Empowerment for people living with dementia

Charlotte van Corven

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Colofon

About the cover The triangles symbolize past, present and future – important for people living with dementia feeling empowered. Moreover, the triangles represent the person living with dementia (middle) being surrounded by family caregivers and healthcare professionals (left and right). The colors on the cover symbolize power and positivity. These same colors are used on the chapter pages; they expand during the thesis, just as knowledge and tools to support empowerment for people living with dementia expands.

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Contents

Chapter 1

General introduction

This thesis addresses the concept of empowerment for people living with dementia. It provides new insights into what empowerment for people living with dementia means and includes, and how empowerment can be promoted both at home and in nursing homes. In this way, this thesis contributes to enabling people living with dementia to live according to their competencies, talents and wishes, and discusses how family caregivers and healthcare professionals can support this.

Dementia

Dementia is an umbrella term used to describe a decline in memory or brain function that impacts an individual's daily life, and this decline goes beyond what might be expected from the usual consequences of ageing (World Health Organisation, 2021). The most common types of dementia are Alzheimer's disease, vascular dementia, frontotemporal dementia and dementia with Lewy Bodies (World Health Organisation, 2021). Currently, dementia affects approximately 55 million people worldwide, and there are nearly 10 million new cases every year (World Health Organisation, 2021). In the Netherlands, around 290,000 people are affected by dementia (Dutch Alzheimer Society, 2021). On average, people live with dementia for 6.5 years (Dutch Alzheimer Society, 2021).

Dementia is a progressive condition, as symptoms worsen over time, but the rate at which dementia progresses varies (Smits et al., 2015). People living with dementia experience a loss of abilities across the cognitive, functional and behavioral domains (van Wijngaarden et al., 2019). Actions which were previously easily performed can become more difficult or even impossible – for example, dressing, having a conversation, taking medicines, or exercising. As a result, participation in activities, social networks, and society can be severely compromised (Miranda-Castillo et al., 2013), and people living with dementia become increasingly dependent on their (in)formal caregivers. Some significant consequences of this are that people living with dementia may feel lonely or isolated (Janssen et al., 2020, Moyle et al., 2011), which can result in decreased well-being (Cohen-Mansfield et al., 2011, Stites et al., 2018). Biomedical research has focused on the search for a curative treatment for dementia, but despite huge efforts, this has not yet been realized (Winblad et al., 2016). It is imperative that people living with dementia remain active and involved in society, as having a meaningful life and remaining engaged are key aspects related to their well-being, quality of life and health (Dewitte et al., 2019, Gerritsen, 2021, Graff, 2019, Motta-Ochoa et al., 2021, van Vliet et al., 2017).

People living with dementia at home and in nursing homes

Almost three quarters of the people living with dementia in the Netherlands reside at home (Dutch Alzheimer Society, 2021). In the Netherlands, during the entire trajectory from (suspected) diagnosis until the person moves into a nursing home or passes away, dementia case managers are assigned as permanently involved professionals. These are typically nurses or social workers with additional training on case management (Huijsman et al., 2020, Reinhoudt-den Boer et al., 2021). Dementia case managers provide and coordinate care and support for people living with dementia and their families. This may also include referring people to other professionals such as physio-, speech or occupational therapists. However, as dementia progresses, living at home may not be possible anymore, for instance when the care needs become too complex, or the care burden on family caregivers becomes too high. People living with dementia may then move into a nursing home. These are facilities with a domestic-style environment that provide 24-hour functional support and care for people who require assistance with daily living, and who often have complex health needs and increased vulnerability (Sanford et al., 2015). Multidisciplinary teams provide care and support in nursing homes. These teams include, among others, nurses and nursing assistants, psychologists, well-being coaches, specialist nurses, elderly care physicians (Koopmans et al., 2017), physiotherapists, dieticians, occupational therapists, and speech therapists.

