodological framework by Whitemore and Knaf [23], we identified two subgroups based on the type of intervention: the stakeholders involvement subgroup, which includes interventions that imply the direct involvement of stakeholders (i.e. healthcare professionals, residents and family carers) in the quality improvement process, and the professional-oriented interventions subgroup, which includes interventions targeted at professionals, to provide them with tools or support during the process (e.g. education, feedback, audit). Within these subgroups, seven categories were identified: three (professional care providers, care providers and family caregivers and patients' involvement) pertaining to the first subgroup and four (ICT implementation, audit, training, feedback and supervision) to the second one. Then, following the three aims that guided the present review, each intervention was described by specifying the core elements of the implementation of changes in nursing home residents' care plans, that is the type of stakeholders involved, the implementation strategies used and how care plans changed, checking whether they resulted in being more comprehensive, accurate or individualized.

Figure 1 Flow chart depicting study selection process

Stakeholders involvement

Professional care providers' involvement

As described in Table 1, this category includes those studies in which care providers participated in the quality improvement process. Three papers [25-27] belong to this category. Studies by Teresi et al. [25] and Hampton et al. [26] aimed to improve documentation and care provision of the targeted problem. The first study aimed to train staff on how to prevent episodes of resident-to-resident mistreatment describing risk factors, such as dementia. The second one aimed to decrease antipsychotic medication occurrences by preventing and predicting disruptive behaviours that may occur in residents with dementia (Table 2). They both delineated the process through which staff, by means of team meetings or coordinated work, developed and implemented a different care approach that resulted in better care documentation. The study by Teresi et al. showed a significant increase in the reporting of the targeted problem by staff ($p < 0.001$), whereas Hampton et al. didn't collect data on reporting but described the supplement form developed to enhance the residents' care plan. However, the methodological quality of these interventions, as measured by the MMAT, was moderate (**) and low (*) respectively. The staff involved in the third study [27] supported the development and implementation of a completely new care plan, which was aimed to reflect all care aspects and needs of residents. Yet, no information was provided on whether and how the new model was implemented in the investigated nursing home and no criteria of the MMAT were met (Table 2).

Table 2 Description of studies

<u>Source</u> (first author, year, Country)	<u>Research methods</u>	<u>Intervention</u>	<u>Implementation strategies</u>	<u>Assessment</u> (care plan-related)	<u>Impact</u>	<u>Overall quality score (MIMAT)</u>
Stakeholders involvement						
Teresi, 2013 USA [25]	Quant.	To evaluate the impact of a training for nursing staff on knowledge, recognition and reporting of resident-to-resident mistreatment (R-REM)	Team meeting to discuss R-REM behaviors to develop a treatment approach that would become part of a resident's care plan; training to staff	R-REM instruments for recognition and documentation	Higher level of recognition and documentation of R-REM ($p < 0.001$)	**
Hampton, 2014 USA [26]	Quant.	To develop and implement a rapid cycle improvement process targeted at gradual dose reductions in antipsychotic	New committee settled within the facility and worked directly with the division charge nurses to modify the care plans so as to identify non-pharmacological interventions to enhance behavior management	Analysis of the Antipsychotic Medication Review Form that was placed in the residents' record: it contains information on medication and non-pharmacological interventions performed	Developed resident care plan supplement form Gradual dose reduction as documented in the record	*
Costa Santos, 2010 Brazil [27]	Qual.	To develop a medical record for residents in a long-stay institution for the elderly	Team meetings to discuss the purpose and composition of the record. The resident's record model was composed of medical, nursing, cognitive, affective, functional and cognitive assessment	Not clear. Some items such as application time and feasibility of questions were verified. No other info about how they were assessed	The model was implemented in the investigate Home for the Aged meeting its needs and the ones of the research group	/

Dijkstra, 2007 The Netherlands [28]	Mixed-method	To promote and evaluate family involvement during care plan meetings	Data collected from care plan meetings held on different wards in which family members participated for the first time: focus on roles of family members, communication and participation	No specific impact on care documentation	By including family members in the care plan meetings, nurses responsible for relatives' care indicated their role in the development of the care plan has been strengthened; doubts of family carers about the implementation of the information into care plans.	***
Veerbeek, 2008 The Netherlands [29]	Quant.	To study the effect of the Liverpool Care Pathway (LCP) on the documentation of care, symptom burden and communication	Implementation of a standardized registration method to monitor physical, psychosocial and spiritual care. It involves both formal and informal caregiver	The degree to which care during the dying phase was documented in writing	Improvements in documentation modest but evident: 8 aspects of care were significantly more often documented in the intervention period ($p < 0.05$)	***
Boorsma, 2011 The Netherlands [30]	Quant.	To determine the effects of multidisciplinary integrated care on residents' quality of care and quality of life	Geriatric assessment and individualized care plan developed and discussed with the resident, the resident's family, the family physicians to be adapted; training to staff	Numbers of agreed on medical, nursing and social actions, based on content analysis of care plans (process outcomes)	Significant improvement in the quality of care provided ($p = 0.07$) and higher number of actions on care plan (medical, nurse care, referral to medical specialist, medication change)	****

Jordan, 2013 UK [31]	Quant.	To explore feasibility and clinical impact of nurse-led medication monitoring	Implementation of the nurse-led medication monitoring profile that requires residents' observation and interviews; review of the records	Clinical gains: new problems identified, changes in medication regimens, number of new care plans in place	More new problems monitored; some therapeutic regimens revised; 8 new care plans in place	****
Noguchi, 2013 Japan [32]	Quant.	To examine the effects of staff training programs for managing behavioral and psychological symptoms of dementia (BPSD)	Implementation of the antecedent-behavior-consequence analysis that requires residents' interviews and observations; care staff training; individualized care plans implementation and feedback	Not specific on care documentation	Two individualized care plans developed	/
Degenholtz, 2014 USA [33]	Quant.	To describe the development and testing of a tailored assessment and care planning process for improving the quality of life (QoL) of nursing home residents	Residents' interviews using QoL questionnaires; answers used to develop QoL care plans; plans placed in the department order book	Care plans were categorized based on the domain area of the issue that was being addressed (functional competence, activities, comfort, food, relationships, religion, security, individuality)	Number of individualized QoL care plans developed in each domain addressed	*
Heiker, 1999 USA [34]	Qual.	To demonstrate how the function of storytelling can be applied in LTC settings and incorporated into the resident's care plan	By listening to an elder's story, a health care provider identifies emerging themes and incorporate them into a personalized care plan	Analysis of the themes emerged during storytelling of the case study presented	Analysis of Patricia's care plan. Professionals set into motion a personalized care plan incorporating meaningful activities after having heard her story and assessed her needs	/

Professional-oriented interventions

Munyisia, 2012 Australia [35]	Mixed-method	To determine the impact of the introduction of an electronic documentation system on care staff members' documentation efficiency	Implementation of a new electronic documentation system; training to staff; comparison with the written procedures	Quantitative analysis of time spent on documentation; qualitative analysis of professionals' satisfaction interviews	Lack of time-saving: proportion of time spent on documentation significantly higher ($p < 0.01$)	***
Daly, 2002 USA [36]	Quant.	To compare the effects of 2 ways of documenting clinical decisions on patients' outcomes (level of care, medication etc.), organizational processes (number of nursing diagnosis, activities etc.).	Implementation of a new computerized system; training to staff; comparison with the written procedures	Number of nursing diagnosis, interventions, activities, time spent on care plan preparation	Computerized care plans more comprehensive: more activities and interventions listed ($p = .001$ and $p = .007$); lack of time-saving	****
Shu-Hui, 2009 Taiwan [37]	Quant.	To develop and implement a new computerized nursing process support system	Implementation of a new computerized system; comparison with original hand-written documentation; training to staff	Quantitative analysis of time spent on documentation; quantitative analysis of satisfaction questionnaires given to professionals	Improved satisfaction in relation to completeness ($p = .006$), organization ($p = .004$) and consistency ($p = .01$) of the nursing records; time-saving	***
Fossum, 2013 Norway [38]	Quant.	To investigate a computerized decision support system (CDSS) and educational program for nursing documentation practice on pressure ulcers (PUs) and malnutrition	CDSS embedded in the existing electronic medical record; training to staff	Documentation audit	More complete and comprehensive documentation of PUs and malnutrition: increase in the number of care indicators reported in the records ($p = .02/.002$)	**

Wagner, 2008 USA [39]	Quant.	To improve the post-fall assessment by using a new reporting system	Use of the computerized form and report of the outcomes in the residents' care plans	Documentation audit	Improved post-fall assessment and documentation of care processes in resident's records ($p < 0.001$)	***
Hansebo, 1999 Sweden [40]	Quant.	To compare nursing care documentation in nursing home wards before and after one year of supervised intervention	Use of RAI/MDS to be incorporated to the existing documentation systems of the wards; training to staff	Number of daily notes and nursing care plans; analysis of their content and structure	Nursing care plan written for all patients; daily notes increased; item related to the psychosocial area less frequently reported	**
Colon-Emeric, 2009 USA [41]	Quant.	To develop order entry algorithms for common problems, to test effects on quality indicators and resource utilization	Use of the algorithm; training to staff	Differences in the selected quality indicators abstracted from the resident's record; quantitative analysis of the satisfaction survey of professionals	Quality improvement in six of the nine measures; no change in resource utilization; staff enthusiastic but during practice computerized order entry algorithm used infrequently	***
Fallon, 2006 Australia [42]	Mixed-method	To introduce evidence-based oral hygiene practice for patients with dementia and identify barriers and facilitators	Staff were trained in the use of oral audit tools; education sessions to introduce best practice; changes to oral hygiene via care plans	Pre-intervention oral audits; care plan ratings	Care plans at facility A were of better quality and more comprehensive ($p < .001$); no improvements at facility B	*

Knox, 2007 Australia [43]	Quant.	To implement a change process using a system of audit and feedback as a means to safely reduce restraint use	Two audits to assess five best practice criteria about organizational documentation and staff education (criterion 1 is care plan-related); identify barriers to achieving 100% compliance with all five criteria; education for staff	Audit to assess the effectiveness of the changes	Decrease in the level of compliance with criterion 1 at site A e no change at site B	***
Heckenberg, 2008 Australia [44]	Quant.	To evaluate, improve and ensure best practice in continence management	Audit of the current practice, improvement of the adherence to best practice and delivery of individualized care plans	Assessment of the level of compliance with each audit criteria in nursing care plans located in residents' file	100% compliance with all audit criteria in audit 1 and 2 was not achieved, there was improvement in the criteria concerning the documented fluid intake for residents	**
Watson-Wolfe, 2014 USA [45]	Quant.	To test the utility of an educational in-service to facilitate the appropriate use of antipsychotics for nursing home residents with dementia	Staff were provided with the results of the first records' audit along with additional education on antipsychotic use	Medical record audit	Increase of nursing documentation of non-pharmacological interventions	**
Ehrenberg, 1999 Sweden [46]	Quant.	To describe the effects on the contents and comprehensiveness of the nursing-care documentation in the patient following an educational intervention	Educational programme based on a specific model for the documentation of nursing care	Records audit	Number of notes more than doubled; significantly increased the reporting of nursing diagnosis, goals, planned and implemented interventions, discharge notes	**

Schrijnemaekers, 2002 The Netherlands [47]	Qual.	To gain insight into compliance with the introduction of a new emotion-oriented care model (EOC)	The EOC is a psychosocial care model for cognitively and behaviorally impaired elderly people. Training to staff on EOC also addressed the system of reporting, the style of writing and the content of a resident-oriented care plan	Analysis of the care plans' content and style; compliance to the model based on the extent to which the relevant aspects of the model can be retrieved from the written reports placed in the plans	No clear differences in the content of reports between the intervention and control homes. All reports brief and lack of information on the behavior	****
Rask, 2007 USA [48]	Quant.	To evaluate the feasibility and effectiveness of a falls management program (FMP)	Development of organizational support and facility preparation to implement the program; training to staff; supervision of corporate officers	Medical record audit	Care process documentation related to the assessment and management of fall risk improved significantly	***
Goldman, 2004 USA [49]	Quant.	To describe the involvement of nurse educators in the implementation process of best care practices	Training to staff by nurse educators on three care protocols (ADL, pain and depression protocol); supervision on care plans	Not specific on care documentation	More sensitive care planning but no information specific on care plans	/
Butterworth, 2003 UK [50]	Quant.	To pilot test the use of a care planning and documentation system	Implementation of the system; training to staff; supervision for the care plan completion	Monthly audit, review, questionnaire surveys and informal feedbacks from visiting professionals	More informative records than before the intervention	/

Professional care providers and family caregivers' involvement

The studies included in this category described the collaboration between care providers and family carers to improve specific care aspects. Specifically, two studies [28, 29] actively involved both professionals and family caregivers in the improvement process. The first one [28], in order to promote family participation in care planning, involved family carers in care plan meetings that were usually organized and attended only by the staff responsible for the treatment and care of residents. However, it was not reported exactly how care plans changed after the intervention. Only the nurses' perception about the strengthening of their roles in the development of residents' care plans and the doubts of family carers on the implementation into the plans of the issues discussed during the meetings were reported. The second one [29] studied the effect of the implementation of a standardized registration method to be used with patients for whom the dying phase had started. The method required an assessment by both nurses and relatives on documentation, symptom burden and communication between patients, professional caregivers and family. Documentation of care during the dying phase increased in all involved settings, showing that some aspects of care were significantly more often documented in the intervention period ($p < 0.05$). Both papers had good methodological quality parameters (***)

Patients' involvement

This category includes studies that actively involved not only staff and family caregivers, but also the elderly persons themselves. In fact, five papers [30-34] described interventions in which the improvement process was also based on the residents' inputs by observing or interviewing them, or by directly involving them in the care planning process. The latter case occurred in the study by Boorsma et al. [30], that depicted the implementation of a multidisciplinary integrated care model to guide the design of individualized care plans. The plans developed were then adapted to personal wishes by discussing it with the resident, the family carers as well as the general practitioner. The majority of the involved residents were affected by cognitive impairment (58.2%). Content analysis of care plans was performed: it emerged a significant improvement in the reporting of the number of actions on care plans and in the quality of care provided as perceived by the residents themselves ($p = 0.07$). The other three papers [31-33] described the implementation of tools or care models that required direct observations of or interviews with residents. Such approaches were used to obtain information to address specific problems or care areas (medication monitoring for people with dementia, managing behavioural and psychological symptoms of dementia and improving the quality of life of nursing home residents, respectively) and consequently to develop individualized care plans. All interventions reported the number of the new individualized care plans developed and put in place. However, one paper did not provide specific information on the care plan assessment [32]. Another intervention [34] used the function of storytelling to be incorporated in the care plan to make it more meaningful for the resident. It introduced a

qualitative case study and the adaptation of the care plan based on the residents' personal information. However, it is important to underline the apparent lack of quality of these intervention studies. In fact, only two of them [30, 31] obtained a very high methodological quality score (****), one study [33] a low score (*) and the remaining two [32, 34] didn't meet any MMAT methodological quality criteria.

Professional-oriented interventions

Implementation of Information and Communication Technology tools

Seven studies implemented Information and Communication Technology (ICT) tools [35-41]. All studies but one [39] specified that the main implementation strategy used was the provision of education targeted at staff to instruct them on how to use ICT tools.

Three studies [35-37] described the implementation of a new computerized documentation system and compared it with the previously hand-written procedures. Munyisia et al. [35] revealed a lack of time-saving for staff in using the new systems that hindered realization of documentation efficiency: twelve months after implementation, the proportion of time spent by caregivers on documentation was significantly higher than when the paper-based system was used ($p < 0.01$). Equally, Daly et al. [36] showed that the new computerized care plan took longer to be completed. However, the implementation of the system resulted in the improvement of care documentation's comprehensiveness, as a significant effect was found in the experimental computerized care plan group in relation to nursing interventions and activities listed ($p = .001$ and $p = .007$). On the other hand, Shu-Hui et al. [37] showed that nurses saved time in preparing the computerized documentation, as they were able to complete a more comprehensive care plan within 48 hours after admission, and that they were significantly satisfied in relation to completeness ($p = .006$), organization ($p = .004$) and consistency ($p = .01$) of the nursing records. The remaining studies [38-41] embedded an ICT tool into the existing care plan format or reporting system. In three studies, the tool implementation positively resulted in a more complete documentation [38-40]. Specifically, Fossum et al. [38] analysing the effects of a computerized decision-support system on residents' pressure ulcers and malnutrition, showed a significant increase in the number of related care indicators reported in the records ($p = .02$ and $p = .002$ respectively). Similarly, Wagner et al. [39] which involved also residents with dementia (64.7%), showed that the implementation of the falls incident reporting system resulted in more complete documentation ($p < 0.001$). Yet, contrary to the other studies included in this category that identified staff education as the main strategy to embed the systems in the care homes, this one just described that the form was routed to the care planning nurse to update the residents' care plans. Hansebo et al. [40] implemented the Resident Assessment Instrument/Minimum Data Set in nursing home wards that housed patients with dementia. The tool gave a comprehensive assessment of the resident and increased the percentage

of daily notes and nursing care plans, but aspects such as psychosocial well-being, activities, mood and behaviour were still infrequently reported [40]. However, in these studies no specific information on how extensively the staff used the ICT device could be retrieved. Another study [41], in which a computerized algorithm for geriatric problems was developed and tested, revealed that the ICT tool was used infrequently by nursing home providers during daily practice except for falls, even if they all agreed that it improved patients' care and saved time. Many involved residents were affected by cognitive impairment (55.4%). The overall methodological quality of these papers, as measured by MMAT, varied from moderate to very high (scoring from ** to ***).

Audit as a guide for the improvement process

In four studies [42-45] auditing was used not only as a tool to assess the effects of the intervention, but also as a model to guide the improvement process. All papers contained the scheme or the reference to the audit tool used within the nursing homes and the description of the following implementation process that introduced changes via care plans. In particular, three studies [42-44] used audit tools to guide the implementation of best practices in the provision of care. In the study by Fallon et al. [42], staff were trained in the use of audit tools designed to be administered directly to residents with dementia in the pre intervention phase with the aim to implement oral health recommendations: care plans were rated after the intervention and appeared to be of better quality and more comprehensive in one facility ($p < .001$) but not in the other one. Yet, this result should be considered with caution as, unlike the other studies of this category, the methodological score of this intervention is low (*). On the other hand, in the other two studies [43, 44] audit tools were used pre and post intervention to determine the level of compliance with the audit criteria in care plans in relation to physical restraint use and continence management respectively. Both studies involved residents with dementia. Findings were controversial, as the level of compliance varied across criteria or involved settings due to management and organizational issues. One purpose of the quality improvement project described by Watson-Wolfe et al. [45] was to test the utility of an educational in-service to facilitate the use of antipsychotic in dementia that was guided by an audit tool commonly used in LTC practice: an increase in the percentage of nursing documentation of non-pharmacological interventions was shown.

Training on documenting and reporting

The papers included in this category [46, 47] presented the implementation of nursing models that included specific training on how to document and report residents' information into care plans. Both studies concerned written procedures, not computerized ones, and respectively had moderate (**) and very high methodological quality (****). In one study [46], that aimed to describe the effects of an educational training on care documentation's content and comprehensiveness, significant improvements were shown, being increased numbers of: notes,

nursing diagnosis, status, goals, outcomes, interventions planned and implemented, and discharge notes (p varies from $< .0001$ to $= .05$). However, the content of the records usually reflected the nurses' judgment rather than the residents' description of symptoms. This was attributed to the language impairment that affected some of the involved residents, in particular those suffering from dementia. In contrast to these findings, the second paper [47], where the educational training on the use of an emotion-oriented approach in the care for residents with dementia also addressed the system of reporting and style of writing, did not observe any differences between intervention and control homes, as reports were still brief and incomplete.

External feedback and supervision

Three intervention studies [48-50] addressed feedback and supervision by appointing external professionals to give support to staff members involved in the quality improvement project. In the project by Rask et al. [48] on the implementation of a fall management program, staff attended an intensive training and a geriatric nurse practitioner and a nurse educator gave support to the facilities through monthly teleconferences during program implementation. The implementation strategy used seemed to be effective, as care process documentation significantly improved in many aspects (p varies according to the aspect of care documentation considered). Nurse educators were also involved in the study by Goldman et al. [49], that aimed to implement three best practice protocols (prevention of decline in the activities of daily living of eating and dressing; recognition of pain symptoms especially in cognitive impaired residents or with communication difficulties; depression). Educators acted as consultants, observing pattern of communication and providing feedback, suggestions or concerns related to care plans. It emerged that the program led to a more sensitive care planning, but no detailed information on care plans was provided. In another study [50] the implementation of a new care planning system included consultation, advice and support from external colleagues and experts. After the intervention, all nursing homes involved in the project turned out to produce more informative nursing records, but no specific data could be retrieved in the paper. Only one study [48] fulfilled all quality criteria as defined by the MMAT (***) , whereas the other two didn't meet them.

Discussion

This integrative review in which 26 articles were included showed that professional care providers, family caregivers and patients were involved in studies concerning elderly residents' care plans. However, in only five of the included studies [30-34] residents were directly involved in the quality improvement process and the family caregivers in only two [28, 29].

The majority of studies [25-27, 29, 31, 36-50] used more than one strategy, such as staff education to the introduction of ICT tools, staff, families and patients involvement in the care planning process, external feedback, supervision and audit

tools to implement the interventions in nursing homes. All these studies focused on the quality of care documentation, indicating that after the intervention was implemented, care plans were more informative, complete and updated. Specifically, the improvement in the care process documentation consisted of an increase in the number of items listed, such as care goals, medication charts, activities, progress and daily notes or, possibly, the revision of the information reported. Thus, these interventions complied with specific care planning requirements and guidelines, as documentation must be accurate, complete, provide evidence of the care given and document changes in the resident's condition [51]. To assess such quality of care documentation, interventions were guided by measurable objectives or quality indicators that could be easily identified and retrieved in the care plans. Similarly, interventions in which the improvement process were guided by specific audit tools and that assessed whether the newly developed care plans met specific criteria, demonstrated increased levels of compliance with documentation and with organizational criteria and the improvement in the implementation of nursing best practices [42-45].

Four studies used implementation strategies that required the direct involvement of residents [32-34] and of all stakeholders at the same time, i.e. residents, family caregivers and professionals [30]. These studies referred to the post-intervention care plans as being more individualized, that is, based on the residents' personal characteristics, experiences and needs. Consistent with the vision of person-centered care that focuses on individuality and care being organized to meet the person's needs [52], these interventions aimed to develop care plans that reflected the residents' personal history, habits in the residential setting and wishes. It is important to highlight that these studies shared the same implementation strategy: in fact, they all involved the residents in the care planning process by observing or interviewing them. Yet, only one of these interventions [30] showed a higher number of actions listed in the new individualized care plan developed. The others [32-34] were less specific, delineating the general care areas addressed in the personalized plan. This issue also accounts for their lower methodological quality score.

Only four studies seemed to be not effective: two of them referred to the implementation of ICT tools [35, 41] showing a lack of documentation efficiency by using the computerized system and its infrequent use by staff respectively. This is in line with recent literature on the adoption of electronic health records, that identifies the disruption of clinical practice and the staff acceptance as major limits to their implementation [53, 54]. Despite this evidence, it is interesting to note that only three studies [35, 37, 41] administered specific questionnaires or surveys to assess staff satisfaction about the implementation of the ICT tools. Another intervention [47] that aimed to implement a new care model and reporting system, showed no clear differences in the content of the residents' reports, that appeared to be still brief and incomplete. Different staff expectations and organizational obstacles were cited as the main barriers to the implementation of the intervention. Eventually, due to the change of the setting's organizational policy, one site

involved in an intervention study showed no compliance with specific care plans' criteria [43]. Thus, it emerged that obstacles related to the organizational context were the main reasons for interventions not being effective in changing care plans. Specifically, staff constraints and change at the policy or management level occurred during the interventions.

Indicators for the quality of care provided in LTC settings highlight the importance of involving the older persons with and without cognitive impairment in the assessment of their preferences and needs as well as reporting in their care plan tailored interventions together with usual and standardized care [20, 55, 56]. However, only few papers explicit the direct involvement of the residents in the care planning process as well as the sharing of the care plan between the resident, the professional and the family caregiver. Furthermore, all interventions analysed in the present review that also included persons with dementia, didn't make any distinction between the care plans of cognitively intact and impaired residents. This is in line with the fact that the care plan's format is traditionally the same for both groups of nursing home residents. Only one study [46] underlined that due to cognitive deficits, the care plans' content of residents with dementia reflected the nurses' observation and judgment rather than the residents' description of symptoms. Considering that the demand for LTC services for people with dementia is increasing worldwide and that international recommendations promote the delivery of an adequate long-term care plan in order to ensure a good quality of life throughout the dementia journey, it becomes crucial to involve cognitive impaired residents, who are the majority of clients of these services, and to develop care plans that accurately describe their special needs [57].

Another finding is that when studies focus on the reporting of residents' personal needs and wishes in their care plans, their methodological score is often not high, due to the lack of measurable items to be retrieved in the tailored documentation. This is in line with the finding that there is more evidence on professional-oriented interventions than on those interventions that involve patients or the organization [22]. Furthermore, it seems that no identification of barriers and facilitators had been performed prior to the implementation of the quality improvement interventions, even if it is a fundamental prerequisite for effective initiatives to changing clinical practice [58, 59].

Strengths and limitations

This review can be used by both clinicians and researchers to inform future interventions and research on the improvement of care plans, identifying effective implementation strategies and key elements that may influence the process. However, some limitations should be taken into account. First, our aim was to present an overview of the type of stakeholders involved and implementation strategies used, without assessing effects estimates or risk of bias in included studies. As a result, the effects of the interventions just described should be interpreted with caution. Secondly, as typical for an integrative review, the studies identified and discussed are heterogeneous, addressing different medical, psychosocial and

organizational conditions. However, we were only interested in the implementation strategies used and how they changed care plans.

Conclusion

The care plan document should provide both individualized and standardized interventions. However, our findings showed that quality improvement projects in nursing homes often did not meet such care plans requirements. Thus, efforts should be made to develop standardized documentation that it is also tailored to the resident's cognitive functioning, needs and personal wishes and that can be reported in the care plans as measurable items such as quality indicators. This can be done by both directly involving the residents in the care planning process and adopting implementation strategies and tools which guide professionals to efficiently reporting the care goals and actions in the residents' care plan. This would allow care plans to be more informative and individualized at the same time and research interventions to be more methodologically robust. Furthermore, considering that the main barriers to the improvement projects were obstacles related to the organizational context and to a lack of satisfaction by professionals about the tools implemented, it seems necessary to involve both the staff and the management to effectively change care plans and improve the care planning process.

References

- [1] Colón-Emeric CS, Lekan-Rutledge D, Utley-Smith Q, Ammarell N, Bailey D, Piven ML, Corazzini K, Anderson RA (2006) Connection, regulation, and care plan innovation: a case study of four nursing homes. *Health Care Manage Rev* **31**, 337–346.
- [2] Sprangers MA, de Regt EB, Andries F, van Agt HM, Bijl RV, de Boer JB, Foets M, Hoeymans N, Jacobs AE, Kempen GI, Miedema HS, Tijhuis MA, de Haes HC (2000) Which chronic conditions are associated with better or poorer quality of life? *J Clin Epidemiol* **53**, 895–907
- [3] Strawbridge WJ, Shema SJ, Balfour JL, Higby HR, Kaplan GA (1998) Antecedents of frailty over three decades in an older cohort. *J Gerontol B Psychol Sci Soc Sci* **53**, S9–16.
- [4] Chappell NL, Reid RC, Gish JA (2007) Staff-based measures of individualized care for persons with dementia in long-term care facilities. *Dementia* **6**, 527–547.
- [5] Happ MB, Williams CC, Strumpf NE, Burger SG (1996) Individualized care for frail elders: theory and practice. *J Gerontol Nurs* **22**, 6–14.
- [6] Dellefield ME (2006) Interdisciplinary care planning and the written care plan in nursing homes: a critical review. *Gerontologist* **46**, 128–133.
- [7] Burt J, Roland M, Paddison C, Reeves D, Campbell J, Abel G, Bower P (2012) Prevalence and benefits of care plans and care planning for people with long-term conditions in England. *J Health Serv Res Policy* **17**, 64–71.
- [8] Jefferies D, Johnson M, Griffiths R (2010) A meta-study of the essentials of quality nursing documentation. *Int J Nurs Pract* **16**, 112–124.
- [9] American healthcare Association (2005) *Appendix PP: Guidance to surveyors for long-term care facilities part II*, Washington, DC: Author.
- [10] Keenan GM, Yakel E, Tschannen D, Mandeville M (2008) Documentation and the Nurse Care Planning Process. In *Patient Safety and Quality: An Evidence-Based Handbook for Nurses*, Hughes RG, ed. Agency for Healthcare Research and Quality (US), Rockville (MD).
- [11] Kontos PC, Miller K-L, Mitchell GJ (2010) Neglecting the importance of the decision making and care regimes of personal support workers: a critique of standardization of care planning through the RAI/MDS. *Gerontologist* **50**, 352–362.
- [12] Bates-Jensen BM, Cadogan M, Osterweil D, Levy-Storms L, Jorge J, Al-Samarrai N, Grbic V, Schnelle JF (2003) The minimum data set pressure ulcer indicator: does it reflect differences in care processes related to pressure ulcer prevention and treatment in nursing homes? *J Am Geriatr Soc* **51**, 1203–1212.
- [13] Schnelle JF, Cadogan MP, Yoshii J, Al-Samarrai NR, Osterweil D, Bates-Jensen BM, Simmons SF (2003) The minimum data set urinary incontinence quality indicators: do they reflect differences in care processes related to incontinence? *Med Care* **41**, 909–922.
- [14] Voutilainen P, Isola A, Muurinen S (2004) Nursing documentation in nursing homes--state-of-the-art and implications for quality improvement. *Scand J Caring Sci* **18**, 72–81.
- [15] Broderick MC, Coffey A (2013) Person-centred care in nursing documentation. *Int J Older People Nurs* **8**, 309–318.
- [16] Lee RH, Bott MJ, Gajewski B, Taunton RL (2009) Modeling efficiency at the process level: an examination of the care planning process in nursing homes. *Health Serv Res* **44**, 15–32.
- [17] Rantz MJ, Hicks L, Grando V, Petroski GF, Madsen RW, Mehr DR, Conn V, Zwygart-Staffacher M, Scott J, Flesner M, Bostick J, Porter R, Maas M (2004) Nursing home quality, cost, staffing, and staff mix. *Gerontologist* **44**, 24–38.
- [18] Long-term care in the European Union, *European Commission*, <http://ec.europa.eu/social/BlobServlet?docId=2781&langId=en>, Accessed May 5, 2015.
- [19] Joint Commission on Accreditation of Healthcare Organizations (2004a) *Comprehensive accreditation manual for long-term care*, Joint Commission Resources, Inc, Oakbrook Terrace, IL.
- [20] Saliba D, Schnelle JF (2002) Indicators of the quality of nursing home residential care. *J Am Geriatr Soc* **50**, 1421–1430.
- [21] Grol R, Grimshaw J (2003) From best evidence to best practice: effective implementation of change in patients' care. *Lancet* **362**, 1225–1230.
- [22] Grol R, Bosch MC, Hulscher ME, Eccles MP, Wensing M (2007) Planning and studying improvement in patient care: the use of theoretical perspectives. *Milbank Quarterly* **85**, 93-138.
- [23] Whittemore R, Knaf K (2005) The integrative review: updated methodology. *J Adv Nurs* **52**,

- 546–553.
- [24] Pluye P, Robert E, Cargo M, Bartlett G, O’Cathain A, Griffiths F, Boardman F, Gagnon MP, Rousseau MC (2011) Proposal: A mixed methods appraisal tool for systematic mixed studies reviews <http://mixedmethodsappraisaltoolpublic.pbworks.com>, Accessed April 1, 2015.
- [25] Teresi JA, Ramirez M, Ellis J, Silver S, Boratgis G, Kong J, Eimicke JP, Pillemer K, Lachs MS (2013) A staff intervention targeting resident-to-resident elder mistreatment (R-REM) in long-term care increased staff knowledge, recognition and reporting: results from a cluster randomized trial. *Int J Nurs Stud* **50**, 644–656.
- [26] Hampton JK, Reiter T, Hogarth J, Doerr J, Bohack K, Popejoy L (2014) Using FOCUS PDSA to improve antipsychotic medication management. *J Nurs Care Qual* **29**, 295–302.
- [27] Santos SSC, Valcarenghi RV, Barlem ELD, Silva BT da, Hammerschmidt KS de A, Silva ME da (2010) Development of a medical record for residents in a long-stay institution for the elderly. *Acta Paulista de Enfermagem* **23**, 725–731.
- [28] Dijkstra A (2007) Family participation in care plan meetings: promoting a collaborative organizational culture in nursing homes. *J Gerontol Nurs* **33**, 22–29.
- [29] Veerbeek L, van Zuylen L, Swart SJ, van der Maas PJ, de Vogel-Voogt E, van der Rijt CC, van der Heide A (2008) The effect of the Liverpool Care Pathway for the dying: a multi-centre study. *Palliat Med* **22**, 145–151.
- [30] Boorsma M, Frijters DHM, Knol DL, Ribbe ME, Nijpels G, van Hout HPJ (2011) Effects of multidisciplinary integrated care on quality of care in residential care facilities for elderly people: a cluster randomized trial. *CMAJ* **183**, E724–732.
- [31] Jordan S, Gabe M, Newson L, Snelgrove S, Panes G, Picek A, Russell IT, Dennis M (2014) Medication monitoring for people with dementia in care homes: the feasibility and clinical impact of nurse-led monitoring. *ScientificWorldJournal* **2014**, 843621.
- [32] Noguchi D, Kawano Y, Yamanaka K (2013) Care staff training in residential homes for managing behavioural and psychological symptoms of dementia based on differential reinforcement procedures of applied behaviour analysis: a process research. *Psychogeriatrics* **13**, 108–117.
- [33] Degenholtz HB, Resnick AL, Bulger N, Chia L (2014) Improving quality of life in nursing homes: the structured resident interview approach. *J Aging Res* **2014**, 892679.
- [34] Heliker D (1999) Transformation of story to practice: an innovative approach to long-term care. *Issues Ment Health Nurs* **20**, 513–525.
- [35] Munyisia EN, Yu P, Hailey D (2012) The impact of an electronic nursing documentation system on efficiency of documentation by caregivers in a residential aged care facility. *J Clin Nurs* **21**, 2940–2948.
- [36] Daly JM, Buckwalter K, Maas M (2002) Written and computerized care plans. Organizational processes and effect on patient outcomes. *J Gerontol Nurs* **28**, 14–23.
- [37] Yeh S-H, Jeng B, Lin L-W, Ho T-H, Hsiao C-Y, Lee L-N, Chen S-L (2009) Implementation and evaluation of a nursing process support system for long-term care: a Taiwanese study. *J Clin Nurs* **18**, 3089–3097.
- [38] Fossum M, Ehnfors M, Svensson E, Hansen LM, Ehrenberg A (2013) Effects of a computerized decision support system on care planning for pressure ulcers and malnutrition in nursing homes: an intervention study. *Int J Med Inform* **82**, 911–921.
- [39] Wagner LM, Capezuti E, Clark PC, Parmelee PA, Ouslander JG (2008) Use of a falls incident reporting system to improve care process documentation in nursing homes. *Qual Saf Health Care* **17**, 104–108.
- [40] Hansebo G, Kihlgren M, Ljunggren G (1999) Review of nursing documentation in nursing home wards- changes after intervention for individualized care. *J Adv Nurs* **29**, 1462–1473.
- [41] Colón-Emeric CS, Schmader KE, Twersky J, Kuchibhatla M, Kellum S, Weinberger M (2009) Development and pilot testing of computerized order entry algorithms for geriatric problems in nursing homes. *J Am Geriatr Soc* **57**, 1644–1653.
- [42] Fallon T, Buikstra E, Cameron M, Hegney D, Mackenzie D, March J, Moloney C, Pitt J (2006) Implementation of oral health recommendations into two residential aged care facilities in a regional Australian city. *Int J Evid Based Healthc* **4**, 162–179.
- [43] Knox J (2007) Reducing physical restraint use in residential aged care: implementation of an evidence-based approach to improve practice. *Int J Evid Based Healthc* **5**, 102–107.

- [44] Heckenberg G (2008) Improving and ensuring best practice continence management in residential aged care. *Int J Evid Based Healthc* **6**, 260–269.
- [45] Watson-Wolfe K, Galik E, Klinedinst J, Brandt N (2014) Application of the Antipsychotic Use in Dementia Assessment audit tool to facilitate appropriate antipsychotic use in long term care residents with dementia. *Geriatr Nurs* **35**, 71–76.
- [46] Ehrenberg A, Ehnfors M (1999) Patient records in nursing homes. Effects of training on content and comprehensiveness. *Scand J Caring Sci* **13**, 72–82.
- [47] Schrijnemaekers VJJ, van Rossum E, van Heusden MJT, Widdershoven GAM (2002) Compliance in a randomized controlled trial: the implementation of emotion-orientated care in psycho-geriatric facilities. *J Adv Nurs* **39**, 182–189.
- [48] Rask K, Parmelee PA, Taylor JA, Green D, Brown H, Hawley J, Schild L, Strothers HS, Ouslander JG (2007) Implementation and evaluation of a nursing home fall management program. *J Am Geriatr Soc* **55**, 342–349.
- [49] Goldman B, Balgobin S, Bish R, Lee RH, McCue S, Morrison MH, Nonemaker S (2004) Nurse educators are key to a best practices implementation program. *Geriatr Nurs* **25**, 171–174.
- [50] Butterworth C (2003) Evaluating a new care planning system in nursing homes. *Nurs Times* **99**, 30–32.
- [51] Peterson AM (2014) Nursing Home Medical Records: Part 2: Documentation Review. *Journal of Legal Nurse Consulting* **25**, 42–48.
- [52] Department of Health (2001) National Service Framework for Older People, HMSO, London, pp. 1-196 <http://www.doh.gov.uk/nsf/olderpeople.htm>, Accessed June 15, 2015.
- [53] Cherry BJ, Ford EW, Peterson LT (2011) Experiences with electronic health records: early adopters in long-term care facilities. *Health Care Manage Rev* **36**, 265–274.
- [54] Kruse CS, Mileski M, Alaytsev V, Carol E, Williams A (2015) Adoption factors associated with electronic health record among long-term care facilities: a systematic review. *BMJ Open* **5**, e006615.
- [55] Vasse E, Moniz-Cook E, Rikkert MO, Cantegreil I, Charras K, Dorenlot P, Fumero G, Franco M, Woods B, Vernooij-Dassen M (2012) The development of quality indicators to improve psychosocial care in dementia. *Int Psychogeriatr* **24**, 921–930.
- [56] van Riet Paap J, Vernooij-Dassen M, Droes RM, Radbruch L, Vissers K, Engels Y (2014) Consensus on quality indicators to assess the organization of palliative cancer and dementia care applicable across national healthcare systems and selected by international experts. *BMC Health Services Research* **14**, 369–378.
- [57] Prince M, Prina M, Guerchet M. (2013) World Alzheimer Report 2013. Journey of Caring: an analysis of long-term care for dementia. Alzheimer's Disease International, London <https://www.alz.co.uk/research/WorldAlzheimerReport2013.pdf>, Accessed September 8, 2016.
- [58] Grol R, Wensing M, Eccles MP (2005) *Improving Patient Care: the Implementation of Change in Clinical Practice*, Elsevier, Edinburgh.
- [59] Vernooij-Dassen M, Moniz-Cook E (2014) Raising the standard of applied dementia care research: addressing the implementation error. *Ageing and Mental Health* **18**, 809–814.

SHARED DECISION-MAKING IN
DEMENTIA CARE PLANNING:
BARRIERS AND FACILITATORS IN
TWO EUROPEAN COUNTRIES

Aging and Mental Health (2017) 21, 31-39
Special issue on Social Health

Elena Mariani,
Myrra Vernooij-Dassen,
Raymond Koopmans,
Yvonne Engels,
Rabih Chattat

ABSTRACT

BACKGROUND: Shared decision-making (SDM) is a means of allowing people with dementia to take part in making choices, be autonomous and participate in social activities. Involving them in SDM is an important way of promoting social health. However, including families and dementia residents in decision-making can be challenging for care staff working in nursing homes. The objective of this study was to identify barriers and facilitators regarding the implementation of an SDM framework for care planning in two nursing homes, one in Italy and one in the Netherlands.

METHODS: Focus group interviews were conducted with healthcare professionals who, after being trained, applied the SDM framework. Content analysis was used to analyze the data.

RESULTS: Six months after the feasibility trial, focus group interviews with healthcare professionals (n=10 in Italy; n=9 in the Netherlands) were held. We found 6 themes and 15 categories. Within these themes, facilitators and barriers were identified. The categories of team collaboration, communication skills and nursing home policy were found to be facilitators to the implementation process, whereas regulations, lack of funding and of involvement of family caregivers were the main barriers. Family attitudes towards SDM could be both. The main difference between countries concerned the residents' cognitive status that influenced their degree of involvement.

CONCLUSION: Communication skills training for professionals, training of family caregivers, and involvement of the management in the implementation process seem to be crucial factors in successfully implementing SDM in nursing homes, and increasing the involvement of families and dementia residents in decision-making.

Background

Shared decision-making (SDM) is a process wherein the healthcare professional and the patient make decisions together [1-3] and has become increasingly widespread [4]. However, SDM is not only used during medical encounters. It does have multiple definitions and applications, depending on the context in which it is used and on the people involved. Nowadays, awareness as to the potential benefits of SDM for people with dementia and their families is increasing. In fact, SDM appears to be the preferred method of allowing people suffering from dementia to participate in decision-making related to their health and daily care [5]. This process also engages both patients and their family caregivers in advance care planning [6, 7] and in making decisions within the care networks [8]. Thereby, this approach overcomes the idea that people with dementia are only passive participants in the decision-making process and are unable to express their own opinions and perspectives. This is in line with the concept of social health, which shifts the focus from disability to ability and remaining capacities, acknowledging the individual's potential to lead a good quality life [9]. Huber et al. [10], who reformulated the WHO definition of Health, delineate three dimensions of social health: the capacity to fulfil one's potential and obligations, the ability to manage life with some degree of independence, regardless of a medical condition, and participation in social activities, including work. Therefore, involving people with dementia in SDM can be seen as a way to optimize their abilities to make choices and to encourage autonomy and participation.

Specific programmes have been developed in Long-term care (LTC) settings to improve the communication and cooperation between staff and family caregivers and to facilitate families' involvement in residents' care and decision-making processes [11-16]. However, these interventions do not directly involve the residents themselves, addressing the need for cooperation and partnership between family members and professionals.

In European countries such as the Netherlands and Italy, SDM is receiving more and more attention. In the Netherlands, the involvement of family caregivers is promoted by a policy called 'family participation', while in Italy the National Health Plan points out the importance of involving citizens in decisions regarding their own care [17]. However, the use of SDM with people with dementia and their families is limited, especially in nursing homes. In fact, it is challenging for staff to involve residents in the decision-making process. This may be due to the cognitive deficits that impair the residents' ability to express their wishes [18], together with other recently described factors that have an impact on the family's involvement in decision-making [19]. These include staff attitudes and behaviour, the extent and quality of staff-family interaction, and contextual, cultural and emotional factors.

In line with the principles of social health, our intervention [17] aimed to implement an SDM framework in two nursing homes. It consisted in involving not only the staff and family caregivers in the care planning process, but also the residents themselves. SDM is considered here as an opportunity for people with dementia to express their opinion and wishes during the care planning process, so that not only

the professionals' or family caregivers' perspectives are taken into account, but also those of the residents [17]. The structured involvement of both family caregivers and dementia residents in care planning through SDM in European Long-term care (LTC) settings is not common practice. Therefore, the analysis of influencing factors experienced by professionals who implement the framework is of utmost importance in order to gather information as to the feasibility of the intervention and how it might be revised [20]. Furthermore, national and cultural-related factors were taken into account. While in Italy and in many other European countries nursing home medical care is provided by family physicians or by on-demand consulting specialists, the Netherlands is the only country that has developed a specific medical discipline, training nursing home physicians for institutionalized elderly people [21, 22]. Moreover, in Italy cultural barriers seem to interfere with decision-making and care provision, as relatives tend to adopt a more paternalistic and protective attitude towards patients and vice versa [23, 24]. The analysis of the differences between the two countries involved might provide useful information on the potential of SDM in different cultures and healthcare systems. Thus, the aim of the present study was to identify barriers, facilitators and influencing factors to the implementation of an SDM framework for care planning in two nursing homes.

Methods

For this explorative study, focus group interviews were chosen to stimulate healthcare professionals to share their opinions and thoughts about the influencing factors they experienced during the implementation of the intervention, those that, in their opinion, hindered or facilitated the implementation process [25]. The intervention is described in Box 1.

Box 1 Intervention description

The intervention was aimed at implementing an SDM framework in nursing homes. The framework consisted of different stages: firstly, professionals involved in care planning and residents' care had to attend a communication skills training course; secondly, they had to perform SDM interviews with residents with dementia and their family caregivers to identify and prioritize needs; thirdly, residents' life-and-care plans were tailored to their actual needs and preferences. Participants were compared with two other control nursing home wards. Inclusion criteria for the professionals of the intervention group who applied the framework were: (1) being a member of the multidisciplinary team; (2) being directly involved in the care planning process; and (3) being a key staff member in the provision of residents' care. Inclusion criteria for the residents and family members were that residents had a diagnosis of dementia based on DSM IV and were supported by a family caregiver who agreed to participate in the study. The Dutch nursing home, in line with its vision, and in order to avoid any sense of exclusion, tried to involve all residents with dementia living in the unit in the SDM interviews, without considering their cognitive level. In contrast, the Italian facility preferred to include only those residents with dementia with higher cognitive skills. For full details on inclusion criteria and intervention procedures, see Mariani et al. [17].

Settings

The study ran within the IMPACT project (Implementation of quality indicators in palliative care study), funded under the EU 7th framework programme. It involved

different European countries, among which Italy and the Netherlands. Given the attention SDM was receiving in both countries, as well as the existing collaboration between the two universities, the framework was developed and implemented in one Dutch and one Italian nursing home.

Nursing homes in both countries were similar in terms of the care planning process organization and regulations. In fact, care plans were composed of four main sections (Problems, Goals, Action, Evaluation) and problem areas that were primarily covered: mental and physical well-being, activities of daily living, and cognitive and social functioning. Furthermore, plans had to be developed by a multidisciplinary team after admission and signed by the professional who was in charge of the plan, the family caregiver and, if possible, the resident. Subsequently, it was compulsory for the plan to be updated once a year and when changes in the resident's condition occurred [17].

Participants

This study presented the qualitative data that emerged during the focus group interviews which were held six months after the training took place and the implementation process started. Inclusion criteria for participants who took part in the focus group interview were: having attended the communication skills training; having been involved in the implementation process of the framework. The majority of participants were healthcare assistants, followed by nurses and recreational activity assistants. Also, one nursing director and one physiotherapist were involved (for more details, see Table 1). Professionals working in the intervention nursing home wards other than those who were directly involved in the implementation process were excluded.

Data collection

Based on a literature review, a semi-structured interview guide (Appendix 1) was developed with the aim of identifying barriers and facilitators during all stages of the implementation process. Skype and face-to-face contacts between the research teams involved were used to refine the questions, which were then translated from English into the two national languages. In each country, the interviews were conducted by an experienced moderator and an assistant moderator. The interviews were recorded and transcribed verbatim.

Data analysis

In each country, the content of the focus group discussions was translated into English. Interview transcripts were coded by using conventional content analysis [26]. Firstly, the interview transcripts were read carefully. Then, meaning units that seemed to capture factors influencing the implementation process were identified and labelled with appropriate codes. Two independent researchers (EM, RC) discussed the codes until consensus was reached. If no consensus could be reached, a third researcher could be consulted. Based on how the identified codes were related and linked, the researchers sorted them into categories. The

categories that emerged were then organized and grouped into main themes.

Results

Nineteen healthcare professionals participated in focus group interviews. Table 1 shows the job description of the healthcare professionals who applied the framework and attended the focus group. One focus group was held in the Italian nursing home (ten participants). In the Netherlands, a focus group interview was also organized. However, only seven out of nine participants could attend it. Thus, an interview with the remaining two professionals was organized: the same semi-structured interview guide as in the focus groups was used and interaction between participants was elicited. In total, 15 categories arranged into six themes were found (Table 2). Within these themes, barriers and facilitators experienced by professionals in each country were identified. Table 3 presents an overview of these influencing factors. The two independent authors who performed the data analysis extracted key words that represented and summarized barriers and facilitators within each identified theme. Key words were discussed until consensus was reached.

Table 1 Respondents characteristics

	<u>The Netherlands</u>	<u>Italy</u>
Male	3	0
Female	6	10
Age	41 (24-56)	49.5 (32-60)
Years of service	3.7 (2-8)	4.4 (2-6)
Healthcare assistants	8	5
Nurses	1	1
Recreational activity assistants		2
Nursing director		1
Physiotherapist		1

Table 2 Themes, categories, codes

<u>THEMES</u>	<u>CATEGORIES</u>	<u>CODES</u>
Professional outcomes and training	Quality of training	Training methods; allotted time to practice
	Professional advantages	Job satisfaction; residents' knowledge
	Quality improvement activities	Development and integration of new practice in care planning; improvement tools; perception of efficacy
Factors associated with environmental factors	Staff workload	Availability of time; staff shortage

	Environment	Adequate environment; allotted time for the interviews
	Nursing home policy and management	Values of the NH; degree of support from management
National economic context and regulation	Lack of funding	Lack of resources; economic aspects of healthcare systems
	Regulations	Existing rules; (lack of) standardization and guidelines
Professionals' relational skills	Team collaboration	Sharing; communicating; interprofessional collaboration
	Communication skills	Attention to non-verbal signs; development of new ways of communication
Care recipients' attitude and cognition	Residents' cognitive status	Degree of cognitive impairment; communication impairments
	Attitude of the family caregivers	Engagement; support; intrusion
	Family caregivers' involvement	Degree of involvement in residents' life; perceptions about care; family ties
Factors associated with own culture	Emotional aspects of family caregivers	Feelings; guilt
	Residents' intimate relationships	Taboo of intimacy; reluctance; embarrassment

Theme: 'Professional outcomes and tools'

This theme consists of three categories, namely 'Quality of training', 'Professional advantages', and 'Quality improvement activities'.

Quality of training

Regarding the communication skills training that healthcare professionals had to complete before applying the SDM framework, both Dutch and Italian professionals found role playing a very useful technique to learn how to involve residents and their family caregivers in an optimal way.

'I found that practising with role playing was very useful. It gave you a chance to practise things you have to deal with in your everyday work.' (Dutch professional)

However, it emerged that Dutch professionals would have preferred to have more time to practise in between the training sessions, in order to present their first experiences in daily practice at the following group training session and thus receive feedback or advice.

Professional advantages

Professional advantages of using the SDM framework perceived by Italian professionals consisted of getting to know the residents better, even if they thought they already knew them before. Furthermore, the professionals experienced

greater job satisfaction following the intervention.

'It is not easy to stop and dedicate time to improving your relationship with residents. However, I noticed how useful it is, even for myself and for my personal satisfaction as a professional.' (Italian professional)

Quality improvement activities

Although the aim of the SDM framework was to involve family caregivers and residents in the care planning process, professionals in both settings went beyond that and developed new best practices or improved care tools that appeared to facilitate their daily clinical practice.

In particular, the healthcare professionals working in the Italian setting, in agreement with the management, decided to modify the existing electronic care plan by adding a new section focused on the residents' psychosocial needs. This decision was taken after the first SDM interviews were performed, recognizing that the care plan did not contain any specific form or section in which this information could be reported in depth.

'The care plan, as it was before, was not adequate for depicting residents' needs. Now, at the beginning of the care plan, we have inserted a box for psychosocial information. This facilitates the collection of some of the residents' needs.' (Italian professional)

Similarly, Dutch professionals started to document more information in the residents' care plan. They stated that embedding this new practice into their daily routine facilitated their work in terms of being more aware of the division of tasks between themselves and family caregivers and being more precise when formulating the residents' care goals. In fact, cooperation with family caregivers was facilitated by writing down the role that they could fulfil in the care of residents, whereas the provision of care activities was facilitated by the formulation of a more specific care goal to meet.

'There's a husband who visits his wife here twice a day, to help her eat. That has been written down in the care plan [...] So we're not going to give her lunch or dinner when we know that her husband will arrive shortly. And should he not arrive at the appointed time, then we'll call him or we'll take a look to see how things are. Before, it wouldn't have been written down, you just hoped the professional who was in charge would know that.' (Dutch professional)

Theme: 'Factors associated with environmental factors'

Three categories emerged: 'Staff workload', 'Environment', and 'Nursing home policy and management'.

Staff workload

Professionals felt that the time and number of staff available during work shifts could affect the possibility of carrying out certain care tasks and participating in the project implementation process. With regard to time availability, Italian

professionals perceived themselves as being quite fortunate in comparison to colleagues working in other nursing homes of the area. They stated that in their organization, their working schedule still allowed them to dedicate time to improvement processes.

'We can define our nursing home as a "Happy Island" because we still have the chance to dedicate time to certain care activities. I know for sure that other nursing homes are not like ours.' (Italian professional)

Dutch professionals acknowledged that not only between residential settings, but even between wards within the same setting, different ways of working exist. Many professionals reported that in their nursing home they have to work hard to accomplish their tasks. Specifically, two of them found it difficult to carve out time to apply what they had learnt during the training.

'You really do suffer from a lack of time. Lack of time to interpret all the things you have learnt in relation to your work. Especially on our ward. It's just the two of us, and we both have to look after ten residents each. So many things need to be done during our shifts. It's easy to completely forget about the training then.' (Dutch professional)

A shortage of staff was mentioned only by Dutch professionals, who considered it a major issue that had an impact on the provision of care. In particular, staff perceived that despite their willingness to fulfil the families' needs, the limited number of professionals working in the ward during the shift affected the degree to which they were able to meet the family caregivers' requests regarding the care of their relatives.

'But they [family caregivers] state things such as: "I want my aunt to have a shower more often." You then discuss this at the multidisciplinary team meeting in which you are told: "We cannot arrange for that, because we are short of staff." You should, in fact, negotiate with the relatives about such things, but that's not possible because of the shortage of staff.' (Dutch professional)

Environment

The importance of an adequate environment that meets the needs of people with dementia, considering their cognitive impairments, emerged in the Italian nursing home. Italian professionals stated that performing the SDM interview in a quiet room and having time to listen, was a facilitating factor for the residents' involvement, who were not distracted by other stimuli and did not feel any time pressure during the conversation.

'The peaceful context facilitated the interview: the resident was saying something and we were listening, giving the time he/she needed' (Italian professional)

Nursing home policy and management

Dutch and Italian staff both declared that support from the management together with the fact that the project's principles reflected the nursing homes' vision and policy were major facilitators of the implementation of the quality improvement project.

'You consider each resident's personal wishes, it fits into the nursing home's policy' (Dutch professional)

'The policy here is to take care of the resident and do your best to make him feel comfortable. These kinds of values have never been lost here.... it is fundamental that the organization believes in such a project first, otherwise it would be difficult to carry out.' (Italian professional)

Thus, when professionals perceived that the intervention was supported by the management and reflected the nursing home policy, they felt confident in accomplishing the tasks required, demonstrating that a positive and shared context provides strong incentives to make a change in healthcare.

Theme: 'National economic context and regulation'

Two categories emerged: 'Lack of funding' and 'Regulations'.

Lack of funding

Lack of funding was a main barrier in both European countries: all professionals stated that financial limitation hindered the implementation not just of this specific intervention, but of any quality improvement project in healthcare. They reported that not enough money was allocated to the national healthcare system in general, affecting the quality of care provided, even at a residential care setting level. In fact, it emerged that the lack of financial resources was linked to staff size and their ability to provide the care residents deserve.