Support from family caregivers

People living with dementia who reside at home are mostly cared for by a single caregiver, usually a spouse, partner or relative (Brodaty and Donkin, 2009). These family caregivers provide care for their loved ones for months or years. It is, therefore, important to note that dementia not only affects the person living with dementia, but also their family members and friends. During the course of dementia, providing the continually intensifying care and support is often physically, emotionally and socially demanding (Brodaty and Donkin, 2009, de Vugt et al., 2005, de Vugt and Verhey, 2013, Joling et al., 2018, Vernooij-Dassen et al., 2017). In addition, communication between people living with dementia and their family caregivers may become more challenging (Jones, 2015). Yet, family caregivers have also reported positive feelings associated with the care they give (Vernooij-Dassen et al., 2017), for example, a sense of personal accomplishment, an increase in family cohesion, and a sense of personal growth and purpose in life (Yu et al., 2018).

When living at home is not possible anymore, moving to a nursing home is a decisive moment in the life of people living with dementia and their family caregivers. Family caregivers may feel unprepared or guilty about nursing home placement (Afram et al., 2015, Cole et al., 2018, Pritty et al., 2020). For people living with dementia, the move may represent the loss of their home and their neighborhood, and may lead to less time spent with their family and friends (Sury et al., 2013). Therefore, it is imperative that nursing home residents maintain their interests, routines, habits and roles in a personalized environment where their family and friends are welcomed, and can contribute to their well-being (Edvardsson et al., 2010, Groenendaal et al., 2019, Owen et al., 2021). However, family caregivers may still experience challenges in connecting with their loved one in a nursing home (Duggleby et al., 2013), and preserving a sense of togetherness. For example, feeling “one” as a couple may be compromised (Førsund et al., 2016, Swall et al., 2020). It is, therefore, of great importance to assist family caregivers in maintaining or establishing a meaningful and supportive connection to their loved one.

A person-centered approach

In recent decades, many stakeholders have continuously searched for optimal care and support both at home and in nursing homes. There has been a shift from task-oriented care, with a focus on the illness, to person-centered care with an emphasis on the whole person. Person-centeredness means that peoples’ values and preferences are elicited, and guide all aspects of their care (American Geriatrics Society Expert Panel on Person-Centered Care, 2016). This is achieved through a dynamic relationship with others who are important to them (American Geriatrics Society Expert Panel on Person-Centered Care, 2016). More specifically, rather than providing care in accordance with routines organized for staff convenience or efficiency, person-centered care focuses on the person living with dementia – their self (who they are, values and beliefs), needs, and relationships with others. It is based on knowing the person in a way that supports their choice and dignity (Edvardsson et al., 2008, Fazio et al., 2018, Kitwood, 1997). Continuing research into interventions that strengthen an inclusive environment with (in)formal caregivers who acknowledge the person’s unique personality and life history remains important (Moniz-Cook et al., 2011, Oyebode and Parveen, 2016). This research may establish ways for people living with dementia to be able to live according to their competencies, talents and wishes, with support from their family, friends and healthcare professionals. Such psychosocial approaches have the potential to enhance the well-being and quality of life of people living with dementia.

Empowerment as a promising concept

The concept of empowerment may contribute to shaping person-centered care for people living with dementia. The World Health Organization defined empowerment as a process through which people gain greater control over decisions and actions affecting their health (World Health Organization, 1998). It may be considered a process that enhances health (Aujoulat et al., 2007) and quality of life (Adams, 2008). However, definitions of empowerment and ways to promote empowerment may differ, depending on the population in which it is applied (Tengland, 2008). For instance, in specific research among people with a chronic illness empowerment was specified, and it suggested that empowerment is a dual process of ‘holding on’ to previous self-representations and roles, while simultaneously ‘letting go’ by integrating the illness and its boundaries into their lives (Aujoulat et al., 2008).

Considering that dementia causes cognitive impairment and behavioral changes that can affect gaining control over decisions and actions, the definition of empowerment may differ between people living with dementia and people living without dementia. As such, it is essential to clearly define empowerment for people living with dementia, as it may help to shape and provide individualized support, for example by being involved in decision-making, improved relationships, maintaining an active life and the use of advance directives for future medical care (Hill et al., 2018, Maki et al., 2020, McConnell et al., 2018, Prato, 2018). However, it is not yet clear what empowerment specifically means and includes for people living with dementia.

To our knowledge, no interventions exist that are explicitly aimed at empowerment for people living with dementia. Therefore, specific research about empowerment is needed for this group to optimally contribute to good care and support. Further, more insight into empowerment may contribute to the development and use of interventions supporting people living with dementia to be able to live the life they want. In this development and evaluation of empowerment interventions, it is necessary to use scientific methods directed at a good theoretical understanding. Moreover, needs, wishes, abilities and views of all stakeholders need to be taken into account to ensure applicability in practice (Moniz-Cook et al., 2011). It is therefore important to gain insight into both the perspectives of people who are living with dementia, their family caregivers, and the perspectives of professionals who offer care and support at home and in nursing homes.

Aims and research questions

The studies in this thesis aim to investigate: (1) what the concept of empowerment for people living with dementia means and includes, and (2) to develop, and evaluate the feasibility, of interventions that promote empowerment for people living with dementia. The following research questions are addressed:

Question 1
What does empowerment for people with dementia mean and include?

Question 2
How can empowerment for people living with dementia be promoted?

Outline and methodology

To answer the first research question, **Chapter 2** explores what the concept of empowerment for people living with dementia means and includes from the perspective of people living with dementia themselves (n=15), their family caregivers (n=16), and healthcare professionals (n=46). We conducted focus group discussions and individual interviews, including both the home and nursing home settings. Qualitative analyses were performed to identify the domains of empowerment. We developed a framework in which all of the domains were incorporated.

Subsequently, **Chapter 3** describes how the concept of empowerment is used within the scientific literature regarding people living with dementia. We performed an integrative review to obtain a broad understanding of the concept, and integrated this knowledge into our conceptual framework based on stakeholder perspectives.

To answer the second research question, **Chapter 4** explores ways in which family caregivers may need support in promoting empowerment. It describes the perspectives of family caregivers (n=31) regarding their interaction and relationship with the person living with dementia in a nursing home. We conducted telephone interviews with family caregivers about how they interact with their loved one in a nursing home, their related experiences, and how they construct a meaningful connection.

Moreover, **Chapter 5** identifies existing empowerment interventions for people living with dementia. We performed an online survey among professionals involved in psychosocial support for people living with dementia across Europe to find out which interventions and projects are considered empowering and why.

Furthermore, **Chapter 6** describes the development and feasibility evaluation of an intervention to promote empowerment of nursing home residents living with dementia. The development and feasibility evaluation followed the first two phases of the British Medical Research Council's (MRC) framework: the development and feasibility phase (Skivington et al., 2021). Alongside the MRC framework, we also used the Intervention Mapping approach in the development phase (Bartholomew et al., 1998), and in the feasibility phase we evaluated Bowen's aspects for feasibility (Bowen et al., 2009).

The general discussion in **Chapter 7** summarizes the main findings, elaborates on these findings and the used methodology, and accordingly formulates implications for practice, education, and future research.

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Chapter 2

Defining empowerment for older people living with dementia from multiple perspectives: a qualitative study

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Abstract

Background and objectives: The concept of empowerment seems promising for people living with dementia to live their life as they want to for as long as possible. Therefore, this study aimed to explore what the concept of empowerment means and includes for people living with dementia from the perspectives of people living with dementia themselves, their family caregivers[1], and healthcare professionals.

Research design and methods: Qualitative research using focus group discussions and individual interviews with people living with dementia (n=15), family caregivers (n=16) and healthcare professionals (n=46) to explore perspectives on empowerment. Audio-recordings were transcribed verbatim, and separately analyzed by two researchers using inductive thematic analysis.

Results: Four themes were identified as important aspects of empowerment: (1) having a sense of personal identity, (2) having a sense of choice and control, (3) having a sense of usefulness and being needed, and (4) retaining a sense of worth. Based on these themes, a conceptual framework of empowerment for older people living with dementia was developed. Empowerment takes place within the person living with dementia, but is achieved through interaction with their environment. The four themes seem to be important both at home and in nursing homes, and in different stages of dementia. However, practical detailing of support differed.