'Well, what you see in our society as a whole is that there is not much money available for healthcare. You notice it in the amount of money that is made available for us and the number of staff that we can employ for the residents. Residents are in fact entitled to more care, and they are in need of more care than we are actually able to give them.' (Dutch professional)

'Lack of time and high costs are the main barriers. Despite the fact that these care issues, such as residents' involvement, are very important, they should always be carefully considered if you really want to spread care practices on a national level.' (Italian professional)

Regulations

Both countries identified organizational regulations as barriers to innovation. However, it is interesting to note that they were considered as barriers in contrasting ways. In fact, Dutch professionals complained about the existence of too many national regulations, finding it difficult to find a balance between the limitations imposed by some regulations and the provision of care to residents.

'There are a lot of rules and regulations, of course. For instance conservation of food, you've got the HACCP (Hazardous Analyses Critical Control Points). You've got to follow all those rules. Often you give priority to the resident rather than the rules. Do you see what I mean?' (Dutch professional)

On the contrary, Italian professionals complained about a lack of regulations or

guidelines that would facilitate the implementation of quality improvement projects, highlighting the importance of standardizing care pathways such as the involvement of residents in care planning so that interventions like this one would be necessarily implemented across all the Italian LTC settings.

'There are no specific rules that favour some aspects of care, even if we know that they would improve the quality of care provided [...] I want to say that, for example, we have always asked residents about their preferences. However, this was not organized and standardized as it is now, so it was more difficult to do it.' (Italian professional)

Theme: 'Professionals' relational skills'

The categories 'Team collaboration' and 'Communication skills' emerged.

Team collaboration

The communication and mutual support between colleagues in carrying out the project tasks favoured the accomplishment of the implementation steps and made them feel more secure. All professionals highlighted the importance of communicating with each other during the project, so that colleagues who were not directly involved in the framework application (i.e., not performing the SDM interviews), could also understand the general sense of the project and the purpose of the activities performed. In fact, Italian interviewees feared that colleagues, without a proper explanation of the framework and of the changes introduced, could perceive its application as an additional and burdensome task and would be unaware of the new care processes developed.

'We need to clearly communicate to everybody what we are doing here. In fact, our colleagues may think that performing such care processes means more work to do. On the contrary, they should consider it as an opportunity that the organization wants to take to improve itself. They also need to be informed about the changes introduced, otherwise they may not fully understand why we have amended the care plan format.' (Italian professional)

Dutch professionals also emphasized the importance of interprofessional collaboration and how a collaborative and multidisciplinary approach eased the accomplishment of involving residents and family caregivers.

'Well, we often invite a physician or a psychologist to the care planning interview. We explain how we see things, they explain how they see things. But of course, the resident himself or herself takes a central role [...] in this way, you almost always come to a satisfying conclusion.' (Dutch professional)

Communication skills

Communication skills that were developed during the training, and further increased during clinical practice, facilitated healthcare professionals in finding an optimal way to communicate with both the family caregivers and the residents. In particular, non-verbal signs were considered of utmost importance

in understanding the dementia residents, and were demonstrated to be effective during the conversation.

'You have to pay attention to the non-verbal reactions of the residents. And I think it's fair to say that we are specialized in that. When, for instance, our residents are seated at the table, then I can tell when something is wrong with someone, even though that person is not saying anything. Something is not right, I can tell from the facial expression.' (Dutch professional)

'Yes, but what we've learned now is that when you put your message across in a well-reasoned way, then the other person will be more likely to think along with you.' (Dutch professional)

'I didn't have many difficulties understanding residents, even the ones with major cognitive impairment. I didn't expect that, I was astonished. In some cases, if you let them talk, you can understand the meaning of what they are saying.' (Italian professional)

Theme: 'Care recipients' attitude and cognition'

Under this theme, the categories 'Residents' cognitive status', 'Attitude of the family caregivers', and 'Family caregivers' involvement' emerged.

Residents' cognitive status

Following its vision, the Dutch nursing home tried to involve all residents with dementia, regardless of the level of cognitive impairment. This could explain why some Dutch interviewees considered the residents' cognitive status a major challenge to their involvement in care planning. In fact, they felt that the residents' cognitive impairment impeded the conversation or the identification of appropriate care objectives. Thus, in some occasions, they had to talk separately with the family caregivers.

'That's right, it can really impede a conversation when the resident is present, because he or she is in the past with his or her thoughts. And then you just sit...that makes it quite difficult to talk. The relatives think that this or that should be done, but the resident feels that she is able to do everything herself. At that point it is no longer possible to have a conversation together. So then you have to say at a certain moment: "It's good that we have been able to talk about this and I'll just make a new appointment".' (Dutch professional)

Attitude of the family caregivers

The attitude of the family caregivers during the SDM interview hindered or facilitated the residents' involvement in the care planning process. Italian professionals reported that when family caregivers had a supportive and encouraging attitude, they felt more comfortable in carrying out the conversation, and were able to consider both the residents' and families' perspectives.

'During some interviews, the family caregivers supported us and suggested issues to discuss. We have learnt a lot from them [...] But sometimes family caregivers

want to substitute themselves for the residents, and answer in their place. This does not facilitate the discussion with residents.’ (Italian professional)

In fact, an intrusive attitude that tended to take control over decision-making limited the extent to which appropriate attention and consideration could be given to both point of views. The professionals themselves admitted that one of the major obstacles to the involvement of residents in the care planning process was when the family tried to substitute themselves for the residents, answering in their place.

‘During one interview, the family caregiver wanted to focus on a topic that was different from the question addressed to the resident. However, the resident kept repeating the same answer, meaning that for her the topic was important. Thus, the psychologist reassured the resident, who consequently started feeling more at ease, and that she had a leading role in the situation. In fact, [at the start of the interview] the resident was really agitated and had spasms, whereas, at the end, she was quiet and peaceful. The family caregiver then understood that the topic was important for her mother.’ (Italian professional)

Family caregivers’ involvement

It emerged that the compliance of family caregivers involved in the SDM interview relied upon many factors. First of all, the usual degree of involvement in the residents’ life was key. In fact, when the relationship between the resident and the family caregivers was not close, or there were conflicts, it was difficult for professionals to conduct the conversation with both of them.

‘It all depends on who it’s about and how strong the ties are between the residents and the relatives. Whenever possible I try to have everyone present at such a meeting to join in the conversation. But sometimes I notice that it’s not working, because there is just one person who is always talking, or I notice that there are conflicts. Then I end the conversation and make a new appointment.’ (Dutch professional)

Another factor seemed to be the involvement of the family caregiver in the resident’s care. Indeed, if families were not very involved in residents’ lives within the nursing home, they tended to delegate control and care tasks to staff. This made it difficult for professionals to include families in the care planning process and to share with them the best ways to satisfy the resident’s needs and preferences.

‘There are relatives who bring their mother to a care home thinking: here she is, you look after her from now on [...] We’ll drop by every Sunday for a cup of tea or coffee. For the rest of the time it’s your job to look after her. That makes it quite difficult to arrange things for the resident.’ (Dutch professional)

Lastly, it appeared that some family caregivers did not feel the need to set up a shared decision-making process for care planning, thinking that staff already knew both them and the residents.

‘Sometimes the family caregiver was astonished and didn’t understand. “You have known us for so many years, why do you ask us this?”’ (Italian professional)

Theme: 'Factors associated with own culture'

Two categories emerged within this theme: 'Emotional aspects of family caregivers' and 'Residents' intimate relationships'.

Emotional aspects of family caregivers

Only in Italy did cultural barriers emerge, and professionals perceived them as interfering with the family caregivers' motivation to share and discuss care aspects. A major influencing factor pertains to the area of emotions, in particular the feelings of guilt experienced by many family caregivers towards institutionalization, that impacted their ability to fully confide in the professionals who care for the residents after nursing home admission.

'Maybe a cultural barrier is represented by the fact that many family caregivers feel guilty about having institutionalized the resident. This is a barrier to sharing, as they are often suspicious towards us, while the residents trust us more right from the beginning' (Italian professional)

Residents' intimate relationships

One resident's psychosocial need that was explored during the project was that of intimate relationships. Italian professionals felt uncomfortable asking residents questions related to this aspect when the family caregiver was present, highlighting the strong taboo of intimacy in the elderly that still exists in Italy. They stated that the majority of relatives, in particular children, did not allow or would not even listen to any questions on the topic, as it made them embarrassed or irritated.

'Many family caregivers are reluctant to talk about the residents' intimate issues. Some of them don't even want the resident to answer, others want to completely ignore the fact that the person can have thoughts about it.' (Italian professional)

Table 3 Barriers and facilitators

	<u>The Netherlands</u>	<u>Italy</u>
Use of Role-play	+	+
Time to practice	-	*
Residents' knowledge	*	+
Professional satisfaction	*	+
Quality improvement activities	+	+
Lack of time	-	+
Lack of staff	-	*
Environment	*	+
NH policy and management	+	+
Funding	-	-
Regulations	-	-
Team collaboration	+	+

Communication skills	+	+
Residents cognition	-	*
Family attitude	+/-	+/-
Lack of families' involvement	-	-
Cultural factors	*	-

- = barrier; + = facilitator; * = no information provided

Discussion

The study identified barriers and facilitators to the implementation of an SDM framework in an Italian and a Dutch LTC setting. The barriers and facilitators identified could be arranged into six themes: professional outcomes and tools, factors associated with environmental factors, national economic context and regulation, communication, care recipients' attitude and cognition, and factors associated with the culture of the country where the framework was applied.

By implementing the SDM framework, our study aimed to change the healthcare routines of the nursing homes involved, standardizing the involvement of residents and their relatives in care planning within daily practice. GroL and Wensing [27] developed a model that describes barriers and incentives for change at different levels of healthcare. Most of our findings could be organized in the categories they described. Social context, particularly the collaboration between colleagues as well as the commitment of management, emerged as the main facilitator that truly encouraged staff to implement the intervention. In fact, professionals of both countries stated that communicating and updating colleagues about the project's steps, objectives and actions, together with managerial support, strongly favoured the changes in clinical practice. This is in line with a review of research by Durlak and DuPre [28], who found how a collaborative process characterized by mutual trust and open communication as well as management support and encouragement represented factors that positively affect implementation. The economic and political context, i.e., financial aspects and regulations, was one of the major barriers. In particular, a lack of financial resources was mentioned by both countries as a factor that affects the implementation of any quality improvement intervention, as already demonstrated by other studies [24,29]. Professionals reported a general lack of resources allocated to their respective national health systems for the provision of healthcare services; this often means that professionals are unable to provide the care they think residents or families deserve. No other specific differences related to the organization of the national health systems were mentioned as interfering with the implementation of the project. The organizational context, that is the general organization of processes within the nursing home and its resources, such as staff, time and structure, varied. In fact, only Dutch professionals perceived a lack of time and staff that hindered the implementation process. Interestingly, in both countries the innovation level, i.e., advantages in practice and attractiveness, seems to have fostered the implementation of

quality improvement activities and tools that went beyond the sole involvement of residents and family caregivers in care planning; a high level of innovation also appears to facilitate the professionals' daily work.

The main differences between the two countries emerged within the group of barriers, namely the factors associated with the national culture and residents' cognition. Only Italian healthcare professionals perceived that some aspects of their own culture may have hindered the involvement of family caregivers in care planning. In fact, a cultural aspect that emerged and interfered with the decision-making process was the taboo of intimacy, which families faced when discussing topics related to residents' intimate relationships. Although companionship and displays of affection and intimacy between residents, such as holding hands, may elicit sympathy in both staff and relatives [30-31], Italian professionals stated that the majority of relatives were highly embarrassed or irritated when this psychosocial need was explored.

Another important difference between the two countries was the degree of involvement of residents with dementia based on their cognitive status. Only in the Netherlands was this perceived as a major issue that hindered the implementation process. Dutch professionals stated that in many cases the residents' cognitive impairment hindered their involvement in care planning. This might be due to the fact that all residents with dementia, regardless of their stage of dementia, were involved in the intervention, whereas Italian professionals tried to involve those dementia residents who had a less impaired cognitive functioning, indicating that the involvement of residents in the early-middle stage of the disease facilitates their engagement in SDM. Yet, it is striking to note that Italian professionals were surprised to discover that many residents were still able to answer some questions. Whitlatch [32] also encouraged the involvement of people with dementia in decision-making, highlighting the fact that their preferences can be assessed through simple preference questions, since the ability to answer these remains stable over time. This is linked to some key principles that underpin the concept of social health, above all the acknowledgment of the remaining abilities in people with dementia and their involvement in social relationships. Thus, our results seem to indicate that professionals tend to take control over decision-making, assuming that residents with cognitive impairments cannot even try to express their own views or answer direct questions.

This tendency can also be identified in the family caregivers' attitude, which was identified as both a barrier and a facilitator in both countries. Furthermore, the extent of involvement of family members in the lives of the people with dementia following placement in care homes hindered or facilitated the communication between staff and families and their engagement in the SDM process. These findings are also supported by Petriwskyj et al. [19], who reported that good communication and relationships between staff and families, as well as a positive attitude of family members, helped to facilitate SDM. In particular, the more families were involved in the care of their loved ones, the more staff members felt confident in sharing and finding with them the best way to satisfy the residents' needs. This is

congruent with other research studies analysed in the critical review by Gaugler [33], which describe how family carers often provide staff with their residents' personal knowledge to support and guide them in delivering more sensitive and individualized care.

Our framework required the direct involvement of both residents with dementia and their family caregivers in the care planning process, allowing professionals to have scheduled moments during their daily practice to ask the residents direct questions about their wishes, and allowing residents, together with their family caregivers, to express their points of view and preferences. The capacity to participate in SDM addresses in particular the first dimension of social health, i.e., '*the capacity to fulfil one's potential and obligations*'. Although the involvement of residents and their families in decision-making is not easy for healthcare professionals, our findings show that it is possible. Indeed, SDM allows residents suffering from dementia to be heard and acknowledged as people who are able to give and receive [34]. At the same time it stimulates professionals, as well as family caregivers, to be aware of and acknowledge residents' autonomy and personhood.

Strengths and limitations

Recognizing the factors that affect the implementation of a new care framework based on SDM in nursing homes may help to improve the involvement of families and residents with dementia at LTC facilities and, possibly, to inform future full trials. However, the limited number of settings and participants may have affected external validity. It is likely that allowing the involvement of all patients regardless of the stage of dementia influenced the differences between countries regarding the participation of cognitive impaired residents in SDM. Another limitation is that the interviews were conducted in two different languages and despite the continuous communication between the research teams, differences in interpretation may have occurred.

Conclusion and implications for practice

This study identified barriers and facilitators to the implementation of an SDM framework for care planning in two LTC facilities. Despite small dissimilarities between the two nursing homes that are mainly due to setting-specific and organizational factors, professionals in both countries experienced similar barriers and facilitators. Overall, these findings indicate that communication skills training is an essential prerequisite for implementing SDM, in order to develop adequate relational modalities to *improve care relationships with* dementia residents. In particular, it seems that embedding the theoretical knowledge that has just been learnt by applying it to clinical practice is a useful approach. Furthermore, the role-play and feedback system seems to represent an effective and appreciated learning technique. Another finding is that it is essential to involve family caregivers in residents' care as it seems that the greater the extent to which families are involved in the lives of residents, the better the communicati-

on between family caregivers and staff, thus improving their engagement in SDM. Consequently, it becomes useful to develop specific education sessions targeted at family caregivers *in order to* address those aspects that may prevent their involvement in decision-making or the full participation of their relatives with dementia, and to allow a better understanding of the positive impact that participation and acknowledgment of their capabilities might have on their loved ones. Furthermore, it seems necessary to involve the nursing home managers in the implementation process framework, as their contribution is essential not only to the accomplishment of the primary objectives of the intervention but also to the improvement of other secondary aspects, as they may allow the implementation of new tools or the development of new best practices. All these aspects indicate how the social environment together with professionals skills and personal attitude may affect the involvement of residents with dementia in decision-making despite their cognitive impairment.

References

- [1] Charles C, Gafni A, Whelan T (1997) Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Social Science and Medicine*, **44**(5), 681–92.
- [2] Charles C, Gafni A, Whelan T (1999) Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Social Science and Medicine*, **49**(5), 651–61.
- [3] Elwyn G, Edwards A, Mowle S, Wensing M, Wilkinson C, Kinnersley P, Grol R (2010) Implementing shared decision making in the NHS. *BMJ*, **341**, 971–973.
- [4] Hoffmann TC, Legare F, Simmons MB, Mc Namara K, Mc Caffery K, Trevena LJ, Hudson B, Glasziou PP, Del Mar CB (2014) Shared decision making: what do clinicians need to know and why should they bother? *MJA*, **201**(1), 35–39.
- [5] Smebye KL, Kirkevold M, Engedal K (2012) How do people with dementia participate in decision making related to health and daily care? A multi-case study. *BMC Health Services Research*, **12**, 241–253.
- [6] Ampe S, Sevenants A, Coppens E, Spruytte N, Smets T, Declercq A, van Audenhove C (2015) Study protocol for 'we DECide': implementation of advance care planning for nursing home residents with dementia. *Journal of advanced nursing*, **71**(5), 1156.
- [7] van der Steen JT (2010) Dying with dementia: what we know after more than a decade of research. *Journal of Alzheimer's Disease*, **22**(1), 37–55.
- [8] Span M, Smits C, Jukema J, Groen-van de Ven L, Ruud J, Vernooij-Dassen M, Hettinga M, Cremers A, Eefsting J, Hettinga M (2015) An interactive web tool for facilitating shared decision-making in dementia-care networks: a field study. *Front. Aging Neurosci.*, **7**, 1–12.
- [9] Vernooij-Dassen M, Leatherman S, Olde Rikkert M (2001) Quality of care in frail older people: the balance between receiving and giving. *BMJ Analysis*, **342**, 1062–1063.
- [10] Huber M, Knottnerus JA, Green L, van der Horst H, Jadad AR, Kromhout D, Smid H (2011) How should we define health? *BMJ*, **343**, d4163.
- [11] Pillemer K, Hegeman CR, Albright B, Henderson C (1998) Building bridges between families and nursing home staff: the Partners in Caregiving Program. *Gerontologist*, **38**(4), 499–503.
- [12] Rosen J, Mittal V, Mulsant BH, Degenholtz H, Castle N, Fox D (2003) Educating the families of nursing home residents: a pilot study using a computer-based system. *J Am Med Dir Assoc*. **4**(3), 128–34.
- [13] Maas ML, Reed D, Park M, Specht JP, Schutte D, Kelley LS, Swanson EA, Trip-Reimer T, Buckwalte CC (2004) Outcomes of family involvement in care intervention for caregivers of individuals with dementia. *Nursing Research*, **53**(2), 76–86.
- [14] Robison, J, Curry L, Gruman C, Porter M, Henderson CR Jr, Pillemer K (2007) Partners in caregiving in a special care environment: cooperative communication between staff and families on dementia units. *Gerontologist*, **47**(4), 504–15.
- [15] Bramble M, Moyle W, Shum D (2011) A quasi-experimental design trial exploring the effect of a partnership intervention on family and staff well-being in long-term dementia care. *Aging Ment Health*, **15**(8), 995–1007.
- [16] Zimmerman S, Cohen WL, Reed D, Gwyther LP, Washington T, Cagle JG, Sloane PD, Preisser JS (2013) Families Matter in Long-Term Care: Results of a Group-Randomized Trial. *Seniors Hous Care J*, **21**(1), 3–20.
- [17] Mariani E, Engels Y, Koopmans R, Chattat R, Vernooij-Dassen M (2016) Shared decision-making on a 'life-and-care plan' in long-term care facilities: research protocol. *Nursing Open*, 1–9.
- [18] Hancock GA, Woods B, Challis DA, Orrell M (2006) The needs of older people with dementia in residential care. *International Journal of Geriatric Psychiatry*, **21**, 43–49.
- [19] Petriwskyj A, Gibson A, Parker D, Banks S, Andrews S, Robinson A (2014) A qualitative metasynthesis: family involvement in decision making for people with dementia in residential aged care. *International Journal of Evidence-Based Healthcare*, **12**, 87–104
- [20] Hulscher ME, Laurant MG, Grol RP (2003) Process evaluation on quality improvement interventions. *Qual Saf Health Care*, **12**(1), 40–6.
- [21] Schols JMGA, Crebolder HFJM, van Weel C (2004) Nursing Home and Nursing Home Physician: The Dutch Experience. *J Am Med Dir Assoc*, **5**, 207–212.
- [22] Koopmans RT, Lavrijsen JC, Hoek JF, Went PB, Schols JM (2010) Dutch elderly care physician: a

- new generation of nursing home physician specialists. *J Am Geriatr Soc.*, **58**(9),1807-9.
- [23] Rinnenburger DE, Alma MG, Bigioni D, Brunetti G, Liberati C, Magliacani V, Monaco G, Reggiani L, Taronna G, Cecchini L (2012) *Ann Ist Super Sanità*, **48**(3), 328-333.
- [24] van Riet Paap J, Vernooij-Dassen M, Brouwer F, Meiland F, Illiffe S, Davies N, Leppert W, Jaspers B, Mariani E, Sommerbakk R, Vissers K, Engels Y (2014) Improving the organization of palliative care: identification of barriers and facilitators in five European countries. *Implementation Science*, **9**, 130.
- [25] Pope C, van Royen P, Baker R (2002) Qualitative methods in research on healthcare quality. *Qual Saf Health Care*, **11**, 148–52.
- [26] Hsieh HF, Shannon SE (2005) Three approaches to qualitative content analysis. *Qualitative Health Research*, **15**, 1277-1288.
- [27] Grol R, Wensing M (2004) What drives change? Barriers to and incentives for achieving evidence-based practice. *Medical Journal of Australia*, **180**, S57-60. Retrieved from <https://www.mja.com.au/journal/2004/180/6/what-drives-change-barriers-and-incentives-achieving-evidence-based-practice>
- [28] Durlak AJ, DuPre EP (2008) Implementation Matters: A Review of Research on the Influence of Implementation on Program Outcomes and the Factors Affecting Implementation. *Am J Community Psychol*, **41**, 327–350.
- [29] Meiland FJ, Droes RM, de Lange J, Vernooij-Dassen M (2005) Facilitators and barriers in the implementation of the meeting centres model for people with dementia and their carers. *Health Policy*, **71**(2), 243-253.
- [30] Wiskerke E, Manthorpe J (2016) New relationships and intimacy in long-term care: The views of relatives of residents with dementia and care home staff. *Dementia*, **0**(0), 1–18.
- [31] Bauer M, Nay R, Tarzia L, Fetherstonhaugh, D, Wellman D, Beattie E (2014) 'We need to know what's going on': Views of family members toward the sexual expression of people with dementia in residential aged care. *Dementia*, **13**, 571–585.
- [32] Whitlatch CJ (2010) Assessing the personal preferences of people with dementia. In *Handbook of Assessment in Clinical Gerontology* (Lichtenberg, P.A., ed), Academic Press, London.
- [33] Gaugler JE (2005) Family involvement in residential long-term care: A synthesis and critical review. *Aging & Mental Health*, **9**(2), 105-118.
- [34] Vernooij-Dassen M, Yun-Hee J (2016) Social health and dementia: The power of human capabilities. *International Psychogeriatrics*, **28**(5), 701–703.

Appendix 1 Focus group interview schedule

STAGES	GENERAL AIM AND ITEMS
1) TRAINING	<ul style="list-style-type: none"> i. AIM To explore issues related to the usefulness of the training in relation to: <ul style="list-style-type: none"> – Content of the training (e.g. Which part of the training did you find more/less useful in order to conduct the interview? Role playing, review of the care plans etc.) – Length ii. AIM To explore how the training was embedded into the clinical practice, if they perceived it as a part of their education or something additional: <ul style="list-style-type: none"> – Training considered part of the continuing education course programme of the NH – Fit in their daily practice schedule iii. AIM To explore if the NHS already promote the knowledge on such topics in relation to: <ul style="list-style-type: none"> – National Health System requires the training on some core issues of the present study (i.e. the involvement of the family carers and/or residents in the decision-making process; sharing of the care plan etc.)
2) SDM INTERVIEWS	<ul style="list-style-type: none"> i. AIM To explore barriers and facilitators to the conduction of the interviews in relation to: <ul style="list-style-type: none"> – Communication problem (e.g. not able to understand what the resident was trying to say/ the communication with the resident was sufficiently good despite the deterioration) – Identification and prioritization of needs (e.g. not able to identify any need/ able to identify his need) – Management of both the resident and family carer during the interview (e.g. not able to involve both in the same way; not able to stop the family carer in case (s)he interferes too much; not able to manage or involve a skeptic family carers when the case/ able to involve them in the same way; family carer perceived as a support for the resident expression or for the needs identification, easy to reach an agreement difficult to reach an agreement) – Previous experience in conducting similar interviews ii. To explore experiences/opinions/feelings regarding intervention program in relation to: <ul style="list-style-type: none"> – Knowledge on the residents and improvement of the quality of care provided – Relationship with the family carers and improvement in the communication with them and/or colleagues – Self-satisfaction
3) CARE PLAN ADAPATION AND MEETING THE GOALS	<ul style="list-style-type: none"> i. AIM To explore barriers and facilitators to the process of adaptation of the care plans in relation to: <ul style="list-style-type: none"> – Operationalization of the content of the SDM interview into specific needs/goals to be added to the care plan – Suitability of the format of the care plan for the registration of (health and psychosocial) needs identified during the interview ii. AIM To explore how the implementation of the SDM framework embeds into the organizational processes of the NH in relation to: <ul style="list-style-type: none"> – Participation (or support) of the management level – NH attention to psychosocial aspect (presence/absence)

- *Cooperation with other colleagues to meet the goals (e.g. when the goal identified during the SDM interview need the intervention of different healthcare professionals)*
 - iii. *AIM To explore the existence of a national policy on the SDM process in relation to:*
 - *National Health System requires the introduction of a sharing process between the residential structure and the resident/family carers about care goals*
 - *National Health System requires a specific format of the care plan*
 - *Existence of cultural aspects that may have influenced the implementation of the SDM framework*
-

THE IMPACT OF A
SHARED DECISION-MAKING
TRAINING PROGRAM ON
DEMENTIA CARE PLANNING
IN LONG-TERM CARE

Journal of Alzheimer's Disease (2018) 64,
1123-1135

Elena Mariani,
Rabih Chattat,
Giovanni Ottoboni,
Raymond Koopmans,
Myrra Vernooij-Dassen,
Yvonne Engels

ABSTRACT

BACKGROUND: shared decision making (SDM) can be a way for staff to adopt international recommendations advocating the involvement of nursing home residents and their family members in care planning and the development of personalized care plans.

OBJECTIVE: the main aim was to analyze the effects of training nursing home staff in the implementation of SDM on agreement of residents' 'life-and-care plans' with the recommendations (primary outcome) and on family caregivers' quality of life and sense of competence, and staff's job satisfaction (secondary outcomes).

METHODS: in the intervention condition, staff attended a training program on the use of SDM with residents and family caregivers in the care planning process. In the control condition, care planning as usual took place. For the primary outcome, in-depth qualitative and quantitative analyses of the care plans were performed. Multivariate Permutation Tests were applied to assess the impact on secondary outcomes.

RESULTS: forty-nine residents and family caregivers and 34 professionals were involved. Overall, many of the care plans developed during the intervention showed a high level of agreement with the care planning recommendations. Both Italian and Dutch care plans showed improvement in the number of clear problem statements ($p < .001$). In Italy, significant improvements ($p < .05$) were also found regarding specific care objectives, documentation of objectives met and of residents and families' involvement. No impact was found on secondary outcomes.

CONCLUSION: the involvement of residents and family caregivers in care planning contributed to an improvement of the residents' care plans, but it did not have an effect on family caregivers and staff outcomes.

Background

A growing number of international policies and standards emphasize Persons with Dementia (PwDs)' choice and autonomy in long-term care (LTC) settings and recommend the involvement of family members and residents in the care planning process [1-4].

However, these international standards do not always specify how to implement these recommendations within the settings. As a result, nursing homes frequently fail in implementing the care planning recommendations. And if they are implemented, care plans rarely meet the requirements of being standardized and individualized at the same time. Furthermore, they often lack measurable items, even when they are tailored to the residents' wishes and preferences [5].

In the past decade, regulations regarding the development of personalized 'life-and-care plans' were in place in Italy and the Netherlands [6, 7], but not systematically implemented in nursing homes. As a result, residents and family caregivers were often not directly involved in the care planning process.