Discussion and implications: Our empowerment framework may provide a basis for developing interventions to empower people living with dementia and to strengthen (in)formal caregivers in this empowerment process. Support for people living with dementia must be adjusted to their personal situation and individual capabilities.

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[1] Family caregivers are in the original article named *informal caregivers*. To reach consistency throughout this thesis, we changed this to *family caregivers*.

Introduction

Dementia causes loss of abilities across cognitive, functional and behavioral domains. As a result, involvement in activities, social networks and society can be severely compromised, and people living with dementia become increasingly dependent on their (in)formal caregivers. The consequence is that people living with dementia may feel lonely or isolated (Moyle et al., 2011), or are not engaging in meaningful activities (Miranda-Castillo et al., 2013), possibly resulting in decreased quality of life (Cohen-Mansfield et al., 2011). As having a meaningful life and remaining engaged is very important for the well-being of people living with dementia (Dewitte et al., 2019, van Vliet et al., 2017), it is imperative that they remain active and involved in society. In the past years, the concept of empowerment has been increasingly used as a means to realize this (Hill et al., 2018, McConnell et al., 2018, Nomura et al., 2009, Prato, 2018, Vann, 2013). However, what empowerment means and includes for people living with dementia is still unclear.

The World Health Organization defined empowerment as a process through which people gain greater control over decisions and actions affecting their health (World Health Organization, 1998). In specific research among people with a chronic illness, empowerment was suggested to be a double process of ‘holding on’ to previous self-representations and roles, while at the same time ‘letting go’ by integrating the illness and its boundaries into their lives (Aujoulat et al., 2008). Considering that dementia causes cognitive impairment and behavioral changes that can affect gaining control over decisions and actions, the concept of empowerment may differ between people living with dementia and people without dementia.

Even though the word ‘empowerment’ is often used in dementia research in describing the aim of an intervention, a theme in the result section, or as a word used to interpret results in the discussion (Giguere et al., 2018, Hobden, 2018, Read et al., 2017), literature on what empowerment means and includes for people living with dementia remains scarce. To the best of our knowledge, only one recent study has conceptualized empowerment for people living with dementia. This study defined empowerment as ‘a confidence-building process whereby people living with dementia are respected, have a voice and are heard, are involved in making decisions about their lives and have the opportunity to create change through access to appropriate resources’ (McConnell et al., 2019). This definition was co-produced with nine members of Dementia Northern Ireland (an organization founded and led by people living with dementia), who may be considered activists in terms of striving to improve the lives of people living with dementia (McConnell et al., 2019). McConnell and colleagues therefore suggest that their general definition of empowerment may not be as relevant to people living with dementia who do not belong to such a group, or are in late stages of dementia. Furthermore, since the relationship between individuals and people in their environment seems central to the empowerment process (Holmstrom and Roing, 2010), it is important to include the perspectives of informal and formal caregivers when defining empowerment for people living with dementia. Therefore, to expand previous research, more input is needed from people living with dementia, and all stakeholders involved in their care and support.

In this study, we aim to explore what the concept of empowerment means and includes for people living with dementia. By incorporating the perspectives of people living with dementia, their family caregivers and healthcare professionals, and including both home and nursing home settings, we aim to advance the understanding of empowerment for older people living with dementia. With this knowledge, we will develop a framework, which can be used in the development of new interventions for people living with dementia with a focus on empowerment.

Design and methods

Design and procedure

We performed a qualitative study with fourteen focus group discussions with people living with dementia (2 focus group discussions, n=11), family caregivers (3 focus group discussions, n=16) and healthcare professionals (8 focus group discussions, n=46), and four individual interviews with people living with dementia. Focus group discussions were organized separately for people living with dementia, family caregivers, and healthcare professionals. One focus group discussion was organized for people living with dementia residing at home and their family caregiver together. Furthermore, focus group discussions were organized for two different settings: people living with dementia residing at home, and those residing in a nursing home. One focus group discussion was organized together for healthcare professionals working in a nursing home or working with people living with dementia residing at home. Table 1 presents an overview of all focus group discussions and individual interviews. The study was conducted in the Netherlands from October 2018 to March 2019. Four organizations affiliated with the Nijmegen University Network for long-term care (UKON) and one other organization providing care and support for people living with dementia, were asked to participate in the study. UKON is an alliance between 15 care organizations in the Netherlands and the department of Primary and Community Care of the Radboud university medical center in Nijmegen. All five approached organizations were willing to participate.