Shared decision-making is a model of medical decision-making, where the healthcare professional and the patient make decisions together [8]. International organizations and policy makers recommend the use of shared decision making (SDM) in the context of dementia to promote PwDs' autonomy during the entire disease trajectory and consider it the best way to engage them and their family caregivers in decision-making [9-11]. Certainly, it is challenging to involve PwDs in decision-making, as the dementia progressively affects their cognitive functioning and decision-making capacity [11]. However, the presence and severity of cognitive impairment cannot be considered the determining factor that accounts for the exclusion from decision-making and meaningful conversations [10-12].

Few studies on the use of SDM have been conducted in nursing homes. Some of them demonstrated that even in advanced stages of dementia it is possible to make shared decisions if residents are adequately supported by professionals and by family caregivers, who help them to translate their preferences and values into decisions [10, 13-15]. Furthermore, it has been shown that both PwDs and their relatives can benefit from participation in SDM [16, 17].

Therefore, the main aim of the present paper was to analyse the effects of training nursing home staff in the use and implementation of SDM on agreement of the residents' 'life-and-care plans' with the recommendations addressing the existing care planning regulations in Italy and the Netherlands, comparing intervention and control group within and between countries. As secondary aims, we explored the effects of the use of SDM in care planning on family caregivers' quality of life, and sense of competence and on professionals' job satisfaction.

Methods

Study Design

To study the effect of the intervention, a mixed-method design was applied. To

explore the agreement of the residents' 'life-and-care plans' with the operationalized international recommendations (Box 1), an in-depth qualitative and a quantitative analysis of the newly developed care plans' contents was performed. Care plans' contents were analysed only post-test, specifically 6 months after the implementation of the program, because the start of the study corresponded with the moment when a structured and systematic care plans' personalization addressing the care planning requirements was introduced. To explore the impact of the SDM training program on participants' outcomes measured with self-report questionnaires, a pre-test/post-test-controlled group design was applied.

Box 1 Operationalization of care planning regulations

In order to operationalize the care planning regulations currently in place in both countries, first an analysis of national and international policies, guidelines and topic-related research projects had been performed [1-4, 18-22]. Then, based on the overview of the national and international documents analyzed, the first author (EM) elaborated an operationalization model that consisted of five recommendations reflecting the international care planning policy applicable to the care plans' personalization in the Italian and Dutch nursing homes (Supplementary Appendix 2). The model was discussed with the authors (YE, RK, RC and MVD) until consensus was reached. Specifically, the operationalized recommendations were: (1) The facility must develop a comprehensive care plan addressing the resident's medical, nursing, mental and psychosocial needs that are identified in the comprehensive assessment. Nursing documentation should be person-centered and give emphasis to psychosocial aspects; (2) The care plan should include a well-defined problem-statement and should outline SMART (Specific, Measurable, Achievable, Realistic, Timely) goals of care; (3) The care plan must provide specific interventions to meet, in accordance with the comprehensive assessment, the interests and the physical, mental, and psychosocial well-being of each resident; (4) The care plan should specify the measurements or a timetable for objectives implementation and identify when care objectives are met; and (5) The nursing team facilitates patients and/or family representative participation in the development and implementation of the resident's care plan, respects patients' beliefs and values the relationship with him/her.

Study Settings and Population

The study took place in Italy and the Netherlands. The nursing homes located in both countries were obliged, according to national regulations, to accomplish similar care planning standards: 'life-and-care plans' were compulsory, developed at admission by a multidisciplinary team, should have been signed for agreement by the resident or the family caregiver and updated at least once a year or whenever relevant changes in the residents' condition occurred [23]. However, in Italy a formal on-site care plans' control was not available whereas in the Netherlands care plans were randomly controlled by the Dutch Healthcare Inspectorate. The study population consisted of triads composed by the PwD, a family caregiver and a professional being one of the main caregiver of that resident, usually a nurse or healthcare assistant.

In both countries, an intervention group was compared to a control group. In the Netherlands, two Dementia Special Care units within the same nursing home were involved. In Italy, two nursing homes participated, being similar in number of residents admitted, staffing patterns and level of medical and psychosocial care provided, according to their charters of services.

The intervention

Both in Italy and the Netherlands, professionals belonging to the intervention group attended interactive communication skills training sessions of 12 hours in total that focused on the principles of SDM and active listening in the dementia context and on their application to the care planning process, considering the policy in place. The training program, that consisted of three meetings of four hours each, involved role-play and both theoretical and practical lessons (Supplementary Appendix 1). After having attended the training, professionals were invited to set up SDM interviews with the residents and their family caregivers: their main task was to stimulate and facilitate the PwD's expression of their preferences and wishes during the conversation and to translate them into care objectives. The purpose of the interview was also explained to family caregivers beforehand and their main role was to support the resident during the whole process, by encouraging the PwD's expression. After the interview, professionals had to update the residents' 'life-and-care plans' by reporting the outcomes of the conversation, i.e. the preferences and goals of care emerged, the actions to be put in place and the monitoring of the interventions set. To show that they agreed with the content, residents and relatives were invited to read and, if they agreed with the content, to sign for agreement the developed care plans. Further details on the implementation phases are described in the study protocol [23]. Professionals belonging to the control group did not receive the training and were not asked to set up the SDM interview.

Study outcomes

The primary outcome was the agreement of the residents' 'life-and-care plans' with the five operationalized recommendations. The primary outcome was determined by calculating the proportion of residents that had a newly developed 'life-and-care plan' in which the resident's preferences and needs were known, documented and met, checking whether they fulfilled the international policy on personalized care planning. In order to do so, each operationalized recommendation was translated into specific and defined items to be retrieved from the 'life-and-care plans' contents (Supplementary Appendix 2). Therefore, care plans of both intervention and control group were qualitatively analysed to explore if they contained those items.

As secondary outcomes, we determined whether the use of SDM improved the family caregivers' quality of life (QoL) and sense of competence, and the professional caregivers' job satisfaction. Pre-and post-test data were compared. As specified in the study protocol [23], one of the secondary outcomes was also the impact on dementia residents' QoL. However, the Dementia QoL instrument (DQoL) [24] appeared to be too difficult for both Italian and Dutch residents. In fact, due to their cognitive impairment, most of them demonstrated not to be able to fully understand the questionnaire's items and consequently to reliably answer the questions even if the researchers, during the administration process, gave them support and explanations. After a meeting between the two research teams

located in Italy and in the Netherlands, it was decided to interrupt its administration. Therefore, data on residents' quality of life are lacking.

Outcome measures

For the primary outcome, first the care plans' structure of the residents' files used in the Dutch and Italian nursing homes were compared, with particular attention to the main sections they were composed of, the terminology used, and the common type of residents' information usually reported. A case report form (CRF) containing the description of the information and details to be checked in the care plans of both countries was developed (Supplementary Appendix 3). The CRF was composed of five main parts: (a) description of the problems/preferences; (b) type of problems/preferences (i.e. psychosocial-medical-mental-nursing); (c) description of objectives and (d) related actions; (e) SDM attitude (i.e. evidence of participation in decision making). The CRF was used to guide the qualitative analysis of the care plans' contents, in order to explore whether they contained the items representing the five recommendations. For each care plan analysed, the CRF was completed and translated into English.

For the secondary outcomes, demographics of participants were collected and residents' dementia stage and abilities to independently perform activities of daily living were assessed pre-and-post intervention. For this purpose, respectively the Global Deterioration Stage (GDS) [25], and the Katz index [26] were used. The GDS provides an overview of the stages of cognitive function: stages 1-3 represent pre-dementia stages whereas 4-7 range from mild to severe dementia stages. The Katz Index ranks functional status in bathing, dressing, toileting, transferring, continence and feeding. Lower scores indicate a higher level of dependency. Family caregivers' QoL and sense of competence were measured using respectively the EuroQoL [27] and the Short Sense of Competence Questionnaire (SSCQ) [28]. The former is a generic health-related quality of life measure with five domains: mobility, self-care, usual activities, pain/discomfort, anxiety/depression. The latter measures the sense of competence of family caregivers of PwDs and consists of three domains: satisfaction with the person with dementia as a recipient of care, satisfaction with one's own performance and consequences of involvement in care for the personal life of the caregiver. A higher score indicates a higher sense of competence. Professional caregivers' job satisfaction was assessed using the Job Satisfaction Questionnaire (JSQ) [29,30], that consists of five factors: autonomy, competence, emotion, initiative and relation. High scores indicate high levels of job satisfaction. Detailed instrument characteristics and psychometric properties are described in the study protocol [23].

Data analysis

Primary outcome

Based on the operationalization model described above, which contains the

description of the five recommendations (Supplementary Appendix 2), two independent researchers (EM and RC) carefully read the CRF (Supplementary Appendix 3) filled for the care plan of each resident. Then, guided by the definition of each item which form the identified five recommendations, they checked whether the items were present or not in the care plan. If no consensus was reached, a third person was consulted (CG). Percentages were calculated considering the number of care plans containing the item out of the total of care plans analysed in each group. The Fischer's exact test was then calculated to analyse whether the level of agreement with the recommendations significantly differed from intervention and control group within and between countries.

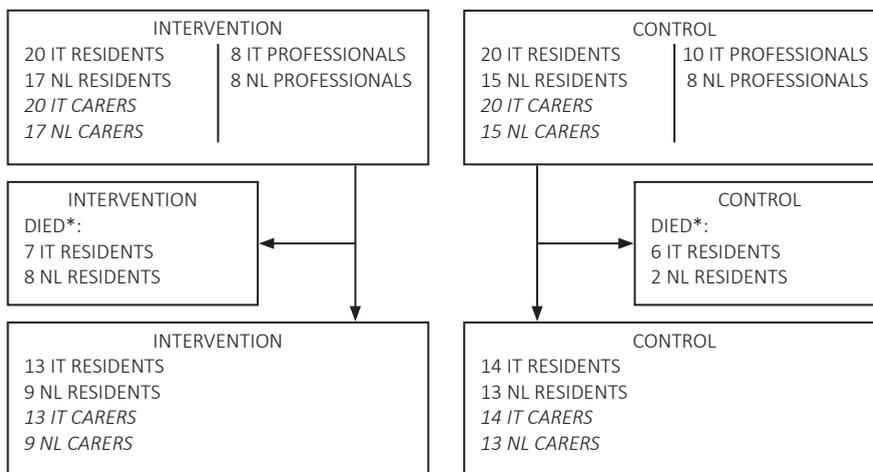
Secondary outcomes

To understand whether and to what extent the intervention had an impact on participants in each country, we analysed each secondary outcome measure (sense of competence, quality of life and job satisfaction) separately. Results of Shapiro–Wilk and Kolmogorov-Smirnov tests suggested to analyse the data on secondary outcomes using Multivariate Permutation Tests [31]. In the model, we analysed one within-subject factor, i.e., Time, with two levels, i.e., pre-test assessment (T0) and post-test assessment (T1), followed by two between-subject factors: the two levels factor Group (Intervention group – Control group) and the two levels factor Countries (Italy – the Netherlands). Fischer and t-student tests were used once the data were subjected to 10000 permutations. The level of significance was established at $p < .05$. Mean (M) and standard deviation (sd) were reported. Statistical analysis was performed using R-statistical software (Version 3.1.3) package flip [32].

Results

As shown in Figure 1, 22 residents were involved in the intervention group (13 in Italy and 9 in the Netherlands) and 27 in the control group (13 in Italy and 14 in the Netherlands). Since support of a family caregiver was required as an inclusion criterion, consequently respectively 27 and 22 relatives were involved. Sixteen professionals were involved in the intervention group (8 in each country) and 18 in the control group (8 in Italy and 10 in the Netherlands).

Baseline characteristics of the included participants are shown in Table 1. The only significant difference regarding participants' characteristics was the age of residents among groups: residents belonging to the intervention group were significantly younger than the control ones ($p = .02$, Control group: 87.89, sd = 6.01; Intervention group: 81.85, sd = 10.90).

Figure 1. Overview of participants

*Family caregivers of the residents who died, were consequently excluded

Table 1 Characteristics of participants

<i>Residents</i>				
	ITA INT	ITA CONT	NL INT	NL CONT
Age (years) (mean and sd)	84.0 (7.3)	88.5(6.2)	78.8 (14.5)	87.1 (5.8)
Gender				
%female	84.6 (n=11)	71.4 (n=10)	77.7 (n=7)	76.9 (n=10)
% male	15.3 (n=2)	28.5 (n=4)	22.2 (n=2)	23.8 (n=3)
Education				
Primary/Secondary	92.3 (n=12)	100 (n=14)	66.6 (n=6)	38.4 (n = 5)
Tertiary	7.6 (n = 1)	0.0	0.0	15.3 (n = 2)
University	0.0	0.0	22.2 (n = 2)	7.6 (n = 1)
Not reported	0.0	0.0	11.1 (n = 1)	38.4 (n = 5)
Marital status				
Unmarried	7.6 (n = 1)	14.2 (n = 2)	11.1 (n = 1)	0.00
Married	23 (n = 8)	14.2 (n = 2)	11.1 (n = 1)	23 (n = 3)
Cohabitant	0.0	0.0	55.5 (n = 5)	53.8 (n = 7)
Widowed	69.2 (n = 9)	71.4(n = 10)	22.2 (n = 2)	23.0 (n = 3)
Global Deterioration Scale (mean and sd)	5.6(.51)	5.3(.93)	4.4(1.23)	5.2(.75)
Activities of Daily Living	0.9(1.04)	1.4(1.95)	1.8(1.96)	3.4(1.50)

Family caregivers

	ITA INT	ITA CONT	NL INT	NL CONT
Age (years)	63.7(9.3)	58.4(9.7)	57.5(10.6)	62(9.7)
Gender				
%female	76.9 (n=10)	50 (n=7)	55.5 (n=5)	53.8 (n=7)
% male	23 (n=3)	50 (n=7)	44.4 (n=4)	46.1 (n=6)
Education				
Primary/Secondary	69.2 (n=9)	85.7 (n=12)	11.1 (n = 1)	15.3 (n = 2)
Tertiary	0.0	0.0	55.5 (n = 5)	38.4 (n = 5)
University	30.7 (n = 4)	14.2 (n = 2)	22.2 (n = 2)	46.1 (n = 6)
Not reported	0.0	0.0	11.1 (n = 1)	0.0
Marital status				
Unmarried	15.3 (n = 2)	14.2 (n = 2)	33.3 (n = 3)	7.6 (n = 1)
Married	61.5 (n = 8)	78.5(n = 11)	55.5 (n = 5)	84.6(n = 11)
Cohabitant	7.6 (n = 1)	0.0	0.0	7.6 (n = 1)
Widowed	15.3 (n = 2)	7.1 (n = 1)	11.1 (n = 1)	0.0

Professional caregivers

	ITA INT	ITA CONT	NL INT	NL CONT
Age (years)	47.8(9.6)	47.1(5.9)	48.8(12.8)	46.1(9.1)
Gender				
%female	100 (n = 8)	100 (n = 8)	75 (n=6)	66.6 (n=8)
% male	0.0	0.0	25 (n=2)	25 (n=3)
Not reported	0.0	0.0	0.0	8.3 (n=1)
Education				
Primary/Secondary	50 (n=4)	62.5 (n=5)	12.5 (n = 1)	0.0
Tertiary	0.0	25 (n=2)	87.5 (n = 1)	91.6(n = 11)
University	50 (n = 4)	12.5 (n=1)	0.0	0.0
Not reported	0.0	0.0	0.0	8.3 (n = 1)
Marital status				
Unmarried	0.0	37.5 (n = 3)	12.5 (n = 1)	0.0
Married	87.5 (n = 7)	62.5 (n = 5)	87.5 (n = 7)	58.3 (n = 7)
Cohabitant	12.5 (n = 1)	0.0	0.0	33.3 (n = 4)
Widowed	0.0	0.0	0.0	8.3 (n = 1)
Years of Service	4.3(1.1)	18.7(6.3)	5.1(3.1)	3.8(1.6)

Primary outcome

In Italy, 13 care plans were analysed in the intervention group and 14 in the control group. In the Netherlands, 9 care plans were analysed in the intervention group and 13 in the control group.

Table 2 Care plans' analysis based on the five recommendations reflecting the international care planning policy

Recommendation 1: The facility must develop a comprehensive care plan addressing the resident's medical, nursing, mental and psychosocial needs that are identified in the comprehensive assessment. Nursing documentation should be person-centered and give emphasis to psychosocial aspects.

ITEM	DEFINITION		INT	CONT	p
MEDICAL and/or MENTAL PROBLEMS	The care plan includes a list of clients' medical and/or mental needs	ITA	13/13 (100%)	14/14 (100%)	NS
		NL	9/9 (100%)	12/13 (92.3%)	NS
		p	NS	NS	
			INT	CONT	p
NURSING PROBLEMS	The care plan includes a list of client's nursing needs	ITA	11/13 (84.6%)	13/14 (92.8%)	NS
		NL	9/9 (100%)	11/13 (84.6%)	NS
		p	NS	NS	
			INT	CONT	p
PSYCHOSOCIAL PROBLEMS	The care plan includes a list of client's psychosocial needs	ITA	8/13 (61.5%)	13/14 (92.8%)	.077
		NL	9/9 (100%)	12/13 (93.3%)	NS
		p	.053	NS	
			INT	CONT	p
PERSONAL PREFERENCES	The care plan includes a list of client's personal preferences	ITA	13/13 (100%)	6/14 (42.8%)	< .001
		NL	9/9 (100%)	10/13 (76.9%)	NS
		p	NS	NS	
Recommendation 2: The care plan should include a well-defined problem-statement and should outline the goals of care.					
ITEM	DEFINITION		INT	CONT	p

PROBLEM STATEMENTS	The care plan includes accurate statement that reflect the client’s individual situation, specifying the functional psychological, medical, nursing problems/deficits that necessitate intervention	ITA	8/13 (61.5%)	0/14 (0%)	< .001
		NL	9/9 (100%)	3/13 (23.1%)	< .001
		p	.053	NS	
			INT	CONT	p
CARE OBJECTIVES	The care plan includes SMART (Specific, Measurable, Achievable, Realistic, Timely) objectives	ITA	8/13 (61.5%)	0/14 (0%)	< .001
		NL	3/9 (33.3%)	4/13 (30.7%)	NS
		p	NS	.041	

Recommendation 3: The care plan must provide specific interventions to meet, in accordance with the comprehensive assessment, the interests and the physical, mental, and psychosocial well-being of each resident.

ITEM	DEFINITION		INT	CONT	p
ACTIONS	The care plan includes individualized, person-centered (pharmacological and non—pharmacological) interventions	ITA	8/13 (61.5%)	6/14 (42.8%)	NS
		NL	9/9 (100%)	10/13 (76.9%)	NS
		p	.054	NS	

Recommendation 4: The care plan should specify the measurements or a timetable for objectives implementation and identify when care objectives are met.

ITEM	DEFINITION		INT	CONT	p
MEASUREMENT/ TIMETABLE	The care plan specifies how and when objectives were implemented	ITA	0/13 (0%)	0/14 (0%)	NS
		NL	7/9 (77.7%)	11/13 (84.6%)	NS
		p	< .001	< .001	
			INT	CONT	p
OBJECTIVES REACHED	The care plan contains evidence that the defined objectives were met	ITA	7/13 (53.8%)	2/14 (14.2%)	.046
		NL	9/9 (100%)	9/13 (69.2%)	NS
		p	.046	< .001	

Recommendation 5: The nursing team facilitates patients and/or family representative participation in the development and implementation of the resident’s care plan, respects patients’ beliefs and values the relationship with him/her.

ITEM	DEFINITION		INT	CONT	p
SHARED DECISION-MAKING	Evidence of discussion and/or participatory decision-making (e.g. date, notes)	ITA	13/13 (100%)	0/14 (0.0%)	< .001
		NL	9/9 (100%)	9/14 (64.2%)	NS
		p	NS	< .001	

Legend: num of care plans containing the item/total of care plans; ITA/NL = Italy/the Netherlands; INT/CONT = intervention/control group

Recommendation 1.

The care plans of both intervention and control groups in the two countries appeared rather comprehensive, as most fulfilled this recommendation. However, in Italy a significant difference (100%; $p < .001$) between the intervention and control group was found in relation to the recording of personal preferences (e.g. *“she enjoys eating fruit during the day”*).

Recommendation 2.

In both countries, the care plans documented by the Italian and Dutch professionals involved in the intervention included more accurate problem statements (61.5% IT; 100% NL; $p < .001$) which reflected the resident’s condition, describing and detailing the recorded problems (e.g. *“due to leg joint problems that affect mobility, she needs the caregivers’ physical support also for short journeys to avoid the risk of falling”*) whereas in the care plans of the control group, problems were less specific (e.g. *“he/she needs assistance with toileting”*). In Italy, in the intervention group SMART objectives were more frequently reported (61.5%; $p < .001$) (e.g. *“provide physical support whenever needed and weekly physiotherapy to maintain correct mobility”*), than in the control group, where objectives were very general and unspecific, (e.g. *“limit aggression”* or *“maintain hygiene”*), not addressing this recommendation. In the Netherlands, similar percentages of care plans including the mentioned item were found in both groups demonstrating a significant difference between the Dutch and Italian control group ($< 33\%$; $p = .041$).

Recommendation 3.

We found a tendency ($p = .054$) that the Dutch intervention group performed better than the Italian one but no significant differences between Dutch intervention and control group were detected.

Recommendation 4.

With regard to the reporting of objectives’ measurement and achievement, the Dutch care plans of both groups significantly (100%; $p < .001$ and 100%; $p = .046$ respectively) complied more than the Italian ones with the fourth recommendation. However, comparing the intervention to the control group within each country, it emerged that the intervention only had a significant impact in Italy on the reporting

of information on the achievement of care objectives (53.8%; $p=.046$).

Recommendation 5.

All Italian care plans of the intervention group addressed this recommendation (100%; $p<.001$). On the contrary, no plans belonging to the control group contained the date in which a discussion with the resident and a family caregiver was performed and when preferences were reported into the care plans and set as care objectives. Although in the Dutch intervention group all care plans showed evidence of SDM as compared to 64.2% in the control group, this difference was not significant. Comparing the countries, the Dutch control group showed significantly higher evidence of SDM than the Italian one ($p<.001$).

Secondary outcomes

After controlling for interactions between time and country, no differences between intervention and control group were found regarding Sense of Competence or Quality of life of family caregivers (Table 3).

Table 3 Family caregivers' sense of competence and quality of life

Sense of competence						
Factor	Factor levels	M	sd	test	test value	p-value
Time	T0 T1	18,59 23,14	5,37 10,32	t	3,08	0,011
Country	ITA NL	25,20 15,55	8,31 5,04	F	10,26	0,001
Group	Intervention group Control Group	22,29 19,71	7,63 9,05	F	2,39	0,323
Country * Time				t	-5,13	0,001
Group * Time				t	0,54	0,631
Group * Country				F	0,44	0,923
Group * Country * Time				t	-0,05	0,971
Quality of life						
Factor	Factor levels	M	sd	test	test value	p-value
Time	T0 T1	71,49 74,91	17,40 13,53	t	2,41	0,023
Country	ITA NL	68,87 78,55	15,46 14,33	F	6,98	0,017

Group	Intervention group Control Group	71,25 74,78	16,92 14,45	F	0,81	0,769
Country * Time				t	-2,55	0,16
Group * Time				t	0,79	0,415
Group * Country				F	8,28	0,008
Group * Country * Time				t	-1,07	0,300

Legend: time = pre-test (T0) and post-test (T1); test = t (t-student) and F (Fischer); test value = value of the statistical test

Equally, no differences between intervention and control group were found for staff members' Job Satisfaction.

Table 4 Professional caregivers' job satisfaction

Job satisfaction						
Factor	Factor levels	M	sd	test	test value	p-value
Time	T0 T1	42,56 43,67	12,27 12,84	t	0,42	0,694
Country	ITA NL	45,03 41,58	10,77 13,64	F	1,94	0,412
Group	Intervention group Control Group	42,84 43,33	14,33 10,97	F	1,46	0,576
Country * Time				t	-1,04	0,301
Group * Time				t	-1,12	0,286
Group * Country				F	1,86	0,454
Group * Country * Time				t	-1,28	0,231

Discussion

We explored the use of SDM to improve personalized care planning in LTC settings in the Netherlands and Italy. The quality criterion for adequate SDM was the level of agreement with the international care planning recommendations. Overall, many of the care plans developed during the implementation of the intervention showed a high level of agreement with the five recommendations derived from the international care planning policy.

As compared to the control setting, the Italian care plans in the intervention group showed significant improvements in five of the ten items which form the identified recommendations. These were recording of the PwD's personal preferences, development of more accurate problem statements and care objectives, reporting of objectives achievement and involvement of both residents and the family

caregivers in care planning.

In the Netherlands, the intervention group significantly more often described accurate problem statements than the control group. No other significant improvements emerged when comparing intervention and control settings. In fact, in the Netherlands, a more general fulfilment of the care planning regulations emerged in care plans of both the intervention and control group. This demonstrated that even when no intervention was provided, Dutch care plans were more personalized than the Italian ones, showing a higher level of agreement with the recommendations. One possible explanation could be that in the Netherlands, unlike in Italy, care plans can be directly checked by the Dutch Healthcare Inspectorate. Consequently, staff members knew that the content of the care plans they developed could be formally assessed in their working setting and this may have influenced the outcomes of the care planning process [33].

The care plans in the intervention and control groups of both countries contained documentation of a comprehensive assessment, as they all had at least a list of mental, nursing, and psychosocial problems as well as personal preferences. However, in Italy the most often reported problems pertained to the medical area. This is in line with studies that highlighted how medical interventions and conditions are more prevalent in care plans than nursing status or psychosocial needs, indicating a lack of patient-centeredness in care documentation [4, 34, 35]. Nevertheless, the implementation of SDM allowed a significant difference in the identification of personal preferences in Italian care plans, demonstrating that the involvement of residents and their families in care planning made the difference in knowing and documenting their wishes regarding social, psychological and relational resident-specific information. In the Netherlands, all care plans in the intervention group reported all types of problems, equally considering the psychosocial and personal areas as well as the nursing, medical and mental ones. Another issue emerged regarding the terminology used in care plans. The definition given by Orrell and Hancock [36] describes an unmet need as 'a situation in which an individual has significant problems for which there is an appropriate intervention which could potentially meet the need'. Thus, a distinction should be made between patients' needs and patients' problems. However, in the care plans of both countries there was not a specific section for needs recording; they were listed in the section 'Problems'. Furthermore, in Italy a specific section for mental problems was missing. These inconsistencies have already been underlined in other reports resulting from the analysis of care plans' contents [1, 37, 38]. This leads to the complex issue regarding the use of a standardized system or electronic tools to support interdisciplinary care planning and to facilitate communication among members of the interdisciplinary team. These tools seem to improve care documentation, and to contribute to comprehensiveness and accurateness of care plans [39-43]. However, other studies underline that the use of methods that standardize communication and assessment might not support patient-centered care, as they fail to identify residents' preferences, particularly the psychosocial ones [34, 44-47]. Indeed, the residents' electronic care plans in Italy were very similar to

each other, being composed of the same actions chosen from a drop-down menu. In the Netherlands, in the involved nursing home, such a drop-down menu was not available, and interventions seemed to be more based on the resident's characteristics and preferences, demonstrating to be more personalized. Therefore, in Italy a new section focused on the residents' psychosocial preferences to be addressed was added during the implementation of the intervention [14].

In the context of LTC settings, care plans should ensure the continuity, quality, and safety of care [46]. Yet, the quality of care provided in nursing homes is still an issue, although measures and indicators to measure nursing home care processes have been developed [48, 49]. In fact, the lack of regular care evaluations, of standardized measures, of measurable objectives and of time frames are often common problems in care plans [50-52]. In our study, no Italian care plans in any group contained any indication on measurability nor a time frame for goal achievement, whereas the Dutch care plans of both intervention and control group were more accurate in setting and measuring SMART care objectives.

In both countries, the SDM training program had no significant impact on the family caregivers' sense of competence and quality of life. These findings conflict with other intervention studies in which SDM improved family caregivers' quality of life [16, 53-55]. However, it is important to underline that these interventions explored the use of SDM within family care dyads living at home and not in LTC settings, which are characterized by different contextual and interpersonal factors. Similarly, although it has been shown that one of the outcomes of patient-centered care is the reduction of stress and the improvement of job satisfaction for professionals [56-58], in the present small-scale study we didn't find significant improvements.

This study was effectively implemented because the guidelines recommending the involvement of residents and family members in the care planning process were translated, in accordance with the management, into a specific training on SDM for staff and successively into moments that were embedded into the daily practice schedule, in which professionals could share with the residents and the family caregivers the planning of their care. This accounts for the continuation of the implementation process in the involved settings once the project formally ended. Furthermore, professionals who participated in the study were involved and consulted during the design of the study [23].

Strengths and limitations

A strength of this study is that it was based on guidelines that were in force in both countries and that it provided an implementation pathway suitable on daily clinical practice. However, the present study also has some limitations. First, we couldn't explore residents' QoL. Despite PwDs with moderate to severe dementia living in LTC settings can reliably report on factors that constitute and influence their QoL in nursing home [59-63], residents with a high degree of cognitive impairment may not be able to complete self-report measures [64]. The instrument chosen to measure the QoL appeared to be too difficult for the residents, whereas observation might have best suited for our purpose [65]. Another limitation is that the small sample

of participants involved does not allow any generalization on the impact of SDM on the subjects involved in the care planning process. Yet, we thought it was necessary to test the intervention in a small population before designing and implementing a fully powered trial. Similarly, the limited number of settings may have affected external validity. Furthermore, in order to be analysed, the Italian and Dutch case report forms filled for each care plan were translated into English, which may have caused differences in interpretation.

Conclusions

Overall, the involvement of residents and family caregivers in care planning contributed to an improvement of the assessment of residents' needs and the planning of their care. In fact, it seems to facilitate the development of more comprehensive and personalized care plans that agree with the recommendations derived from international care planning policy. With respect to the secondary outcomes, the impact of the SDM training program was not significant on the professionals and family caregivers involved in the study. Indeed, care planning is a very complex process that involves many subjects and factors that interact at different levels. Therefore, special attention is needed to take into account all the contextual and interpersonal factors that may influence the intervention at the care plans and at the participants level.

References

- [1] Scharlach, A, Robinson, B, Dal Santo, TS, Giunta, N and Mills-Dick, K (2000) Assuring quality care management under long-term care insurance. Available from: http://cssr.berkeley.edu/pdfs/QALTC_entire.pdf, Accessed on January 20, 2017.
- [2] American Healthcare Association (2005) Appendix PP: Guidance to surveyors for long-term care facilities part II. Washington, DC.
- [3] European Commission (2008) Long-term Care in the European Union. Available from: ec.europa.eu/social/BlobServlet?docId=2781&langId=en, Accessed on January 20, 2017.
- [4] Broderick, MC and Coffey, A (2013). Person-centred care in nursing documentation. *International Journal of Older People Nursing*, **8**, 309–318.
- [5] Mariani, E, Chattat, R, Vernooij-Dassen, M, Koopmans, R, and Engels, Y (2017a) Care Plan Improvement in Nursing Homes: An Integrative Review. *Journal of Alzheimer's Disease*, **55**, 1621–1638.
- [6] Direzione generale sanità e politiche sociali (2014) Linee guida per la elaborazione e gestione della cartella sociosanitaria nei servizi socio sanitari accreditati per anziani e persone con disabilità. Available from: http://salute.regione.emilia-romagna.it/documentazione/rapporti/linee-guida-per-la-elaborazione-e-gestione-della-cartella-socio-sanitaria-nei-servizi-socio-sanitari-accreditati-per-anziani-e-persone-con-disabilita-dicembre-2014/at_download/file/documento%20cartella%20socio%20sanitaria_9%20dicembre%202014_2014_def.pdf, Accessed on February 15, 2018.
- [7] Mot, E (2010) The long-term care system for the elderly in the Netherlands. Enepri research report No. 90. Available from: http://www.ancien-longtermcare.eu/sites/default/files/LTCSysteminThe%20Netherlands_RR90.pdf, Accessed on February 15, 2018.
- [8] Bronner, K and Hamann, J (2018) Shared decision-making and important medical and social decisions in the context of early diagnosis of Alzheimer's disease. *Biomarkers for preclinical Alzheimer's disease*, **137**, 259-270.
- [9] van der Steen, JT, Radbruch, L, Hertogh, CM, de Boer, ME, Hughes, JC, Larkin, P et al. (2013) White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European association for palliative care. *Palliat Med.*, **28**, 197–209.
- [10] Miller, LM, Whitlatch, CJ and Lyons, KS (2014) Shared decision-making in dementia: a review of patient and family carer involvement. *Dementia*, **15**, 1141-1157.
- [11] Winblad, B, Amouyel, P, Andrieu, S, et al. (2016) Defeating Alzheimer's disease and other dementias: a priority for European science and society. The Lancet Neurology Commission. *Lancet Neurology*, **15**, 455–532.
- [12] Daly, L, Bunn, F and Goodman, C (2016) Shared decision-making for people living with dementia in extended care settings: protocol for a systematic review. *BMJ Open*, **6**, 1-6.
- [13] Smebye, KL, Kirkevold M, and Engedal, K (2012) How do people with dementia participate in decision making related to health and daily care? A multi-case study. *BMC Health Services Research*, **12**, 241–253.
- [14] Mariani, E, Vernooij-Dassen, M, Koopmans, R, Engels, Y and Chattat, R (2017b) Shared decision-making in dementia care planning: barriers and facilitators in two European countries. *Ageing and Mental Health*, **21**, 31-39.
- [15] Fetherstonhaugh, D, Tarzia, L, Bauer, M, Nay, R and Beattie, E (2016) "The Red Dress or the Blue?": How Do Staff Perceive That They Support Decision Making for People With Dementia Living in Residential Aged Care Facilities? *Journal Appl Gerontol.*, **35**, 209-226.
- [16] Menne, HL, Tucke, SS, Whitlatch, CJ and Feinberg, LF (2008). Decision-making involvement Scale for individuals with dementia and family caregivers. *American Journal of Alzheimer's disease & other dementias*, **23**, 23-29.
- [17] Fetherstonhaugh, D, Tarzia L, and Rhonda, N (2013) Being central to decision making means I am still here!: The essence of decision making for people with dementia. *Journal of Aging Studies*, **27**, 143–150.
- [18] Waerthove centrum voor verpleeghuissorg (2003) Care of older people in the Netherlands. Available from: https://www.ttk.ee/public/Netherlands_Elders.pdf, Accessed on January 15, 2017.
- [19] Società Italiana di Gerontologia e Geriatria (2005) Linee guida della SIGG per RSA. Available

- from: <http://www.sigg.it/public/doc/DASCARICARE/253.pdf?r=0,7686089>, Accessed February 5, 2017.
- [20] EUSTaCEA Project, under Daphne III Program (2010) European Charter of rights and responsibilities of older people in need of long-term. Available from: http://www.age-platform.eu/images/stories/22495_EN_06.pdf, Accessed January 15, 2017.
- [21] Progetto AIDA-Advancing Integration for a Dignified Ageing (2013) Linee guida socio-sanitarie rivolte a persone anziane e disabili in condizioni di fragilità. Available from: http://www.projectaida.eu/wp-content/themes/thunderbolt/docs/doc_aida-1.pdf, Accessed February 18, 2017.
- [22] Dutch Ministry of Healthcare, Welfare and Sport (2016) Healthcare in the Netherlands. Available from: https://investinholland.com/nfia_media/2015/05/healthcare-in-the-netherlands.pdf, Accessed January 15, 2017.
- [23] Mariani, E, Engels, Y, Koopmans, R, Chattat, R, and Vernooij-Dassen, M (2016) Shared decision-making on a 'life-and-care plan' in long-term care facilities: research protocol. *Nursing Open*, **3**, 179-187.
- [24] Brod, M, Stewart, AL, Sands, L and Walton P (1999) Conceptualization and measurement of QoL in dementia: the dementia QoL instrument (DQoL). *Gerontologist*, **39**, 25-35.
- [25] Reisberg, B, Ferris, SH, de Leon, MJ and Crook T (1982) The Global Deterioration Scale for assessment of primary degenerative dementia. *Am J Psychiatry*, **139**, 1136-9.
- [26] Katz, S, Ford, AB, Moskowitz, RW, Jackson, BA and Jaffe, MW (1963) Studies of illness in the aged. The index of ADL: a standardized measure of biological and psychosocial function. *JAMA* **185**, 914-919.
- [27] The EuroQol Group (1990) EuroQol-a new facility for the measurement of health-related QoL. *Health Policy*, **16**, 199-208.
- [28] Vernooij-Dassen, M, Felling, AJ, Brummelkamp, E, Dautzenberg, MG, van den Bosch, GA and Grol R (1999). Assessment of caregiver's competence in dealing with the burden of caregiving for a dementia patient: A Short Sense of Competence Questionnaire (SSCQ) suitable for clinical practice. *Journal of the American Geriatrics Society*, **47**, 256-257.
- [29] Ekvall, G (2001) Manual job satisfaction "Manual Arbetstillfredsställelse" (in Swedish). Stockholm: *Ekvall Organisationspsykologi*.
- [30] Orrung Walli, A, Edbg, AK, Beck, I and Jakobsson, U (2013) Psychometric properties concerning four instruments measuring job satisfaction, strain and stress of conscience in a residential care context. *Archives Gerontology and Geriatrics*, **57**, 162-171.
- [31] Pesarin, F (2001) *Multivariate Permutation Tests with Applications in Biostatistics*. Wiley, New York.
- [32] Finos, L (2014) flip: Multivariate Permutation Tests. R package version 2.4.3. <https://CRAN.R-project.org/package=flip>
- [33] Zorginstituut Nederland (2017) Kwaliteitskader Verpleeghuiszorg. Samen leren en verbeteren. Available from: <https://www.zorginstituutnederland.nl/publicaties/publicatie/2017/01/13/kwaliteitskader-verpleeghuiszorg>, Accessed February 23, 2018.
- [34] Hansebo, G, Kihlgren, M and Ljunggren, G (1999) Review of nursing documentation in nursing home wards – changes after intervention for individualized care. *J Adv Nurs*, **29**, 1462-1473.
- [35] Tornvall, E, Wilhelmsson, S, Wahren, LK (2004) Electronic nursing documentation in primary health care. *Scand J Caring Sci*, **18**, 310-7.
- [36] Orrell, M and Hancock, G (2004) *CANE: Camberwell Assessment of Need for the Elderly. A needs assessment for older mental health service users*. Gaskell, London.
- [37] Ehrenberg, A and Ehnfors, M (1999) Patients problems, needs, and nursing diagnosis in Swedish nursing home records. *Nursing diagnosis*, **10**, 65-76.
- [38] Adams-Wendling, L, Piamjarajakul, U, Bott, M and Taunton, RL (2008) Strategies for translating the resident care plan into daily practice. *J Gerontol Nurs*, **34**, 50-6.
- [39] Daly, JM, Buckwalter, K and Maas, M (2002) Written and computerized care plans. Organizational processes and effect on patient outcomes. *J Gerontol Nurs*, **28**, 14-23.
- [40] Lindner, SA, Davoren, JB, Vollmer, A, Williams, B and Landefeld, CS (2007) An electronic medical record intervention increased nursing home advance directive orders and documentation. *J Am Geriatr Soc.*, **55**,1001-6.

- [41] Wagner, LM, Capezuti, E, Clark, PC, Parmelee, PA and Ouslander, JG (2008) Use of a falls incident reporting system to improve care process documentation in nursing homes. *Qual Saf Health Care*, **17**, 104-108.
- [42] Yeh, SH, Jeng, B, Lin, LW, Ho, TH, Hsiao, CY, Lee, LN and Chen SL (2009) Implementation and evaluation of a nursing process support system for long-term care: A Taiwanese study. *J Clin Nurs*, **18**, 3089-3097.
- [43] Fossum, M, Ehnfors, M, Svensson, E, Hansen, LM and Ehrenberg, A (2013) Effects of a computerized decision support system on care planning for pressure ulcers and malnutrition in nursing homes: An intervention study. *Int J Med Inform*, **82**, 911-921.
- [44] Achterberg, WP, van Campen, C, Pot, AM, Kerkstra, A and Ribbe, MW (1999) Effects of the Resident Assessment Instrument on the care process and health outcomes in nursing homes. A review of the literature. *Scand J Rehabil Med.*, **31**, 131-7.
- [45] Karkkainen, O and Eriksson, K (2004) Structuring the documentation of nursing care on the basis of a theoretical process model. *Scand J Caring Sci*, **18**, 229-36.
- [46] Keenan, GM, Yakel, E, Tschannen, D et al. (2008) Documentation and the Nurse Care Planning Process. In: Hughes RG, editor. *Patient Safety and Quality: An Evidence-Based Handbook for Nurses*. Rockville (MD): Agency for Healthcare Research and Quality (US). Available from: <https://www.ncbi.nlm.nih.gov/books/NBK2674/>, Accessed February 23, 2018.
- [47] Kontos, PC, Miller, M and Mitchell, GJ (2009) Neglecting the Importance of the Decision Making and Care Regimes of Personal Support Workers: A Critique of Standardization of Care Planning Through the RAI/MDS. *The Gerontologist*, **50**, 352-362.
- [48] Saliba, D and Schnelle, JF (2002) Indicators of the quality of nursing home residential care. *J Am Geriatr Soc*, **50**, 1421-1430.
- [49] Castle, NG and Ferguson, JC (2010) What Is Nursing Home Quality and How Is It Measured? *Gerontologist*, **50**, 426-442.
- [50] Voutilainen, P, Isola, A and Muurinen, S (2004) Nursing documentation in nursing homes – state-of-the-art and implications for quality improvement. *Scand J Caring Sci*, **18**, 72-81.
- [51] Levinson, R (2013) Skilled nursing facilities often fail to meet care planning and discharge planning requirements. Department of Health and Human Services. OEI-02-09-00201. Available from: <https://oig.hhs.gov/oei/reports/oei-02-09-00201.pdf>, Accessed February 23, 2018.
- [52] Hdanz auditors (2014) The 10 most common problems with care plans in aged care. Available from: http://hdanz.co.nz/wp-content/uploads/2015/09/HDSS-10-Most-common-problems-around-Care-Plans-Aged-Care-_Oct141.doc, Accessed February 28, 2018.
- [53] Whitlatch, CJ, Judge, K, Zarit, SH, and Femia, E (2006) Dyadic intervention for family caregivers and care receivers in early-stage dementia. *The Gerontologist*, **46**, 688-694.
- [54] Reamy, AM, Kim, K, Zarit, SH, and Whitlatch, CJ (2011) Understanding discrepancy in perceptions of values: individuals with mild to moderate dementia and their family caregivers. *The Gerontologist*, **51**, 473-483.
- [55] Hilgeman, MM, Allen, RS, Snow, AL, Durkin, DW, DeCoster, J and Burgio, LD (2014) Preserving Identity and Planning for Advance Care (PIPAC): Preliminary outcomes from a patient-centered intervention for individuals with mild dementia. *Aging & Mental Health*, **18**, 411-424.
- [56] McCormack, B et al. (2010) Developing person-centred practice: nursing outcomes arising from changes to the care environment in residential settings for older people. *International Journal of Older People Nursing*, **5**, 93-107.
- [57] McKeown, J, Clarke, A, Ingleton, C, Ryan, T and Repper, J (2010) The use of life story work with people with dementia to enhance person-centered care. *International Journal of Older People Nursing*, **5**, 148-158.
- [58] Jeon, YH et al. (2012) Staff outcomes from the Caring for Aged Dementia Care REsident Study (CADRES): a cluster randomised trial. *International Journal of Nursing Studies*, **49**, 508-518.
- [59] Kane, RA, Kling, KC, Bershadsky, B, Kane, RL, Giles, K, Degenholtz, HB, Liu, J and Cutler, LJ (2003) Quality of life measures for nursing home residents. *Journals of Gerontology-Series A, Biological Sciences and Medical Sciences*, **58**, M240-M248.
- [60] Cahill, S and Diaz-Ponce, AM (2011) 'I hate having nobody here. I'd like to know where they all are': Can qualitative research detect differences in quality of life among nursing home residents with different levels of cognitive impairment? *Aging Ment Health*, **15**, 562-72.

- [61] Moyle, W, Fetherstonhaugh, D, Greben, M, Beattie, E and AusQo, L (2015) Influencers on quality of life as reported by people living with dementia in long-term care: a descriptive exploratory approach. *BMC Geriatr*, **15**, 50.
- [63] Mjørud, M, Engedal, K, Røsvik, J and Kirkevold, M (2017) Living with dementia in a nursing home, as described by persons with dementia: a phenomenological hermeneutic study. *BMC Health Services Research*, **17**, 85-93.
- [64] Gerritsen, DL, Steverink, N, Ooms, ME, de Vet, HC and Ribbe, MW (2007) Measurement of overall quality of life in nursing homes through self-report: the role of cognitive impairment. *Qual Life Res*, **16**, 1029-37.
- [65] Mabire, JB, Gay, MC, Vrignaud, P, Garitte, C and Vernooij-Dassen, M (2016) Social interactions between people with dementia: pilot evaluation of an observational instrument in a nursing home. *Int Psychogeriatrics*, **28**, 1005-15.

Supplementary Appendix 1. *Training programme: basic structure and goals*

- **FIRST MEETING - Principles of SDM, active listening and care planning**
Main objectives and activities of the meeting (4 hours):
 - a) Give information on the general structure of the training and its objectives
 - b) Participants write on a post-it their expectations on the training
 - c) Made clear the training objectives and discuss the participants' expectations, so that their attention focuses on the contents of the training
 - d) General introduction on the basic principles of SDM and active listening
 - e) Each participant is stimulated to identify his/her perceived strength and limitation about the social interactions with dementia patients and family caregivers: barriers and facilitators. 5 minutes.
 - f) Theory on SDM and on active listening in dementia context
 - g) Theory on the care planning policy in place
 - h) Self-management theory
 - i) Exercise: person A talks to person B, person B does not respond, so person A has to talk for 5 minutes. Afterwards, discussion how they (person A) experienced this.
 - j) Use of vignettes on interactions with dementia residents and/or relatives in group
- **SECOND MEETING - Structuring the SDM interactions and gaining information**
Main objectives and activities of the meeting (4 hours):
 - k) Summary of the last session: active listening and self-management as tools to realize SDM
 - l) When and if SDM is used in daily practice? Question for participants and discussion
 - m) Role-play (1 professional; 1 family carer; 1 resident) to simulate how it normally works in daily practice. In the meantime, the audience is given questions/parameters to be checked to guide their observation.
 - n) Perform a "correct" role-play, based on the SDM principles and then discussion
 - o) Questions to the group "How is it possible to let the patient and family carers being understood?" "What are the positive effects?"
 - p) Ask professionals to practice the SDM principles during their work and ask them to bring along a care plan the next time.
- **THIRD MEETING - Understanding the importance of applying the SDM framework and the active listening approach**
Main objectives and activities of the meeting (4 hours):
 - q) Summary of the last session
 - r) Practice on SDM and active listening using other vignettes and role-play
 - s) General discussion and final conclusions

Supplementary Appendix 2. Operationalization model for care plans' analysis**Recommendation 1**

The facility must develop a comprehensive care plan addressing the resident's medical, nursing, mental and psychosocial needs that are identified in the comprehensive assessment. Nursing documentation should be person-centered and give emphasis to psychosocial aspects.

ITEM	DEFINITION	NUMBER OF CARE PLANS and PROPORTION (%)
MEDICAL NEEDS	The care plan includes a list of client's medical needs	
NURSING NEEDS	The care plan includes a list of client's nursing needs	
PSYCHOSOCIAL NEEDS	The care plan includes a list of client's psychosocial needs	
PERSONAL PREFERENCES	The care plan includes a list of client's personal preferences	

Recommendation 2

The care plan should include a well-defined problem-statement and should outline the goals of care.

ITEM	DEFINITION	NUMBER OF CARE PLANS and PROPORTION (%)
PROBLEM- STATEMENTS	The care plan includes an accurate statement that reflect the client's individual situation, specifying the problems/deficits that necessitate intervention	
CARE OBJECTIVES	The care plan includes SMART (Specific, Measurable, Achievable, Realistic, Timely) objectives	

Recommendation 3

The care plan must provide specific interventions to meet, in accordance with the comprehensive assessment, the interests and the physical, mental, and psychosocial well-being of each resident.

<u>ITEM</u>	<u>DEFINITION</u>	<u>NUMBER OF CARE PLANS and PROPORTION (%)</u>
<i>ACTIONS</i>	The care plan includes individualized, person-centered (pharmacological and non—pharmacological) interventions	

Recommendation 4

The care plan should specify the measurements or a timetable for objectives implementation and identify when care objectives are met.

<u>ITEM</u>	<u>DEFINITION</u>	<u>NUMBER OF CARE PLANS and PROPORTION (%)</u>
<i>MEASUREMENT/TIMETABLE</i>	The care plan specifies how and when objectives were implemented	
<i>OBJECTIVES REACHED</i>	The care plan contains evidence that the defined objectives were met	

Recommendation 5

The nursing team facilitates patients and/or family representative participation in the development and implementation of the resident's care plan, respects patients' beliefs and values the relationship with him/her.

<u>ITEM</u>	<u>DEFINITION</u>	<u>NUMBER OF CARE PLANS and PROPORTION (%)</u>
<i>SHARED DECISION-MAKING</i>	Evidence of discussion and/or participatory decision-making (e.g. date)	

Supplementary Appendix 3. Case report form

<p><u>Problems/preferences</u> (write down the description of problems/ preferences given in the care plan)</p> <p>1. _____</p> <p>2. _____</p> <p>3. _____</p>	<p><u>Type of problems/preferences</u> (please tick if it is psychosocial, medical and/or mental, or nursing)</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 5%;"></th> <th style="width: 30%;">Psycho social</th> <th style="width: 30%;">Medical Mental</th> <th style="width: 35%;">Nursing</th> </tr> </thead> <tbody> <tr> <td>1.</td> <td></td> <td></td> <td></td> </tr> <tr> <td>2.</td> <td></td> <td></td> <td></td> </tr> <tr> <td>3.</td> <td></td> <td></td> <td></td> </tr> </tbody> </table>		Psycho social	Medical Mental	Nursing	1.				2.				3.			
	Psycho social	Medical Mental	Nursing														
1.																	
2.																	
3.																	
<p><u>Objectives</u> (write down the description of objectives given in the care plan)</p> <p>Objective 1. _____</p> <p>Objective 2. _____</p> <p>Objective 3. _____</p>																	
<p><u>Actions</u> (write down the description of actions given in the care plan for each objective and the belonging discipline)</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 25%;"></th> <th style="width: 40%;">Discipline</th> <th style="width: 35%;">Actions planned</th> </tr> </thead> <tbody> <tr> <td>Objective 1</td> <td></td> <td></td> </tr> <tr> <td>Objective 2</td> <td></td> <td></td> </tr> <tr> <td>Objective 3</td> <td></td> <td></td> </tr> </tbody> </table>			Discipline	Actions planned	Objective 1			Objective 2			Objective 3						
	Discipline	Actions planned															
Objective 1																	
Objective 2																	
Objective 3																	
<p><u>Shared decision making attitude</u> (please report the evidences contained in the care plan about these issues if available)</p> <ul style="list-style-type: none"> Evidence of discussion and/or participatory decision-making <p>.....</p> <p>.....</p>																	

Definitions

- ✓ ***Problems and preferences*** (Problems describe something that residents should have satisfied in order to have a satisfactory QoL or to achieve a particular thing). Problems can pertain to the psychosocial, medical or nursing area:
 - i. *Psychosocial problems* (social, psychological and relational-related issues such as company and relationship, daytime and recreational activities’ participation, psychological distress etc...). Please report the personal preferences listed, for example for food, music, social activities, biographical

notes etc...

- II. *Medical and/or mental problems** (physical, mental and health-related issues such as physical, sensory or cognitive deficits, comorbidity, use of medication, treatments, behavioral symptoms, etc...)

*Please note that in Italy medical and mental problems are reported under the same section 'Medical problems', whereas in the Netherlands they are kept separated

- III. *Nursing problems* (nursing care-related issues such as autonomy, mobility, continence, feeding etc...)

- ✓ ***Objectives*** (Description of care goals and results to be met. They should be based on the residents' problems and preferences. In care plans, objectives can be listed in the section 'Goals/Objectives')
- ✓ ***Actions*** (Description of the interventions planned to meet the objectives. In care plans, actions can be listed in the section 'Interventions/Actions')
- ✓ ***Objectives reached*** (Description whether the objectives have been met)
- ✓ ***Shared decision-making attitude*** (To check if there are evidences in the care plan that a Shared Decision-making approach has been adopted, check whether in the care plan some documentation about these issues emerge:
 - I. Evidence of discussion and/or participatory decision-making (*for example, is somewhere written that an SDM interview between the triad was conducted?*)

GENERAL DISCUSSION

Introduction

This thesis concerns the development and implementation of a Shared Decision-Making (SDM) framework in Dutch and Italian Long-term care (LTC) settings to support the implementation of a more personalized care planning process. In this chapter we are going to answer our five research questions and discuss the main findings.

Main findings and conclusions

When do professionals working in LTC settings consider a person with dementia in need of palliative care? (Chapter 2)

The vignette study described in Chapter 2 showed that the identification of the starting point of palliative care in persons with dementia (PwDs) remains unclear. In fact, we found a discrepancy of opinions not only between countries and LTC settings, but even among staff members working in the same setting. Indeed, professionals identified three time-points: (1) at an early stage of dementia; (2) when signs and symptoms of advanced dementia are present; (3) when curative treatment for co-morbidities has no longer a beneficial effect. Specifically, most of them stated that only when residents face the advanced stage of the disease, they consider them in need of palliative care.

Although differences between the involved European countries were expected, due to different national regulations and cultures, we did not expect so much variations in opinions within each country or even more within services, indicating that there are differences in definitions of palliative care between staff members working in the same setting.

We concluded that, although at the international level many professionals and organizations are working to find an optimal definition of palliative care in dementia and to improve the access to it by developing specific guidelines and regulations, at the national and local level these guidelines are often not yet implemented into LTC services for the elderly or integrated into a specific national policy.

What are the core elements of the implementation of changes in nursing homes' care plans? (Chapter 4)

The integrative review presented in Chapter 4 identified and explored three core elements of the implementation of changes in nursing homes' care plans: the implementation strategies used, the target groups involved and how care plans changed in terms of being more comprehensive, accurate, or individualized. It emerged that the interventions that used multiple strategies, like the combination of different implementation activities such as education, use of information technology tools, supervision, audit and feedback, were effective in improving the quality of care documentation. Specifically, the analyzed interventions were effective in improving specific standardized aspects of the care plans, being the number of items listed, such as activities, care goals, medication charts etc. The interventions made care plans more informative and complete. However, it is important to underline that the implementation activities used were mainly

directed to staff members. Furthermore, most of those interventions didn't really impact on the personalization of care plans: in other words, they didn't improve the reporting of residents' personal information, wishes and preferences.

As a conclusion, most of the interventions included and analyzed in the review did not develop care plans which provided both standardized and individualized interventions, as care planning policies recommend.

What are the main barriers and facilitators regarding the implementation of an SDM framework in nursing homes? (Chapter 5)

To implement SDM in care planning in long-term care, it is important to identify the potential factors that facilitate or hinder the implementation process. Nineteen healthcare professionals who implemented the framework in Italy and the Netherlands participated in focus interviews to explore this question. The barriers and facilitators found could be arranged into six themes: professional outcomes and tools, factors associated with environmental factors, national economic context and regulations, professionals' relational skills, care recipients' attitude and cognition, cultural factors. No previous studies reported on influencing factors affecting the use of SDM in care planning in LTC settings. In fact, previous implementation studies found in literature aimed to identify barriers and facilitators only regarding the implementation of advance care planning in nursing homes. In line with the fact that our intervention study tried to incorporate SDM in the nursing home's clinical practice and organizational context, most of the factors identified could be organized in the categories described in the model developed by Grol and Grimshaw [1], which focuses on barriers and incentives to achieving change in practice.

We found many similarities among Italy and the Netherlands. In particular, the social context was a main facilitator, as both the collaboration between colleagues and the support of the management was fundamental to change the healthcare routines in both nursing homes. Furthermore, if professionals really recognized the usefulness and purpose of changing practice, the effort necessary to implement the new care pathway was not perceived as particularly burdensome. Interestingly, both in Italy and the Netherlands the economic context was indicated as hindering the implementation of any change in healthcare, because staff members said that not enough money is allocated to social and nursing services. The difference that emerged between professionals of the two countries concerned the taboo of intimacy. Indeed, a resident's psychosocial need that was explored during the project was that of intimate relationships, and Italian caregivers were less prone than the Dutch ones to explore this care aspect. Another difference was the degree of involvement of residents with dementia, as in the Netherlands all residents were involved regardless of level of cognitive functioning. In fact, when the residents in the more advanced stages had to be involved, Dutch professionals considered their severe cognitive impairment a major issue that impeded the conversation and their active involvement.

We concluded that, despite some differences, the main facilitators and barriers overlap among the two Countries.

Is it feasible for professionals to implement the SDM framework during their daily practice and what are the main factors that allow nursing homes' residents with dementia and their families to be involved in the care planning process? (Chapter 5)

It emerged that for professionals it was feasible only when specific conditions and prerequisites were satisfied. In particular, the results showed a top-down and bottom-up approach to implementing SDM within the involved settings. Specifically, the top-down factor affecting implementation was the involvement of the management level in the project: professionals felt supported and free to carve out the needed time to have the interview with the resident and the family caregiver, allowing SDM implementation during their daily practice. In fact, one of the main feasibility limits cited by both Italian and Dutch professionals, was how to manage time in a very busy daily schedule. Thus, knowing that the management considered the care plan's discussion as part of their job and entrusted them with the interview task, facilitated their engagement in the project. The bottom-up factors were education and the collaboration between colleagues. The education provided to staff as part of the intervention allowed them to efficiently manage the interviews and the relational issues that could arise with both family caregivers and dementia residents. Furthermore, it emerged that the interprofessional collaboration allowed SDM implementation through information exchange on residents and family caregivers, mutual support on care tasks and the acceptance of changing the usual care pathway to embed the SDM process into their working routine. Indeed, when professionals recognized the need to modify something in their daily clinical practice, they better interacted with the management level and changes were put in place. As a result, the Italian professionals developed a new section of the care plan and the Dutch ones decided to improve the collaboration with family caregivers by specifying in the care plans also the roles families have in the care of their loved ones within the nursing home.

We concluded that the interaction between the top-down and bottom-up level enabled to put the framework into practice. In turn, this new nursing home culture that was developed within the involved settings, allowed the residents and their family caregivers to have their say during the care goals discussions. Regarding families and residents, the main factors affecting family caregivers' involvement, were their attitude toward staff and the willingness to be aware of the care objectives of their beloved ones: when the attitude was negative and they tended to delegate all the care to staff, SDM couldn't be implemented. At the same time, if the level of cognitive impairment of residents was too advanced, their involvement was not feasible anymore, but they could remain present when the plan was made. Nevertheless, in such cases the family caregivers could still be and were actively involved.

How do the care plan's contents change by involving the residents with dementia and their family caregivers? (Chapter 6)

Our intervention improved the personalization of the residents' care plans in the

involved nursing homes. In order to measure the changes to care plans, international policy on personalized care planning were operationalized in five recommendations and it was analyzed whether they were reflected in the care plans developed after the implementation of the SDM framework. The recommendations referred to the: (1) development of a comprehensive care plan including psychosocial aspects; (2) definition of problem statements and goals of care; (3) provision of specific interventions; (4) specification of goals' measurements and achievement; and (5) involvement of clients and relatives. Overall, it emerged that, at baseline, care plans developed by Dutch professionals were already more personalized and SMART than the Italian ones. This ceiling effect will have contributed to the fact that in the Netherlands hardly any significant improvements were made between baseline and posttest.

Comparing intervention and control group within countries, Italian care plans were significantly more accurate in the recording of PwDs' personal preferences and of their involvement in care planning as well as in defining their problems and the objectives achieved. The Dutch care plans contained more precise problem statements. Furthermore, Italian care plans became more measurable, as they contained indications on how care goals' achievement was measured, and less medical-oriented, as the information related to the psychosocial area increased after the implementation of the SDM framework. More precisely, the electronic care plan was modified during the project, and a new section that could be used to register social, psychological and relational information on residents was added. We concluded that the involvement of residents and family caregivers improved the assessment of residents' needs and the planning of their care, facilitating the development of more personalized and comprehensive care plans.

Discussion of main findings

Involvement along the LTC journey

The main finding of our study is that it is feasible to involve PwDs in care conversations in LTC settings and that it leads to the improvement of personalization of their care documentation. By being present, the persons with dementia affirm their value of human beings, a spiritual dimension that does not need cognitive and language functions to be expressed [2, 3]. At the same time professionals, by involving PwDs, recognize, respect and support the sense of identity and self-worth of PwDs. Citing their own words *"I didn't have many difficulties understanding residents, even the ones with major cognitive impairment. I didn't expect that, I was astonished. In some cases, if you let them talk, you can understand the meaning of what they are saying."* *"Something was not right, I could tell from the facial expression"* (Chapter 5). In our study, involvement is considered a fundamental principle that should be acted along the whole long-term care journey, from admission to the end-of-life phase. From our study described in Chapter 2, it emerged discrepancies in the professionals' opinions in defining when palliative care should start. This data

supports the importance of involving the PwDs and their families before the end stages of the disease, from the beginning of the journey. This is in line with the consensus definition of Advance Care Planning (ACP) Rietjens, et al. [4], who define it as a process that ‘enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate’. If this definition is appropriate for any kind of patients, efforts should be made to make it applicable for PwDs and their families, by developing frameworks that imply their involvement.

Personalization of care plans

The care plan, among all the documentation available in LTC settings, is the only one that should accurately describe the residents’ characteristics, wishes, needs and care. Our study showed that through involvement of the resident and the family it is possible to develop more personalized care plans in which measurable items, goals and actions are documented, and that reflect the residents nursing and psychosocial preferences. This fulfills an important element of person-centered care called ‘person-directed care planning’ [5] that empowers residents and their family caregivers to co-create their care plans [6, 7]. ‘Person-directed care planning’ is an element in many European and non-European long-term care policies [8], but infrequently implemented in daily practice. One reason to this lack of implementation is that the link between involvement in care planning and improved outcomes in nursing homes is not always evident, while it is more evident in other care settings [5]. But it is important to underline that engagement should be considered as a fundamental value in itself, regardless measurable financial or health outcomes [9]. In fact, this is the principle that underpinned our project (Chapter 3). Ideally, it should not be possible to develop a personal care plan if the person himself, and the family caregiver for the needed support, is not included at any stage in care planning, following the principle advocated by the Dementia Alliance International “*Nothing about us, without us*”.

Tools that facilitate SDM

Persons with dementia appreciate to be involved in everyday decision-making and are able to make some decisions [10, 11]. Overall, there is a lack of studies on the use of specific tools that could facilitate everyday decision-making in PwDs [12]. Recently, some tools specific for the dementia context have been developed for registering SDM and tailored-related information [13-15] or ACP preferences [16]. However, care plans in nursing homes are standardized care documentation and not necessarily adequate for the purpose of being tailored and individualized. Indeed, in our case, the electronic care plan adopted in the Italian LTC setting, did not appear to be appropriate for recording the personalized information that emerged by involving PwDs and their family caregivers, and it was necessary to modify it. This is in line with studies that demonstrated that not always ICT tools are efficient in developing complete care documentation [17, 18].

SDM adaptation to the nursing home context

The concept of SDM, as originally conceptualized, has no different definition based on the healthcare setting in which it is applied [19]. However, the dementia context is very complex and SDM needs to be adapted to such a complexity [20]. Van de Pol [21] conceptualized an SDM model for frail older people, concluding that given their complex multi-morbidity and treatment wishes, it requires a dynamic and continuous dialogue between professional, patient and proxy decision maker. Although she developed this model for general practitioners, this is particularly true considering nursing homes, characterized by a multidisciplinary approach and teamworking. Peisah, et al. [22] proposed the concept of ‘collaborative decision-making’, a complementary approach to SDM in which it becomes fundamental ‘how’ and ‘why’ the decision is taken and where collaboration underpins the development of the care plan and the basic care processes carried out within a nursing home, such as bathing, feeding and dressing. Certainly, some residents really appreciate to be involved in the care planning process, while others prefer to leave it up to family members and/or nursing home staff [5, 23]. Therefore, as described in our research protocol, ‘SDM is considered an opportunity for PwDs to express their opinion and wishes’, not a requirement (Chapter 3), as respecting the choice not to be involved is also person-centered care. Furthermore, it is common that staff tends to take everyday care decisions on behalf of PwDs [24, 25] and that family caregivers often do not participate in residents’ day-to-day decisions, although the latter have a greater impact on residents’ quality of life than treatment decisions [26]. Thus, the starting point of the SDM interviews was a list of basic needs selected from the CANE [27] which considers not only the staff’s and family carers’ point of view, but also the residents’ one.

Operationalization of SDM

Providing meaningful engagement is a key component of person-centered care [28]. In our study, we considered SDM the approach that allows a meaningful engagement of both PwDs and family caregivers. It is necessary to measure the effects of SDM. However, it is challenging to operationalize concepts such as engagement or empowerment [29]. Indeed, SDM requires operational phases, such as registering and documenting resident’s preferences and choices, so that they can be executed [28]. Thus, we tried to operationalize the impact of SDM onto the care plans by searching five operationalized recommendations in the developed care plans, reflecting international care planning policy that required the involvement of the residents and the tailoring of personalized care documentation. Furthermore, the lack of policy guidance that could help professionals working in LTC settings in supporting residents’ autonomy and decision-making is a widespread problem [30]. In both countries, recommendations advocating the use of SDM were in place, but they were not mandatory and did not contain practical information on how to implement them in the different healthcare settings. For this reason, we tried to develop a structured SDM framework, accepted by the management level, that provided education to professionals and required a given time to share the care

plans during their daily work.

Nursing home culture

When complex interventions are implemented in LTC settings, very often the main barriers that arise are lack of time to perform certain care tasks, high turnover and lack of communication and trust between managers and healthcare professionals [31]. Concerning decision-making, professionals usually find it difficult not only to carve out the time to support residents in the decision-making process during their daily work, but also complain about a general lack of adoption of a specific decision-making policy by the LTC setting that could guide them in the process as well as difficulties in managing the wishes of the family caregivers, especially when they know that they are different to the residents' ones [30]. Furthermore, it is common that in LTC settings a paternalistic approach exists, as professionals and family caregivers tend to substitute for the residents [32-34]. In our study, we found similar barriers. However, it appeared to be possible to change the nursing home culture: although professionals often say there is no time or they have not enough knowledge, if the organization supports the intervention and education is provided, they just consider the involvement of residents in care planning as part of their job. Indeed, implementing SDM principles in daily routine requires the involvement of the whole organization, specifically staff from both the organizational and the clinical level [35] and professionals must be authorized and given the time to use them [26]. Furthermore, it has been shown that SDM is often not used because healthcare professionals tend to identify more problems in it than opportunities [13]. However, it has also been reported that professionals are particularly motivated to maintain the best practices that improve residents' wellbeing [31].

It has been proven before that education is the way through which healthcare professionals can learn the importance and usefulness of SDM [36, 37]. Education should be tailored to staff needs and technique such as role-play demonstrated to be effective regardless staff roles and literacy level [31]. Our training programme was very practical, as we performed role-play and gave them 'homework' in between the sessions, i.e. experience in their daily work the strategy discussed the previous time and discuss the outcomes in group during the next session. Staff found the role-play technique very useful. In this project, we did not train family caregivers, although they play an important role in the decision-making process and they also have a need for a related-education [19]. Another issue concerning LTC practices regarded inspections: while some studies suggest that such practices are ineffective in implementing changes [38], in the study by Colon-Emeric, professionals stated that they could have been effective. In our case, in the Netherlands, unlike in Italy, care plans could be directly checked by the Dutch Healthcare Inspectorate and this might have contributed to the more personalized Dutch care plans than the Italian ones already at baseline. Our intervention did have a significant impact on care planning, but we did not influence staff job satisfaction nor family caregivers' quality of life and sense of competence.

The right to be a person

The lack of SDM in nursing homes is a major ethical problem, because it means that the participation of PwDs and their family caregivers in decision-making is not valued and, consequently, the residents' autonomy and dignity is not enough preserved [39]. The principle that underpinned our study was that PwDs need to be acknowledged as persons, having the right to receive decision-making support, not to be excluded a priori. In a study by Hirschman [40], it emerged that while PwDs focus on the opportunity to be involved in the decision-making process, family caregivers focused on the PwDs' abilities to participate. This indicates that for many residents being involved is more important than making a decision [26]. Another study [5] reaffirms this concept, by showing that residents and family caregivers value the opportunities of formal engagement in nursing homes and that their wishes to be engaged in care planning should always be considered, even if the capacity to co-decide is absent. Overall, residents would like staff to dedicate more time to communicate with them and to meet their communication needs, not just their day-to-day basic care needs [39]. Furthermore, many residents perceive staff members as those who can take care of their preferences and desires within LTC settings [41]. In our study, SDM was a mean through which PwDs could be fully considered and taken into account, beyond the specific outcomes (i.e. the care goals) reached through the decision-making process with staff and families. Yet, it is also important to underline that the level of participation varies among the target groups: for many family caregivers, being involved in everyday care decisions can be burdensome and they might prefer not to be involved [42]. In our study, some family caregivers felt embarrassed in discussing specific topics and preferred avoiding them (for example their loved ones' longing for intimate relationships), and staff understood and respected these choices.

Methodological considerations

This study involved two countries, Italy and the Netherlands, contributing to our knowledge on the use of SDM to improve personalized care planning in European LTC settings. However, only four nursing homes and a total of 49 residents and family caregivers and 34 professionals were involved. Thus, because of the limited number of settings and participants the external validity is limited. Furthermore, while in the Netherlands two units of the same setting were involved as control and intervention group, assuring homogeneity of the sample, in Italy two different nursing homes were enrolled. Although they were very similar in the number and type of services provided, as described in their charter of services, their different inner organization and procedures might have had an impact on the implementation process.

On the other hand, the international nature of the research project enabled a new insight on SDM implementation in the European context. Italy and the Netherlands are different from each other, but they do have a number of important aspects in common. In fact, in both countries a multidisciplinary team assesses the resident,

and developing a ‘life-and-care plan’ is compulsory. These care plans are similar in terms of their basic structure and should be shared with residents and families whenever possible. Moreover, policies advocating the use of SDM are in place in both countries, but unfrequently implemented in nursing homes. Thus, it was interesting to study whether the same implementation process could be adapted in nursing homes in two European countries. More precisely, we found out that not only the influencing factors were similar in Italy and the Netherlands, but also in other European countries [31, 43-46].

Another important issue, that led to missing data, was the level of deterioration of our target population. In the Netherlands, three quarters of residents living in LTC settings are aged 80 years or older and suffer from severe health and cognitive problems [47]. In Italy the trend is the same [48, 49]. As already affirmed, one of our aims was to include all PwDs living in the involved nursing home wards. As described in our study protocol, we wanted to examine whether the intervention had an effect on their quality of life. To that aim, we chose the Dementia quality of life instrument [50]. However, it appeared to be too difficult for the cognitive level of the residents, despite our effort in guiding them during its administration. Probably, an observational tool could have best suited for our purpose [51]. As a consequence, data on residents’ quality of life are lacking.

Implications for practice, policy and research

Recommendations for practice

International regulations state that to be comprehensive, care plans should be based on a standardized assessment of residents’ medical, nursing, mental and psychosocial needs and that both residents and families should be involved in the care processes to determine their personal needs, wishes and also to make care choices [19, 52-54]. However, in our study we have seen that there is a need for integrating the available recommendations and guidelines into the nursing home’s care procedures, otherwise professionals don’t know how to translate their willingness to fulfill such requirements into practical care tasks. Thus, we recommend the inclusion of both the organizational and clinical level in developing a structured pathway that can be implemented during daily routines. Furthermore, we recommend specific training for professionals and family caregivers. In the present intervention study, education was focused on the implementation of structured nursing personalized care pathways with the help of SDM. However, as described in Chapter 1, the idea of this study started during the IMPACT project, that aimed to develop optimal strategies to improve the organization of palliative cancer and dementia care in Europe. From the study described in Chapter 2, it emerged that it was very challenging for professionals to identify the time point when palliative care should start. Indeed, international guidelines consider the use of SDM as the unique way to provide optimal palliative care, as only by involving the PwDs and their family caregivers before the terminal stage, professionals can

become aware of their preferences and provide care in line with their values [55, 56]. Therefore, we recommend specific training for professionals on proactive palliative care together with SDM principles and tools to reduce discrepancies in professionals' opinions as well as in care provision and to really provide nursing home residents optimal care from admission to death, enhancing their autonomy and placing high value on their preferences and wishes.

During our project, we had to face the complex issue regarding the assessment of the quality of the care provided in nursing homes. Quality indicators concerning the reporting of both standardized and individualized care exist [57, 58] but they are rarely implemented. In order to measure the impact of SDM on personalized care planning, it was necessary to operationalize the existing care recommendations as well as the involvement of residents and family caregivers into measurable items and, at the same time, to modify the care tools in place and make them adaptable to that aim. Therefore, we recommend implementing a process that is at the same time flexible, well-defined and tailored to the organizational needs of the setting. In particular, since staff and organization readiness are fundamental enablers for the use of SDM in nursing homes, we recommend the involvement of both the clinical and the organizational level during the project development phase. Grol and Grimshaw [1] found that combined interventions are more effective than single interventions. In line with their overview, our intervention was composed by a combination of different interventions such as education on SDM, practical training and supervision in between sessions, the development of formal opportunities of engagement with residents and family caregivers scheduled in the professional caregivers' daily practice. Thus, we recommend the development of multilevel interventions as our appeared effective on the care planning process.

Recommendations for policy

Article 3 developed by the United Nations Convention on the Rights of Persons with Disabilities [59], affirms the following principle '*Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons*'. Although PwDs face an inevitable progressive cognitive impairment, we believe that this principle must be applied also to this target population and should guide research interventions in LTC settings. However, the persons who care for PwDs should believe in such principles first, acknowledging their importance. Therefore, training staff members working in nursing homes on the contents of these policies and how to apply them in their organizations should be assured, both at the clinical and organizational level. Furthermore, given the important role family caregivers play in maintaining PwDs' autonomy once admitted to the nursing home, also a specific training for them is desirable. In the Netherlands, national quality frameworks concerning individualized care planning for palliative patients [60] as well as for nursing homes promoting patient autonomy and uniqueness, compassion, attention for the family and communication with the residents [61] are in place. In Italy, a new law regarding a living will [62] has entered into force 31 January 2018 and gives the possibility to declare a person's own

wishes to receive the preferred kind of healthcare in the event of incapacity. Article 5 of the law describes the shared care planning process that should result into a written document. This law has been adapted also for the dementia context by the Italian Association of Psychogeriatrics, that developed ten principles to promote the shared care planning process for PwDs [63]. Since SDM offers the opportunity to translate these principles into practice, we believe that public awareness on this topic should be promoted and increased through education of the public and of volunteers of associations and charities that support people affected by dementia and their families, especially in two countries both committed to developing 'dementia-friendly communities' [64].

Recommendations for future research

The evidence of plasticity also in a damaged brain is properly used to develop early dementia interventions [65]. However, in our study we tried to involve all residents, regardless of level of cognitive functioning, recognizing their residual abilities and their sense of identity. Thus, we think it is important to develop interventions also for moderate and late-stage dementia that capitalize their remaining capacities, with the main aim to include them in their social environment and acknowledge their dignity as persons.

The capacity to participate in SDM addresses in particular the first dimension of social health, i.e. *'the capacity to fulfill one's potential and obligations'* [66]. Indeed, in the research field there is an increasing attention to better understand how the experiences of social engagement of PwDs impact on their well-being [67] and to determine the influencing factors that can improve social health or have an impact on those interventions that aim to improve social health [68]. Our study shows that it is feasible to involve in care planning PwDs at different stage of the disease and their family members and that influencing factors might facilitate or hinder this process. Future research could integrate these influencing factors identified in recent literature when planning interventions that require the involvement of PwDs and their families, adapting the concept of social health to the LTC context. Furthermore, it is recommended to perform an RCT with a larger number of settings, residents and countries in order to improve external validity and generalizability of the framework. Another interesting issue concerns the impact of the framework on secondary outcomes. In fact, the intervention was not significant on the professionals' job satisfaction and family caregivers' sense of competence and quality of life. Thus, more attention should be paid to the contextual and interpersonal factors and searching for adequate instruments to assess the secondary outcomes, trying to explore whether there is an effective link to PwDs' involvement and the improvement of the professionals and families' outcomes we have identified or whether other outcomes could be mainly affected.

References

- [1] Grol R, Grimshaw J (2003) From best evidence to best practice: effective implementation of change in patients' care. *Lancet* **362**, 1225-1230.
- [2] Cipriani G, Borin G (2010) Religious/spiritual dimension in dementia. *G GERONTOL* **58**, 3.
- [3] Jewell A (2011) *Spirituality and Personhood in Dementia*, Jessica Kingsley Publishers, London.
- [4] Rietjens JAC, Sudore RL, Connolly M, van Delden JJ, Drickamer MA, Droger M, van der Heide A, Heyland DK, Houttekier D, Janssen DJA, Orsi L, Payne S, Seymour J, Jox RJ, Korffage IJ, Care EAfP (2017) Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol* **18**, e543-e551.
- [5] Scales K, Lepore M, Anderson RA, McConnell ES, Song Y, Kang B, Porter K, Thach T, Corazzini KN (2019) Person-Directed Care Planning in Nursing Homes: Resident, Family, and Staff Perspectives. *J Appl Gerontol* **38**, 183-206.
- [6] Chen J, Mullins CD, Novak P, Thomas SB (2016) Personalized Strategies to Activate and Empower Patients in Health Care and Reduce Health Disparities. *Health Educ Behav* **43**, 25-34.
- [7] Pioneer Network (2011) Continuum of Person-Directed Culture. <https://www.pioneernetwork.net/Providers/Continuum/>
- [8] Edvardsson D, Backman, A., Bergland, Å., Björk, S., Bölenius, K., Kirkevold, M., Winblad, B. et al. (2016) The Umeå ageing and health research programme (U-Age): Exploring person-centred care and health-promoting living conditions for an ageing population. *Nordic Journal of Nursing Research*.
- [9] McAllister M, Dunn G, Payne K, Davies L, Todd C (2012) Patient empowerment: the need to consider it as a measurable patient-reported outcome for chronic conditions. *BMC Health Serv Res* **12**, 157.
- [10] Feinberg LF, Whitlatch CJ (2001) Are persons with cognitive impairment able to state consistent choices? *Gerontologist* **41**, 374-382.
- [11] Feinberg LF, Whitlatch CJ (2002) Decision-making for persons with cognitive impairment and their family caregivers. *Am J Alzheimers Dis Other Demen* **17**, 237-244.
- [12] Davis R, Ziomkowski MK, Veltkamp A (2017) Everyday Decision Making in Individuals with Early-Stage Alzheimer's Disease: An Integrative Review of the Literature. *Res Gerontol Nurs* **10**, 240-247.
- [13] Span M (2016) Developing an interactive web tool to facilitate shared decision-making in dementia care networks: a participatory journey. Amsterdam: Vrije Universiteit.
- [14] Whitlatch CJ, Orsulic-Jeras S (2018) Meeting the Informational, Educational, and Psychosocial Support Needs of Persons Living With Dementia and Their Family Caregivers. *Gerontologist* **58**, S58-S73.
- [15] Goeman DP, Dickens M, Iliffe S, Pond D, O'Keefe F (2017) Development of a discussion tool to enable well-being by providing choices for people with dementia: a qualitative study incorporating codesign and participatory action research. *BMJ Open* **7**, e017672.
- [16] Groen-van de Ven L, Pelgrum-Keurhorst M, Uitdehaag M, Smits C (2018) CONVERSATION GUIDE DEMENTIA: A TOOL THAT SUPPORTS ADVANCE CARE PLANNING CONVERSATIONS. *Innov Aging*. **2**.
- [17] Munyisia EN, Yu P, Hailey D (2012) The impact of an electronic nursing documentation system on efficiency of documentation by caregivers in a residential aged care facility. *J Clin Nurs* **21**, 2940-2948.
- [18] Colón-Emeric CS, Schmader KE, Twersky J, Kuchibhatla M, Kellum S, Weinberger M (2009) Development and pilot testing of computerized order entry algorithms for geriatric problems in nursing homes. *J Am Geriatr Soc* **57**, 1644-1653.
- [19] Ervin K, Blackberry I, Haines H (2017) Shared Decision Making in Residential Aged Care: A Framework Synthesis. *Open Journal of Nursing* **7**, 23.
- [20] Groen-van de Ven L, Smits C, Span M, Jukema J, Coppoolse K, de Lange J, Eefsting J, Vernooij-Dassen M (2018) The challenges of shared decision making in dementia care networks. *Int Psychogeriatr* **30**, 843-857.
- [21] van de Pol MH, Fluit CR, Lagro J, Slaats YH, Olde Rikkert MG, Lagro-Janssen AL (2016) Expert and patient consensus on a dynamic model for shared decision-making in frail older patients. *Patient Educ Couns* **99**, 1069-1077.

- [22] Peisah C, Sorinmade OA, Mitchell L, Hertogh CM (2013) Decisional capacity: toward an inclusionary approach. *Int Psychogeriatr* **25**, 1571-1579.
- [23] Mignani V, Ingravallo F, Mariani E, Chattat R (2017) Perspectives of older people living in long-term care facilities and of their family members toward advance care planning discussions: a systematic review and thematic synthesis. *Clin Interv Aging* **12**, 475-484.
- [24] Boyle G (2008) The Mental Capacity Act 2005: promoting the citizenship of people with dementia? *Health Soc Care Community* **16**, 529-537.
- [25] Manthorpe J (2013) Mental capacity and dementia: A review. Part 2. *J Dementia Care* **21**, 3.
- [26] Daly RL, Bunn F, Goodman C (2018) Shared decision-making for people living with dementia in extended care settings: a systematic review. *BMJ Open* **8**, e018977.
- [27] Orrell M, Hancock G (2004) Camberwell Assessment of Need for the Elderly., Gaskell, London.
- [28] Fazio S, Pace D, Flinner J, Kallmyer B (2018) The Fundamentals of Person-Centered Care for Individuals With Dementia. *Gerontologist* **58**, S10-S19.
- [29] Shier V, Khodyakov D, Cohen LW, Zimmerman S, Saliba D (2014) What does the evidence really say about culture change in nursing homes? *Gerontologist* **54 Suppl 1**, S6-S16.
- [30] Tarzia L, Fetherstonhaugh D, Bauer M, Beattie E, Nay R (2015) "We Have to Work Within the System!": Staff Perceptions of Organizational Barriers to Decision Making for Older Adults With Dementia in Australian Aged Care Facilities. *Res Gerontol Nurs* **8**, 286-292.
- [31] Colón-Emeric C, Toles M, Cary MP, Batchelor-Murphy M, Yap T, Song Y, Hall R, Anderson A, Burd A, Anderson RA (2016) Sustaining complex interventions in long-term care: a qualitative study of direct care staff and managers. *Implement Sci* **11**, 94.
- [32] Sims-Gould J, McKay HA, Feldman F, Scott V, Robinovitch SN (2014) Autonomy, choice, patient-centered care, and hip protectors: the experience of residents and staff in long-term care. *J Appl Gerontol* **33**, 690-709.
- [33] Eloranta S, Arve S, Isoaho H, Aro I, Kalam-Salminen L, Routasalod P (2014) Finnish nurses' perceptions of care of older patients. *Int J Nurs Pract* **20**, 204-211.
- [34] Goodman C, Baron NL, Machen I, Stevenson E, Evans C, Davies SL, Iliffe S (2011) Culture, consent, costs and care homes: enabling older people with dementia to participate in research. *Aging Ment Health* **15**, 475-481.
- [35] Ampe S, Sevenants A, Coppens E, Spruytte N, Smets T, Declercq A, van Audenhove C (2015) Study protocol for 'we DECide': implementation of advance care planning for nursing home residents with dementia. *J Adv Nurs* **71**, 1156-1168.
- [36] Légaré F, Moumjid-Ferdjaoui N, Drolet R, Stacey D, Härter M, Bastian H, Beaulieu MD, Borduas F, Charles C, Coulter A, Desroches S, Friedrich G, Gafni A, Graham ID, Labrecque M, LeBlanc A, Légaré J, Politi M, Sargeant J, Thomson R (2013) Core competencies for shared decision making training programs: insights from an international, interdisciplinary working group. *J Contin Educ Health Prof* **33**, 267-273.
- [37] Chen EH, Kanzaria HK, Itakura K, Booker-Vaughns J, Yadav K, Kane BG (2016) The Role of Education in the Implementation of Shared Decision Making in Emergency Medicine: A Research Agenda. *Acad Emerg Med* **23**, 1362-1367.
- [38] Anderson RA, Issel LM, McDaniel RR (2003) Nursing homes as complex adaptive systems: relationship between management practice and resident outcomes. *Nurs Res* **52**, 12-21.
- [39] Bollig G, Gjengedal E, Rosland JH (2016) Nothing to complain about? Residents' and relatives' views on a "good life" and ethical challenges in nursing homes. *Nurs Ethics* **23**, 142-153.
- [40] Hirschman KB, Joyce CM, James BD, Xie SX, Karlawish JH (2005) Do Alzheimer's disease patients want to participate in a treatment decision, and would their caregivers let them? *Gerontologist* **45**, 381-388.
- [41] Cameron N, Fetherstonhaugh D, Bauer M, Tarzia L (2018) How do care staff in residential aged care facilities conceptualise their non-verbal interactions with residents with dementia and what relevance has this for how residents' preferences and capacity for decision-making are understood? *Dementia (London)*, 1471301218798422.
- [42] Helgesen AK, Athlin E, Larsson M (2015) Relatives' participation in everyday care in special care units for persons with dementia. *Nurs Ethics* **22**, 404-416.
- [43] Deutschman M (2001) Interventions to nurture excellence in the nursing home culture. *J Gerontol Nurs* **27**, 37-43.

- [44] Specht JK (2013) Evidence based practice in long term care settings. *J Korean Acad Nurs* **43**, 145-153.
- [45] Caspar S, Cooke HA, Phinney A, Ratner PA (2016) Practice Change Interventions in Long-Term Care Facilities: What Works, and Why? *Can J Aging* **35**, 372-384.
- [46] Lourida I, Abbott RA, Rogers M, Lang IA, Stein K, Kent B, Thompson Coon J (2017) Dissemination and implementation research in dementia care: a systematic scoping review and evidence map. *BMC Geriatr* **17**, 147.
- [47] Verbeek-Oudijk D, van Campen C (2017). Ouderen in verpleeghuizen en verzorgingshuizen
- [48] Montemurro F (2012). Indagine sulle RSA in Italia. <http://www.quotidianosanita.it/allegati/allegato3485654.pdf>
- [49] ISTAT (2016). Condizioni di salute e ricorso ai servizi sanitari
- [50] Brod M, Stewart AL, Sands L, Walton P (1999) Conceptualization and measurement of quality of life in dementia: the dementia quality of life instrument (DQoL). *Gerontologist* **39**, 25-35.
- [51] Mabire JB, Gay MC, Vrignaud P, Garitte C, Vernooij-Dassen M (2016) Social interactions between people with dementia: pilot evaluation of an observational instrument in a nursing home. *Int Psychogeriatr* **28**, 1005-1015.
- [52] Allen EJ (2015) *Nursing Home Federal Requirements: Guidelines to Surveyors and Survey Protocols (8th Ed.)*, Springer Publishing Company, New York.
- [53] American Healthcare Association (2005), Appendix PP: Guidance to surveyors for long-term care facilities part II. Washington, DC.
- [54] European Commission (2008), Long Term Care in the European Union ed. DG for Employment SAaEO, Brussels.
- [55] van der Steen JT, Radbruch L, Hertogh CM, de Boer ME, Hughes JC, Larkin P, Francke AL, Jünger S, Gove D, Firth P, Koopmans RT, Volicer L, (EAPC) EAfPC (2014) White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med* **28**, 197-209.
- [56] Winblad B, Commission TLN (2016) Defeating Alzheimer's disease and other dementias: a priority for European science and society *Lancet Neurol* **15**, 77.
- [57] Saliba D, Schnelle JF (2002) Indicators of the quality of nursing home residential care. *J Am Geriatr Soc* **50**, 1421-1430.
- [58] Vasse E, Moniz-Cook E, Rikkert MO, Cantegreil I, Charras K, Dorenlot P, Fumero G, Franco M, Woods B, Vernooij-Dassen M (2012) The development of quality indicators to improve psychosocial care in dementia. *Int Psychogeriatr* **24**, 921-930.
- [59] United Nations Convention on the Rights of Persons with Disabilities [A/RES/61/106] (2006). <http://www.un.org/esa/socdev/enable/rights/convtexte.htm>
- [60] Kwaliteitskader palliatieve zorg Nederland (2017). <https://shop.iknl.nl/shop/netherlands-quality-framework-for-palliative-care/238613>
- [61] Zorginstituut Nederland (2017). Kwaliteitskader Verpleeghuiszorg <https://www.zorginstituutnederland.nl/publicaties/publicatie/2017/01/13/kwaliteitskader-verpleeghuiszorg>
- [62] Legge 22 dicembre 2017. Norme in materia di consenso informato e di disposizioni anticipate di trattamento (Gazzetta Ufficiale Serie Generale, n. 12 del 16 gennaio 2018).
- [63] Cembrani F, Asiola F, Bianchetti A, Ferrannini L, Mossello E, Scapati F, Trabucchi M (2018) Associazione Italiana di Psicogeriatra.
- [64] Williamson T European Foundations' Initiative on Dementia 2016.
- [65] Hill NL, Kolanowski AM, Gill DJ (2011) Plasticity in Early Alzheimer's Disease: An Opportunity for Intervention. *Top Geriatr Rehabil* **27**, 257-267.
- [66] Huber M, Knotnerus JA, Green L, van der Horst H, Jadad AR, Kromhout D, Leonard B, Lorig K, Loureiro MI, van der Meer JW, Schnabel P, Smith R, van Weel C, Smid H (2011) How should we define health? *BMJ* **343**, d4163.
- [67] Vernooij-Dassen M, Moniz-Cook E, Jeon YH (2018) Social health in dementia care: harnessing an applied research agenda. *Int Psychogeriatr* **30**, 775-778.
- [68] Dröes RM, Chattat R, Diaz A, Gove D, Graff M, Murphy K, Verbeek H, Vernooij-Dassen M, Clare L, Johannessen A, Roes M, Verhey F, Charras K, Taskforce IsH (2017) Social health and dementia: a European consensus on the operationalization of the concept and directions for research and practice. *Aging Ment Health* **21**, 4-17.

SUMMARY
SOMMARIO
SAMENVATTING
DATA MANAGEMENT
ACKNOWLEDGEMENTS
PUBBLICATION LIST
PHD PORTFOLIO
CURRICULUM VITAE

8

Summary

This thesis reports on the development and implementation of a Shared Decision-Making framework in Dutch and Italian long-term care settings, to support the implementation of a more personalized care planning process.

Chapter 1 elaborates on the background and aims of this study. Dementia is a disease that progressively impairs the cognitive functioning of the person who is affected. As the disease progresses, the demand of continuous support increases and the family is challenged in providing adequate care. As a consequence, many persons with dementia (PwDs) need to be placed in long-term care (LTC) settings, which offer an opportunity for the PwDs and their families to be supported and to receive specialized professional care. Once admitted, both the PwD and the family first need to adapt to the new environment and staff needs to make efforts to involve, stimulate and communicate with the resident and his family. Particularly, the involvement of PwDs in meaningful activities that require the combination of cognitive stimulation, social interaction and leisure, may decrease the progression of the disease and increase the people's quality of life and sense of identity.

Shared Decision-Making (SDM) in LTC settings is an approach that enables professionals to focus on a resident's personal interests and values, collaborating with him and his family caregiver and allowing their involvement in the care process. In the past decade, several international care planning policy and guidelines that recommend the involvement of residents and family representatives in the development of care plans have been developed. However, these guidelines are hardly known, implemented and SDM is not common practice in nursing homes. There are two main reasons for such a lack of implementation. Firstly, PwDs are often excluded a priori from decisions regarding their care, although it has been demonstrated that the presence and severity of cognitive impairment cannot be considered the determining factor that accounts for the exclusion from decision-making. Secondly, national and international guidelines and policies do not always specify how to implement these requirements within the nursing homes and how to adapt them to their inner organization. As a consequence, inclusion is not guaranteed and care plans often fail to be person-centered.

The idea to develop an SDM framework in Italy and the Netherlands arose as both countries were involved in the IMPACT project (IMplementation of quality indicators in Palliative Care sTudy), an FP7 EU-funded research project that aimed to develop optimal strategies to improve the organization of palliative cancer and dementia care in Europe. International guidelines consider the use of SDM as the unique way to provide optimal palliative care. It is particularly recommended to be applied as soon as possible. Thus, involvement in care planning should be provided from admission and along the LTC journey.

Both in Italy and in the Netherlands, requirements for personalized care planning in LTC are in place, such as the involvement of the family caregivers and/or of the residents in the planning process and the development of personalized care plans, but they are not always implemented in a standardized way. Thus, our intervention

was developed to provide support to two Italian and Dutch nursing homes during the implementation of a more personalized care planning process and evaluate it.

Chapter 2 describes the results of a vignette study that explored when professionals in long-term care settings consider a person with dementia in need of palliative care. Eighty-five professionals working in 13 LTC settings located in 6 countries (the Netherlands, Italy, Norway, France, Poland and Germany) were given a case vignette describing the situation of a woman with dementia living in a nursing home and showing specific symptoms. Professionals were asked if they would consider the lady in need of palliative care. Their answers were analysed using the constant comparative method. Three different time points in the disease trajectory when people with dementia were considered to be eligible for palliative care emerged: (1) early in the disease trajectory; (2) when signs and symptoms of advanced dementia are present; and (3) from the time point that curative treatment of co-morbidities is futile. We found discrepancies in opinions not only between European countries but even between staff members working in the same LTC setting. These results showed that it is very challenging for professionals to identify the time point when palliative care and proactive care planning should start. This study provided important background information to be considered in the development of a framework to timely and better engage residents and their families in decisions on daily care provision.

Chapter 3 contains the research protocol of a controlled, prospective feasibility trial of which the results are described in this thesis. This study concerned an SDM intervention to improve the life-and-care plan in LTC settings, of which the intervention and outcome measures were based on international guidelines. Participants are triads composed of the resident with dementia, a family caregiver and the professional usually taking care for the resident. Professional caregivers of two nursing homes, one located in Italy and one in the Netherlands, would receive a specific training in SDM principles and will guide the SDM interview in the triad. The interview aimed to identify needs and wishes of the resident with dementia in order to tailor a more personalized 'life-and-care plan'. The family caregiver had the role to facilitate and support the resident's expression. The primary outcome was the proportion of residents whose preferences and needs, together with the related actions to meet them, are known, documented and satisfied in their 'life-and-care plans'.

Chapter 4 reports on the results of an integrative review aimed at identifying the core elements of the implementation of changes in nursing homes' care plans. Twenty-six journal articles describing the implementation of healthcare interventions that changed residents' nursing care plans were included. For each intervention, three elements were analysed: the type of stakeholders involved, the implementation strategies used and how care plans changed. The stakeholders involved were professionals, family caregiver, and patients but very few studies

involved residents and family caregivers in the quality improvement process. As regards the implementation strategies used, most frequently adopted were technology implementation, audit, training, feedback and supervision. Eventually, most interventions changed the residents' care plans in terms of developing a more standardized care documentation that primarily focused on its quality, but only some of them developed more tailored care plans that focused on individualized needs. These results confirmed that in nursing homes often care plans are not individualized, and not based on residents' specific needs and preferences, and that professionals should be provided with more efficient tools to report care goals and actions in care plans.

In **Chapter 5** we explored the results of focus group interviews conducted among those professionals who were trained during the project and who implemented the SDM framework in the involved nursing homes. Ten staff members in Italy and nine in the Netherlands were invited to participate in a focus group held in their nursing home to explore their opinions on the framework implementation. Content analysis was used to analyse the data. The barriers and facilitators emerged were organized in 6 themes and 15 categories. Overall, results were comparable in both countries. In both countries, team collaboration, communication skills and nursing home policy were found to be facilitators for the implementation process, whereas regulations, lack of funding and of involvement of family caregivers were mentioned as the main barriers. Family attitudes towards SDM can both facilitate or hinder the process. The main difference among Italy and the Netherlands concerned the residents' cognitive status that influenced their degree of involvement in care planning.

In **Chapter 6** the impact of the SDM training program on dementia care planning in long-term care, with a controlled trial as study design, is presented. The main aim was to analyse the effects of training nursing home staff on the implementation of SDM, measured as the agreement of residents' life-and-care plans with the recommendations from international care planning regulations. Specifically, the recommendations referred to the: (1) development of a comprehensive care plan including psychosocial aspects; (2) definition of problem statements and goals of care; (3) provision of specific interventions; (4) specification of goals' measurements and achievement; and (5) involvement of clients and relatives. Family caregivers' quality of life and sense of competence, and staffs' job satisfaction were secondary outcomes. In the intervention condition, staff was trained in the use of SDM with residents and family caregivers in the care planning process. In the control condition, care planning as usual took place. For the primary outcome, care plans were analysed qualitatively and quantitatively. Multivariate Permutation Tests were performed to assess the impact on secondary outcomes. Forty-nine residents and related family caregivers as well as 34 professionals were involved. Both Italian and Dutch care plans showed significant improvement in the number of clear problem statements ($p < 0.001$). In Italy, significant improvements were

also found regarding specific care objectives, documentation of objectives met and of residents and families' involvement ($p < 0.05$). Thus, many of the care plans developed during the intervention showed a high level of agreement with the care planning recommendations, as they contained more frequently measurable items, goals and actions were better documented, and reflected more accurately the residents nursing and psychosocial preferences. Regarding secondary outcomes, no effects were found on professionals' job satisfaction nor on family caregivers' sense of competence and quality of life.

Chapter 7 summarizes the main findings and conclusions of the study, discusses the theoretical and methodological considerations and delineates implications for practice, policy and research. In our study, involvement of LTC setting residents and their family is considered a basic principle that should be acted along the whole long-term care journey, from admission to the end-of-life phase.

Overall, this thesis contributes to the information and expertise about integrating the existing recommendations and guidelines related to care planning into the nursing home's care procedures and about enhancing the PwDs' autonomy and placing high value on their preferences and wishes. Indeed, only by involving the PwDs and their family caregivers before the end-stage, nursing homes' professionals can become aware of residents' preferences and provide adequate care, in line with their values.

Our findings show that it is feasible to incorporate SDM in the nursing home's clinical practice and organizational context. Furthermore, engaging the residents and the family caregivers resulted in improving the personalization of their care documentation, fulfilling an important principle of the person-centered approach. Following this approach, we tried to involve most residents with dementia, regardless of level of cognitive functioning, considering engagement as a fundamental value in itself. In fact, SDM is a mean through which residents with dementia and families can be fully considered and taken into account, beyond the specific outcomes reached through the decision-making process with staff. From our study, it emerges that training professionals on the SDM principles as well as involving both the clinical and organizational level, i.e. managers, are important requisites to implement the framework and to consider it as part of staff daily schedule. Furthermore, it appears that professionals should be provided with specific tools for the dementia context aimed at facilitating every-day decision-making.

Recommendations for future research concern performing a fully powered randomized control trial with a larger number of settings, residents and countries in order to improve external validity and generalizability of the SDM framework. Furthermore, since our study identified influencing factors that might facilitate or hinder the process in LTC settings, future research could integrate these factors when planning interventions that require the involvement of PwDs and their families.

Sommar

Questa tesi descrive uno studio di ricerca i cui obiettivi sono quelli di sviluppare un protocollo, basato sui principi del 'Processo Decisionale Condiviso', e di implementarlo in due strutture residenziali per anziani, una italiana ed una olandese, con lo scopo finale di rendere la pianificazione delle cure degli ospiti con demenza il più personalizzata possibile.

Il **Capitolo 1** descrive l'impianto teorico e gli obiettivi dello studio. La demenza è una malattia che progressivamente deteriora il funzionamento cognitivo della persona che ne è affetta. Via via che la malattia progredisce, la supervisione continua della persona che ne soffre diventa necessaria e la famiglia si trova sempre più in difficoltà nel gestire la patologia in modo adeguato. Una possibile conseguenza è che le persone con demenza siano ricoverate in strutture residenziali per anziani, che offrono cure specifiche e professionali. Una volta ricoverate, sia le persone con demenza che le loro famiglie si devono adattare al nuovo ambiente ed a sua volta lo staff deve imparare a conoscere le loro abitudini e a trovare modalità comunicative e di stimolazione adeguate. Infatti, è risaputo che il coinvolgimento degli ospiti con demenza in attività significative di stimolazione cognitiva, sociale e ricreativa abbiano un effetto positivo sulla velocità di progressione della malattia e sul loro senso di efficacia ed identità.

Il 'Processo Decisionale Condiviso' nelle strutture residenziali per anziani è un approccio che permette agli operatori di struttura di focalizzarsi sugli interessi personali degli ospiti e sui loro valori, aumentando la collaborazione con le famiglie e l'inclusione nel percorso di pianificazione delle cure.

Negli ultimi dieci anni, sono state elaborate diverse linee guida e protocolli internazionali che ribadiscono l'importanza di coinvolgere l'ospite e la sua famiglia nel percorso di cura. Tuttavia, queste linee guida sono poco conosciute e scarsamente implementate nelle strutture residenziali. Questo è dovuto principalmente a due ragioni. La prima, è che le persone con demenza vengono escluse a priori dal percorso di cura, nonostante sia stato dimostrato che la presenza e gravità del disturbo cognitivo non possano essere considerati fattori che giustificano la loro esclusione. La seconda ragione, è che spesso queste linee guida non contengono le indicazioni su come implementare i requisiti richiesti e come adattarli all'organizzazione interna delle strutture. Di conseguenza, molto spesso l'inclusione nel percorso di cura non è garantita e i piani di cura degli ospiti nelle strutture residenziali per anziani non sono personalizzati.

L'idea di implementare un protocollo basato sui principi del 'Processo Decisionale Condiviso' in Italia ed in Olanda nasce dal fatto che entrambi i Paesi erano coinvolti nel progetto IMPACT (IMplementation of quality indicators in PAlliative Care sTudy), finanziato dall'Unione Europea all'interno del programma quadro FP7, il cui obiettivo era quello di sviluppare delle strategie per migliorare la qualità delle cure palliative rivolte ai malati oncologici e con demenza in Europa. Le più importanti società scientifiche internazionali considerano l'utilizzo del 'Processo Decisionale Condiviso' come una delle modalità più adatte per erogare le cure palliative. In

particolare, raccomandano di erogarle il prima possibile, ed è per questo che il coinvolgimento degli ospiti con demenza e della loro famiglia dovrebbe avvenire da subito, non appena sono ammessi all'interno delle strutture residenziali.

Sia in Italia che in Olanda vigono dei requisiti per la personalizzazione della pianificazione delle cure, tra cui coinvolgimento degli ospiti e della loro famiglia nella percorso di cura e sviluppo di piani di cura personalizzati. Tuttavia questi requisiti sono poco implementati e comunque non in modo standardizzato. Perciò, il nostro intervento aveva lo scopo di supportare due strutture residenziali, una italiana ed una olandese, nell'implementare un percorso di cure personalizzato ed infine di valutarlo.

Il **Capitolo 2**, riporta i risultati di uno studio in cui sono state esplorate le opinioni dei professionisti che lavoravano in strutture residenziali, per capire se e quando consideravano gli ospiti con demenza bisognosi di cure palliative. Ad ottantacinque operatori di 13 strutture residenziali per anziani localizzate in 6 Paesi europei (Olanda, Italia, Norvegia, Francia, Polonia e Germania), era stata data una vignetta in cui veniva descritta la situazione di una donna con demenza che viveva in una casa di riposo e che mostrava specifici sintomi. Ai professionisti veniva chiesto se secondo loro la signora così descritta era bisognosa di cure palliative. Dall'analisi delle loro risposte, sono emersi tre principali momenti in cui andrebbero erogate le cure palliative: (1) ad inizio malattia; (2) quando si sviluppano sintomi e segni di una demenza allo stadio avanzato; (3) dal momento in cui il trattamento delle comorbidità diviene inutile. Abbiamo riscontrato delle discrepanze nelle risposte non solo tra Paesi diversi, ma anche tra i professionisti operanti all'interno della stessa struttura residenziale. Questo indica che per gli operatori è molto complesso capire quando le cure palliative dovrebbero essere fornite alle persone con demenza, ovvero in quale fase di malattia. A partire da queste informazioni, abbiamo pensato di sviluppare lo studio oggetto della presente tesi, che appunto ha lo scopo di coinvolgere il prima possibile le persone con demenza ed i loro familiari nel percorso di cura all'interno delle strutture residenziali.

Il **Capitolo 3** contiene il protocollo di ricerca dello studio, che è uno studio controllato di fattibilità. Lo studio riguarda l'intervento portato avanti nelle strutture residenziali per migliorare i piani di cura degli ospiti residenti in struttura, come indicato nelle linee guida internazionali. I partecipanti sono stati suddivisi in triadi, composte da un ospite con demenza, il suo familiare e l'operatore di struttura che di norma segue quell'ospite. Le strutture residenziali coinvolte sono due, una in Italia ed una in Olanda: gli operatori di queste due strutture residenziali hanno ricevuto una specifica formazione sui principi del 'Processo Decisionale Condiviso' ed hanno condotto un'intervista all'interno della triade. L'intervista, condotta in fase di sviluppo o di aggiornamento del piano di cura, serviva per comprendere bisogni e desideri della persona con demenza, il cui contributo veniva facilitato dalla presenza del familiare. Il risultato principale indagato era la proporzione di ospiti i cui bisogni, valori e desideri venivano segnalati e debitamente documentati

nel piano di cura, insieme alle azioni per soddisfarli.

Nel **Capitolo 4** sono descritti i risultati di una revisione integrativa della letteratura, il cui scopo era quello di identificare gli elementi centrali del processo di implementazione dei cambiamenti di piani di cura nelle strutture residenziali. Nella revisione sono stati inclusi 26 articoli scientifici che descrivevano interventi che in qualche modo andavano a modificare i piani di cura dei residenti di strutture residenziali. Per ogni intervento, sono stati analizzati tre elementi: la popolazione coinvolta nel processo di implementazione, le strategie utilizzate ed il tipo di cambiamento prodotto. La popolazione coinvolta era costituita da operatori, famigliari e residenti in alcuni casi, anche se in pochi studi gli ospiti ed i loro famigliari erano direttamente inclusi nel percorso di miglioramento. Per quanto riguarda le strategie, le più utilizzate erano: gli audit, l'uso di tecnologie, la formazione, il feedback e la supervisione. La gran parte degli interventi miglioravano genericamente la qualità della documentazione. Solo pochi invece rendevano più personalizzati i piani di cura, basandoli cioè sui reali bisogni individuali. Questo rispecchia la realtà delle strutture residenziali per anziani, dove la documentazione in genere soddisfa gli standard di qualità ma rimane troppo standardizzata e troppo poco individualizzata.

Nel **Capitolo 5** sono riportati i contenuti dei focus group organizzati con gli operatori che avevano ricevuto la formazione sui principi del 'Processo Decisionale Condiviso' e che avevano implementato il relativo protocollo nelle strutture residenziali coinvolte nel progetto. Dieci membri dello staff in Italia e nove in Olanda sono state invitati ad esprimere le proprie opinioni rispetto al percorso di implementazione del protocollo. Dall'analisi delle interviste sono state quindi estrapolate le barriere ed i facilitatori che hanno ostacolato e favorito il percorso, organizzandoli concettualmente in 6 temi ed in 15 categorie. Complessivamente, i risultati emersi sono simili in Italia ed in Olanda. Infatti, in entrambi i Paesi, i facilitatori sono risultati essere: la collaborazione all'interno del team, le abilità comunicative e la vision della struttura residenziale. Al contrario, i regolamenti, la mancanza di risorse economiche e lo scarso coinvolgimento standardizzato delle famiglie nel percorso di cura avevano reso difficile l'applicazione del progetto. L'atteggiamento dei famigliari risultava essere sia una barriera che un facilitatore a seconda dei casi. La maggior differenza che emergeva tra i due Paesi, era il grado di disabilità cognitiva degli ospiti, che aveva influenzato il loro coinvolgimento nel progetto.

Il **Capitolo 6** presenta i risultati riguardanti l'impatto del presente studio sui piani di cura sviluppati dalle strutture residenziali coinvolte nel progetto. Lo scopo finale era quello di analizzare gli effetti dell'uso del 'Processo Decisionale Condiviso', misurando il grado di accordo tra i nuovi piani di cura elaborati dallo staff e le raccomandazioni internazionali. Nello specifico, le raccomandazioni riguardavano: (1) lo sviluppo di piani di cura completi che includono anche aspetti psicosociali; (2) la definizione chiara dei problemi e degli obiettivi di cura; (3) l'erogazione di specifici interventi; (4) l'aggiunta delle misure per verificare la realizzazione degli

obiettivi di cura; (5) il coinvolgimento di utenti e famigliari. Risultato secondario era vedere se ulteriori cambiamenti si verificavano anche a livello della qualità di vita e del senso di competenza dei famigliari e della soddisfazione verso il proprio lavoro degli operatori. Le due strutture residenziali in cui venivano applicati i principi del 'Processo Decisionale Condiviso' erano confrontate con altre due strutture residenziali per anziani in cui la pianificazione delle cure avveniva invece come sempre. Terminato lo studio, i piani di cura sono stati analizzati sia dal punto di vista qualitativo che quantitativo. I risultati secondari sono stati analizzati mediante dei test multivariati. Quarantanove ospiti con relativi famigliari e 34 operatori sono stati coinvolti nello studio. Sia i piani di cura italiani che olandesi hanno mostrato un miglioramento significativo ($p < 0.001$) per quello che riguarda il numero di problemi più chiaramente descritti. In Italia poi, altri miglioramenti significativi hanno riguardato obiettivi di cura maggiormente specifici con più preferenze psicosociali, documentazione degli obiettivi soddisfatti e coinvolgimento di ospiti e famigliari ($p < 0.05$). Perciò, molti dei piani di cura sviluppati durante lo studio mostravano un più alto livello di accordo con le raccomandazioni internazionali. Per quello che riguarda i risultati secondari, non sono stati trovati effetti né sulla qualità di vita e sul senso di competenza dei famigliari, né sul livello di soddisfazione lavorativa degli operatori.

Il **Capitolo 7** riassume i risultati principali e le conclusioni dello studio, riporta le considerazioni teoriche e metodologiche e delinea le implicazioni nella pratica clinica, nella ricerca e di rilevanza sociale. Nel nostro studio, il coinvolgimento della persona con demenza e della sua famiglia è un principio cardine, che riteniamo dovrebbe essere considerato lungo tutto il percorso residenziale, da quando cioè si è ammessi in struttura sino alle fasi finali della vita.

Complessivamente, questa tesi fornisce un esempio concreto su come sia fattibile incorporare i principi del 'Processo Decisionale Condiviso' nei percorsi clinici delle strutture residenziali e su come sia possibile tenere in conto le preferenze ed i valori degli ospiti con demenza. Infatti, solo coinvolgendo gli ospiti e le loro famiglie è davvero possibile erogare dei servizi personalizzati, che si basino sulle loro esigenze individuali.

Il presente studio mostra che in effetti il coinvolgimento dell'utenza si è dimostrata avere un'influenza positiva sulla personalizzazione dei piani di cura, soddisfacendo uno dei requisiti cardine dell'approccio centrato sulla persona. Abbiamo quindi cercato di includere il maggior numero di ospiti con demenza, qualunque fosse il loro livello di funzionamento cognitivo, considerando il coinvolgimento come un valore importante già di per se stesso, a prescindere dagli obiettivi e dalle decisioni raggiunte con lo staff a seguito dell'inclusione.

Elementi di particolare rilevanza che sono emersi, sono la formazione degli operatori ed il coinvolgimento dei coordinatori di struttura: sono infatti risultati fattori che hanno permesso un'efficace implementazione del protocollo, permettendogli di avere spazio all'interno della routine clinica. Inoltre, è apparso come necessario fornire agli operatori degli strumenti che siano maggiormente adatti alle persone

con demenza, facilitando le loro possibilità di prendere delle decisioni condivise rispetto alle cure quotidiane.

Per quanto riguarda le implicazioni di questo studio nell'area della ricerca, si raccomanda di allargare il campione oggetto di studio all'interno di uno studio controllato randomizzato, al fine di migliorare la validità esterna e la generalizzabilità dei risultati. Infine, dato che il nostro studio ha permesso di identificare dei fattori che influenzano in senso positivo e negativo l'utilizzo del protocollo, le ricerche future dovrebbero tenerne conto nel momento in cui sviluppano degli interventi che prevedono il coinvolgimento degli ospiti con demenza e dei loro familiari nelle strutture residenziali.

Samenvatting

Dit proefschrift beschrijft de ontwikkeling van een framework voor gezamenlijke besluitvorming in Nederlandse en Italiaanse verpleeghuizen, om de implementatie van individuele zorgplannen te ondersteunen.

Hoofdstuk 1 beschrijft de achtergrond en doelstelling van deze studie. Dementie is een progressieve aandoening die de cognitie van een persoon met dementie aantast. Naarmate dementie vordert, neemt de vraag naar continue zorg toe waardoor het voor familie steeds moeilijker wordt om passende zorg te verlenen. Hierdoor komen uiteindelijk veel mensen met dementie terecht in verpleeghuizen, waar ondersteuning en professionele zorg kan worden geboden. Wanneer iemand met dementie wordt opgenomen in een verpleeghuis, zal deze persoon en diens familie zich moeten aanpassen aan de nieuwe omgeving. Het is de taak van de zorgverleners in het verpleeghuis om de nieuwe bewoner te betrekken, te activeren en te helpen communiceren met andere bewoners. Door het betrekken van mensen met dementie bij betekenisvolle activiteiten om de cognitie en sociale interactie te optimaliseren, wordt de progressie van dementie mogelijk geremd, wat de kwaliteit van leven en het ervaren van de eigen identiteit ten goede komt. Gezamenlijke besluitvorming is een methode die zorgverleners helpt om te focussen op persoonlijke waarden en interesses van de bewoner, en hem of haar samen met de familie het zorgplan op te stellen of aan te passen. In de afgelopen tien jaar zijn er verschillende internationale richtlijnen gepubliceerd om de betrokkenheid van mensen met dementie en hun familie in het zorgproces te stimuleren. Deze richtlijnen zijn echter niet breed bekend laat staan geïmplementeerd. Hierdoor is gezamenlijke besluitvorming nog geen algemene praktijk in verpleeghuizen. Nog steeds worden mensen met dementie vaak buitengesloten bij het maken van besluiten, ook al is het bewezen dat de mate van cognitieve beperkingen niet kan worden beschouwd als de bepalende factor die uitsluiting van besluitvorming verklaart. Bovendien specificeren lang niet alle nationale en internationale richtlijnen hoe bepaalde maatregelen in de zorg moeten worden geïmplementeerd en hoe ze kunnen worden aangepast aan de bestaande organisatiestructuren. Het gevolg is dat zorgplannen vaak niet persoonsgericht zijn.

Het idee om een framework voor gezamenlijke besluitvorming in Italië en Nederland te ontwikkelen is ontstaan tijdens het IMPACT project (IMplementation of quality indicators in Palliative Care sTudy). Beide landen namen deel aan dit Europese FP7 project dat als doel had om optimale strategieën te ontwikkelen om de organisatie van palliatieve zorg voor mensen met kanker en mensen met dementie te verbeteren. Internationale richtlijnen beschouwen het gebruik van gezamenlijke besluitvorming als de meest optimale manier om palliatieve zorg te verlenen. Daarbij wordt aanbevolen om gezamenlijke besluitvorming zo vroeg mogelijk te introduceren. Het betrekken van mensen met dementie bij het tot stand komen van de zorg begint daarom al op het moment van opname in een verpleeghuis. Zowel in Italië als in Nederland zijn er al maatregelen genomen die de betrokkenheid van mensen met dementie en hun familie bevorderen en die

het gebruik van gpersonaliseerde zorgplannen stimuleren. Deze maatregelen worden echter niet op een gestandaardiseerde geïmplementeerd. Daarom was het ons doel om twee verpleeghuizen in Italië en Nederland te ondersteunen in het implementeren van meer persoonsgerichte zorg en om deze zorg te evalueren.

Hoofdstuk 2 beschrijft de resultaten van een vignettestudie waarin zorgverleners werkzaam in verpleeghuizen zijn gevraagd naar hun mening wanneer iemand met dementie in aanmerking komt voor palliatieve zorg. Vijfentachtig zorgverleners uit 13 verpleeghuizen in zes landen (Nederland, Italië, Noorwegen, Frankrijk, Polen en Duitsland) kregen een casusbeschrijving van een persoon met dementie die recentelijk was opgenomen in een verpleeghuis. Vervolgens werd hen gevraagd of deze persoon in aanmerking kwam voor palliatieve zorg. Hun antwoorden zijn geanalyseerd en met elkaar vergeleken. Er werden drie verschillende momenten genoemd: (1) vroeg in het ziekte-traject; (2) bij symptomen van gevorderde dementie; of (3) wanneer het behandelen van co-morbiditeiten niet langer toereikend is. Deze studie toont aan dat zorgverleners in Europa, maar ook binnen één land en zelfs binnen één instelling verschillende meningen hebben over wanneer mensen met dementie in aanmerking komen voor palliatieve zorg. Dit bewijst dat het voor zorgverleners lastig is om te bepalen wanneer ze met palliatieve en proactieve zorg moeten starten. De resultaten van deze studie dragen daarom bij aan het ontwikkelen van een framework voor het tijdig betrekken van mensen met dementie en hun familie in het besluitvormingsproces.

Hoofdstuk 3 beschrijft het protocol van een gecontroleerde prospectieve haalbaarheidsstudie, waarvan de resultaten in dit proefschrift worden beschreven. Deze studie bevat een gezamenlijke besluitvormingsinterventie met als doel om het zorgplan voor mensen met dementie in verpleeghuizen persoonsgericht te maken. De interventie en uitkomstmaten waren gebaseerd op internationale richtlijnen. Deelnemers aan het gezamenlijke besluitvormingsgesprek zijn de persoon met dementie, een naaste en een professioneel zorgverlener. Er werd beschreven dat zorgverleners van twee verpleeghuizen, één in Italië en één in Nederland, getraind zouden worden in het toepassen van gezamenlijke besluitvorming en het coördineren van gesprekken met de persoon met dementie en diens naaste. In deze gesprekken zijn de wensen en behoeften van mensen met dementie geïdentificeerd om zorgplannen te kunnen personaliseren. De naaste kon tijdens deze gesprekken de persoon met dementie ondersteunen in het verwoorden van diens wensen en behoeften. De primaire uitkomstmaat was het aantal mensen met dementie waarvan de wensen en behoeften, samen met de activiteiten om aan de wensen en behoeften tegemoet te komen, beschreven waren in het zorgplan.

Hoofdstuk 4 beschrijft de resultaten van een integratieve review, met als doel het identificeren van de kernelementen voor het implementeren van veranderingen in zorgplannen in verpleeghuizen. Zesentwintig publicaties beschrijven het

implementeren van veranderingen in zorgplannen. Voor elke interventie zijn drie elementen geanalyseerd: het type stakeholders dat bij de interventie betrokken was, de implementatiestrategieën die gebruikt zijn en hoe de zorgplannen zijn veranderd. De betrokken stakeholders waren zorgverleners, mantelzorgers en patiënten. Slechts in een enkele studie waren patiënten en naasten betrokken bij het kwaliteitsverbetertraject. De implementatiestrategieën die het meest werden gebruikt waren het implementeren van technologie, audit, training, feedback en supervisie. Uiteindelijk hebben de meeste interventies tot een verandering in het zorgplan gezorgd door een meer gestandaardiseerde manier van documenteren. Slechts in een enkele interventie zijn individuele zorgplannen ontwikkeld waarin gefocust werd op de persoonlijke voorkeuren van de patiënt. Deze resultaten laten zien dat zorgplannen in verpleeghuizen vaak niet persoonsgericht zijn en dat zorgverleners behoefte hebben aan meer efficiënte middelen om zorgdoelen en acties in zorgplannen te documenteren.

In **Hoofdstuk 5**, hebben we de resultaten beschreven van focusgroepinterviews gehouden met de zorgverleners die zijn getraind in het toepassen van gezamenlijke besluitvorming. Tien zorgverleners in Italië en negen in Nederland zijn uitgenodigd om deel te nemen aan de focusgroepinterviews gehouden in het verpleeghuis waar ze werkzaam zijn met als doel om hun mening te inventariseren met betrekking tot de implementatie van het framework voor gezamenlijke besluitvorming. Een inhoudelijke analyse is gebruikt om de data van de focusgroepinterviews te analyseren. De belemmerende en bevorderende factoren die hieruit naar voren kwamen werden samengevoegd in zes thema's met vijftien categorieën. De resultaten in Italië en Nederland waren vergelijkbaar. In beide landen bleken samenwerking, communicatie en het beleid van de instelling belangrijke bevorderende factoren te zijn. Regelgeving, een gebrek aan financiering en betrokkenheid van de naasten werden genoemd als de belangrijkste belemmerende factoren. De instelling van familieleden ten opzichte van gezamenlijke besluitvorming kan zowel een bevorderende als belemmerende factor zijn. Het belangrijkste verschil tussen Italië en Nederland was de mening over of en hoe een beperkte cognitie van de persoon met dementie de betrokkenheid bij het besluitvormingsproces beïnvloedt.

In **Hoofdstuk 6** is de impact van de training in gezamenlijke besluitvorming in verpleeghuizen door middel van een gecontroleerde, prospectieve interventie beschreven. Het hoofddoel was om het effect van het trainen van zorgverleners in verpleeghuizen op het implementeren van gezamenlijke besluitvorming bij bewoners met dementie te analyseren. Als uitkomstmaat hebben we gekeken of de zorgplannen voldoen aan indicatoren uit internationale richtlijnen over individuele zorgplannen. De aanbevelingen verwezen naar: (1) het ontwikkelen van een zorgplan inclusief psychosociale aspecten; (2) definiëren van een probleem- en doelstelling; (3) het uitvoeren van specifieke interventies; (4) de specificatie van doelen; en (5) de betrokkenheid van de bewoner met dementie en diens naaste. De kwaliteit van leven en het gevoel van competentie bij naasten, en de werktevreden-

heid van zorgverleners waren secundaire uitkomsten. In de interventiegroep zijn zorgverleners getraind in het toepassen van gezamenlijke besluitvorming met mensen met dementie en hun naasten. In de controlegroep vond gebruikelijke zorg plaats. Voor de primaire uitkomsten zijn zorgplannen op een kwalitatieve en kwantitatieve manier geanalyseerd. Multivariate Permutation Tests werden uitgevoerd om de impact op de secundaire uitkomsten te meten. Negenenveertig mensen met dementie en hun naasten en 34 zorgverleners zijn geïncludeerd. In Nederland bleken de zorgplannen voorafgaande aan de interventie al vaker aan de richtlijnen te voldoen dan in Italië. Zowel in Italië als in Nederland werd bij de nameting een significante verbetering met betrekking tot de probleembeschrijvingen gevonden ($P < 0.001$). In Italië werden ook significante verbeteringen gezien met betrekking tot specifieke zorgdoelen, documentatie van behaalde doelen en de betrokkenheid van mensen met dementie en hun naasten ($p < 0.05$). Veel van de zorgplannen die gedurende de interventie werden gemaakt, lieten een grote mate van overeenkomst zien met de aanbevelingen, aangezien er vaker meetbare items, doelen en acties, en de psychosociale wensen en behoeften van mensen met dementie en het personeel in werden beschreven. Op de secundaire uitkomsten werden geen effecten gevonden wat betreft de werktevredenheid, gevoel van competentie van de naaste, of de kwaliteit van leven.

In **Hoofdstuk 7** werden de belangrijkste resultaten binnen een theoretisch kader geplaatst en vergeleken met andere studies. Hierbij zijn ook methodologische beperkingen alsmede aanbevelingen voor de praktijk, het beleid en toekomstig onderzoek geformuleerd. In mijn proefschrift is het betrekken van mensen met dementie in verpleeghuizen en hun naasten een basisprincipe dat ingevoerd zou moeten komen in de gehele keten van langdurige zorg, van opname tot en met de terminale fase.

Dit proefschrift levert een bijdrage aan de informatie over het integreren van bestaande aanbevelingen en richtlijnen met betrekking tot individuele zorgplannen in de verpleeghuissetting, en het versterken van de autonomie van mensen met dementie door meer nadruk te leggen op hun wensen en behoeften. Alleen door het tijdig betrekken van mensen met dementie en hun naasten, kunnen zorgverleners zorg leveren in lijn met de wensen en behoeften van mensen met dementie.

Onze bevindingen laten zien dat het mogelijk is om gezamenlijke besluitvorming in te voeren in de verpleeghuissetting. Bovendien resulteerde het betrekken van mensen met dementie en hun naasten in het verbeteren van persoonlijke informatie in de zorgplannen, wat een belangrijke bijdrage is voor persoonsgerichte zorg. Voortbordurend op deze methode, hebben we geprobeerd alle mensen met dementie, ongeacht mate van cognitief functioneren, te betrekken in de zorg. Gezamenlijke besluitvorming is een methode waardoor mensen met dementie en hun naasten meegenomen kunnen worden in het zorgproces, dat verder reikt dan het besluitvormingsproces van zorgverleners. Uit onze studie blijkt dat het trainen van zorgverleners, alsmede het betrekken van managers belangrijke voorwaarden zijn voor het implementeren van individuele zorgplanning en om gezamenlijke

besluitvorming onderdeel te laten worden van de dagelijkse zorgverlening. Daarbij blijkt dat zorgverleners de juiste handvatten moeten worden aangereikt om alledaagse besluitvorming te stimuleren.

Vanwege de positieve resultaten van onze pilotstudie raden we aan om een gepowerde gerandomiseerde gecontroleerde internationale studie uit te voeren.

Data Management

This thesis is based on the results of the implementation of an SDM framework in care planning for long-term care residents with dementia in Italy and the Netherlands. The medical and ethical review board Committee of the University of Bologna and of the Radboudumc, Nijmegen, have given approval to conduct this study.

This study has received funding from the EU 7th Framework Programme FP7/2011-2015 under Grant Agreement n°258883.

In our studies the participants involved provided written informed consent during the data collection moment, at baseline. The participating subjects filled in the research form on paper. The paper data is stored in a locked archive of the Department of Psychology, University of Bologna (room num. 42, closet num. 2209).

All paper quantitative data were entered into the computer by use of Excel and the qualitative data by use of Word (Microsoft Office, Redmond, Washington, USA). The privacy of the participants in this study is warranted by use of encrypted and unique individual subject codes. This code corresponds with the code on the participants' informed consent.

Data were converged from Excel to R-statistical software (Version 3.1.3) package flip. In 2019, the data is monitored by prof. Chattat, Department of Psychology, University of Bologna.

The participants' data for the analyses of the studies as presented in chapters 4, 5 and 6 is stored in a database of the Department of Psychology, University of Bologna (num.2038, hard disk num. 2039). The data presented in chapter 2 is stored in a database of IQ-Healthcare. These databases are only accessible by the project lead and research management.

The data will be saved for 15 years after termination of the study. Using these participants data in future research is only possible after a renewed permission by the subjects as recorded in the informed consent. The dataset analyzed during this study is available from the corresponding author on reasonable request.

Acknowledgements

I consider this thesis as a true journey that started well before I applied to be an external PhD candidate at Radboud University. Indeed, it all started in 2011, when I made my first step into research with the IMPACT project. And along my path, I met many wonderful people that allowed me to be here today, giving me the encouragement and confidence I needed to both begin and complete the PhD programme.

My very first 'GRAZIE' goes to my Italian co-promotor, Prof. Rabih Chattat. Dear Rabih, you are way more of a supervisor. Without you, I wouldn't have obtained my PhD because I wouldn't have had the opportunity to become a researcher. But first of all, I wouldn't know that research is not just a computer and a dataset, but it is a job that empowers persons with dementia, their families and the whole community to develop new instruments and new perspectives on the topic. Thanks to you, I learned that without passion about your own work, no job can be considered well-done. And thanks to you, I also learned that the word, 'academic', doesn't mean distance or hierarchy of roles, but means to work shoulder to shoulder to reach an objective as well as amusement! Rabih, I won't ever be your 'badante' nor I will ask you 'Do you remember?', because I perfectly know that sometimes my memory is even worse than yours!

And now it is time to thank my Dutch supervisors. Let's start with my promotors. Prof. dr. Myrra Vernooij-Dassen. Dear Myrra, before I met you, I didn't know the motto that I now profoundly love, and have interiorized, '*Work hard, play hard!*' To me you are a real example of how to be a successful woman, passionate, self-confident, and strong but who still remains easygoing and funny. You are able to bring out the best from people without ever being pushy and I just love that! I really hope to develop some of your characteristics one day. But first, I need to know your secret: where do I find the source of your never-ending energy?

Prof. dr. Raymond Koopman. Dear Raymond, we mainly talked and saw each other during our countless skype meetings. We can say that our professional relationship was mainly internet-based (perhaps it even qualifies as an E-relationship!). However, your professional guidance was always present and timing and your precise advices allowed my research to be rigorous and accurate. So thank you very much for your precious help as a promotor.

I have to specially thank Prof. dr. Yvonne Engels, my Dutch co-promotor. Dear Yvonne, your motherly nature really supported me through these years. It took me quite a lot to complete the programme, as through these six years many events occurred: I changed work twice, I moved, I married, I had a baby...in few words, life went by. But thanks to your professional but super-delicate, patient, encouraging and friendly presence, you always comforted me, giving me the right advice at the right me. 'The eyes are the windows into the soul'. Indeed, you have the ability to

talk to people looking at their eyes, and understanding what they are saying. At least this is true to me, because you were always able to choose the right word to say to me in every situation. So thank you for your support, for the conversations and the exchange of pictures we had.

And now my dear paranympths. Dear Jasper, you have always been a good friend to me, from the beginning of the IMPACT project and through the whole PhD trajectory. In life there are few certainties but I always had one: Jasper will be my paranympth when (if I ever!) get the PhD! You provided me with a friendly and professional support these years, and you even edited my thesis. So thank you very much. You love travelling as I do, so I hope one day to meet you either in Italy or the Netherlands or somewhere else in the world, why not?!

Annick, 'Ciao'! Your kindness and sweetness put me at ease immediately when I first met you, and it was such a nice surprise when I discovered your love for Italy and Italian! When I thought about the day of the defence, I had in mind I needed a person 'gentile e dolce' by my side, and who else but you? So 'grazie' for your presence.

Thanks also to the University collaborators, who helped me with the data collection and analysis: Giovanni, Chiara and Angélique. And thanks to the nursing homes that accepted to be part of my research. This thesis is made thanks to your work too!

Last but not least, my family and friends. Love, trust and support are the concepts that summarize your unique contribution to this thesis: without those three words, no other words could have been written to shape this book.

A special thanks for my husband Stefano: you have always taken care of me, even when I was tired and very busy. You were there when I decided to take this path and many others in my life, never judging but always encouraging, giving me the time and space I needed and believing in me. You were there, you are here, you always will be. A special word also to my baby girl Letizia. I finished the last chapter of this thesis 3 months after you were born. When I think about it, I really don't know how I manage to do it! Despite the tiredness, you gave me the strength and love I needed to write such an important part of the manuscript. Indeed, you are pure energy that runs through my veins, so thank you darling!

Publication list

Thesis

- Mariani E**, van Riet Paap J, Chattat R, Koopmans R, Kerhervé H, Leppert W, Forycka M, Radbruch L, Jaspers B, Vissers K, Vernooij-Dassen M, Engels Y (2015) Identification of the palliative phase in people with dementia: a variety of opinions between healthcare professionals. *BMC Palliative Care* **14**, 56.
- Mariani E**, Engels Y, Koopmans R, Chattat R, Vernooij-Dassen M (2016) Shared decision-making on a 'life-and-care plan' in long-term care facilities: research protocol. *Nursing Open* **3**, 179-187.
- Mariani E**, Chattat R, Vernooij-Dassen M, Koopmans R, Engels Y (2017) Care Plan Improvement in Nursing Homes: An Integrative Review. *Journal of Alzheimer's Disease* **55**, 1621-1638.
- Mariani E**, Vernooij-Dassen M, Koopmans R, Engels Y, Chattat R (2017) Shared decision-making in dementia care planning: barriers and facilitators in two European countries. *Aging and Mental Health* **21**, 31-39.
- Mariani E**, Chattat R, Ottoboni G, Koopmans R, Vernooij-Dassen M, Engels Y (2018) The Impact of a Shared Decision-Making Training Program on Dementia Care Planning in Long-Term Care. *Journal of Alzheimer's Disease* **64**, 1123-1135.

Other

- Iliffe S, Davies N, Vernooij-Dassen M, van Riet Paap J, Sommerbakk R, **Mariani E**, Jaspers B, Radbruch L, Manthorpe J, Maio L, Haugen D, Engels Y (2013) Modelling the landscape of palliative care for people with dementia: a European mixed methods study. *BMC Palliative Care* **12**, 30.
- Davies N, Maio L, van Riet Paap J, **Mariani E**, Jaspers B, Sommerbakk R, Grammatico D, Manthorpe J, Ahmedzai S, Vernooij-Dassen M, Iliffe S (2014) Quality palliative care for cancer and dementia in five European countries: some common challenges. *Aging and Mental Health* **18**, 400-410.
- van Riet Paap J, Vernooij-Dassen M, Brouwer F, Meiland F, Iliffe S, Davies N, Leppert W, Jaspers B, **Mariani E**, Sommerbakk R, Vissers K, Engels Y (2014) Improving the organization of palliative care: identification of barriers and facilitators in five European countries. *Implementation Science* **9**, 130.
- Mignani V, Ingravallo F, **Mariani E**, Chattat R (2017) Perspectives of older people living in long-term care facilities and of their family members toward advance care planning discussions: a systematic review and thematic synthesis. *Clinical Intervention in Aging* **12**, 475-484.
- Ingravallo F, Mignani V, **Mariani E**, Ottoboni G, Melon MC, Chattat R (2018) Discussing advance care planning: insights from older people living in nursing homes and from family members. *International Psychogeriatrics* **30**, 569-579.
- Ottoboni G, Chattat R, Camedda C, Galletti M, Macripò S, **Mariani E**, Ingravallo F (2019) Nursing home staff members' knowledge, experience and attitudes regarding advance care planning: a cross-sectional study involving **12** Italian

nursing homes. *Aging Clin Exp Res*.

Ottoboni G, Gallelli T, **Mariani E**, Rebecca Soluri V, Nunziata S, Tessari A, Savary JP, Chattat R (2019) Remote home physical training for seniors: guidelines from the AAL-supported MOTION project. *Eur J Ageing* **16**, 25-37.

PhD Portfolio

Name PhD candidate: <i>E. Mariani</i>		PhD period: <i>07-05-2013 – 12-11-2019</i>	
Department: <i>IQ Healthcare</i>		Promotor(s): <i>Prof. dr. M.J.F.J. Vernooij-Dassen</i> <i>Prof. dr. R.T.C.M. Koopmans</i>	
Graduate School: <i>Radboud Institute for Health Sciences</i>		Co-promotor(s): <i>Prof. dr. Y.M.P. Engels</i> <i>Dr. R. Chattat</i>	
		Year(s)	ECTS
TRAINING ACTIVITIES			
a)	Courses & Workshops <ul style="list-style-type: none"> – 4 years post graduate training in psychotherapy-specialization in Cognitive Behavioral Therapy (Studi Cognitivi S.p.A, Milano, Italy) – NCEBP Introduction course for PhD students (Radboudumc, Nijmegen, the Netherlands) – ‘Psychological assessment tools and models for patients in need of palliative care and for their families.’-Italian Society for Palliative Care (SICP) workshop (SICP, Bologna, Italy) – Effective writing and publishing scientific papers- Heuvellandcursus (Maastricht University, Slenaken, the Netherlands) – Rising the standards: better evaluation of psychosocial interventions in dementia care-InterDem Academy Masterclass (InterDem, Glasgow, UK) – Integrative Review Masterclass (Radboudumc, Nijmegen, the Netherlands) 	2011-2014 2013 2013 2014 2014 2016	120 2.0 0.5 3.0 0.5 0.2
b)	Seminars & lectures <ul style="list-style-type: none"> – Residential seminar in Forensic Neuropsychology (Italian Society for Neuropsychology, Bertinoro, Italy) 	2017	1.0

c)	<i>Symposia & congresses</i>		
	– European Association for Palliative Care (Prague, Czech Republic) poster presentation	2013	1.0
	– Alzheimer Europe (Glasgow, UK) poster presentation	2014	1.0
	– Italian Society for Gerontological Psychology (Torino, Italy) oral presentation	2014	0.3
	– Palliative care Research Centre and European Association for Palliative Care Research Network (Amsterdam, the Netherlands) oral presentation	2014	1.0
	– Alzheimer Europe (Ljubljana, Slovenia) poster presentation	2015	1.0
	– Italian Society of Gerontology and Geriatrics (Napoli, Italy) poster presentation	2016	0.3
	– Italian Society for Gerontological Psychology (Fano, Italy) oral presentation	2017	0.3
	– National Health System, Emilia Romagna Region (Ravenna, Italy) oral presentation	2017	0.3
d)	<i>Other Reviewer Scientific Papers</i>		
	– Journal of Alzheimer’s Disease	2017-2018	5.0
TEACHING ACTIVITIES			
e)	<i>Lecturing</i>		
	– Teacher of ‘Psychology of Ageing’ for the Master degree course (Faculty of Psychology, University of Bologna)	2019	1.0
f)	<i>Supervision of internships / other</i>		
	– /	/	/
TOTAL		138.7	

Curriculum Vitae

Elena Mariani was born in Faenza, Italy, on February 23, 1984. After graduating secondary school, she studied Psychology at the University of Bologna, obtaining a Bachelor degree in 2006 in 'Psychological Science and Techniques'. In 2009 she attained a Master degree in 'Neuropsychology and Life-long Functional Rehabilitation' with a thesis, supervised by prof. Chattat, on the motivation of healthy elderly people to attend memory training courses. Once graduated, she went to the UK to work as an au-pair in St. Alban, near to London, for 6 months: there, she attended an English school to improve her English. After that, she came back to Italy to do the compulsory internship of 6 months to become a psychologist: she did it in a memory clinic in Ravenna, increasing her theoretical and practical knowledge on psychology of ageing and dementia. In 2011 she started working as a researcher assistant of prof. CHATTAT at the Department of Psychology of the University of Bologna on the IMPACT project (IMplementation of quality indicators in Palliative Care sTudy), an EU-funded research project that aimed to develop optimal strategies to improve the organization of palliative cancer and dementia care in Europe. That year, during weekends, she also started attending a 4 years post graduate training at a private psychotherapy school recognized by the Ministry of Education to become a psychotherapist. In May 2013 she enrolled as an external PhD at Radboud University Medical Center in Nijmegen. In 2017 she stopped working for the University of Bologna and started working in a nursing home in Lugo for two years, leading cognitive stimulation therapy with persons with dementia and providing staff training and consultation. Since 2019 she works in a hospital-based memory clinic in Forlì, performing neuropsychological testing for the assessment and diagnosis of dementia and cognitive impairment in older adults, providing them with cognitive intervention programmes as well as psychological support to family caregivers. Elena is married with Stefano Naldi and in July 23, 2018, on the day of their second wedding anniversary, their daughter Letizia was born.