Table 1. *Overview of focus group discussions and individual interviews.*

	People living with dementia	**Family caregivers**	**Healthcare professionals**	
Nursing home setting[a]	4 individual interviews 1 focus group discussion (n=3)	1 focus group discussion (n=4)	4 focus group discussions (n=4, n=8, n=6 and n=5)	1 focus group discussion with healthcare professionals working in a nursing home setting (n=4) and at home (n=1)
Home setting[a]	1 focus group discussion (n=5)	2 focus group discussions (n=5 and n=5)	3 focus group discussions (n=6, n=8 and n=4)	
	1 focus group discussion with people with dementia (n=3) and their family caregiver (n=2)			

[a] Context for person living with dementia

Participants

In each organization, a contact person approached persons living with dementia, family caregivers and/or healthcare professionals to participate in a focus group discussion. This was done either by email, by letter, or face-to-face. Purposive sampling methods were used in approaching participants to achieve variation in participant characteristics (Moser and Korstjens, 2018). For example, we considered the living situation of the person living with dementia, the severity of dementia, the relationship with the relative for family caregivers and the occupation of healthcare professionals as relevant characteristics. Eligibility criteria for people living with dementia included a diagnosis of dementia and willingness to participate in a group discussion. Family caregivers were eligible to participate if they were relatives or partners providing a broad range of assistance to someone living with dementia (not necessarily a person living with dementia participating in our study). Healthcare professionals were eligible to participate if they provided care or support for people living with dementia. No further inclusion criteria were set for healthcare professionals in order to include views from different occupations and educational levels.

Data collection

A focus group interview guide was developed in a collaboration of the research team (all authors) and an advisory expert team for this study. The advisory expert team consisted of a nursing assistant, dementia case manager and quality assurance officer of participating long-term care organizations and assured that the design of the research project and data collection was suitable for all stakeholders. Questions aimed to explore what the concept of empowerment means and includes for people living with dementia, so were based on three topics: definition of empowerment, current care and support regarding empowerment, and potential improvements in care and support regarding empowerment. Broad open-ended questions were asked, followed by questions on themes that were introduced by participants. No pilot was done beforehand. The focus group interview guide was adapted after analysis of the first eight focus groups. The adapted interview guide contained more in-depth questions regarding themes mentioned in the previous discussions. The interview guide is shown in Additional file 1.

For people living with dementia residing in a psychogeriatric nursing home unit, individual interviews were performed instead of focus group discussions. They provided verbal consent, and written informed consent was provided by their family caregiver. The moderators took the severity of dementia into account when asking questions: in case of more severe dementia, more simple questions were asked, e.g. instead of “what comes to mind when you hear the word empowerment?”, we asked “do you know the word empowerment?” or “when do you feel good?”.

Discussions were facilitated by a moderator (AB or DG, both experienced conversation leaders) and lasted approximately 60 minutes with people living with dementia, and 90 minutes with family caregivers and healthcare professionals. Focus group discussions and interviews took place at locations most comfortable for the participants, i.e. a location of the participating organizations (nursing home, day care center, or office building). One or two observers were also present (CvC, MW). Both moderators and observers were female. Both moderators and observers were female. No other people were present during the focus group discussions besides the moderator, observer and participants. Potential participants read, understood, and agreed with the participant information letter and provided informed consent. Participants completed a brief sociodemographic questionnaire. Before starting the discussion, an introduction round was held in which the moderator, observer, and participants introduced themselves, and the aim and reasons for the study were explained. The discussions were tape-recorded with participants’ consent and transcribed verbatim. Transcripts were not returned to participants for comments or correction, and no repeat interviews were carried out. The moderator and observer held a debriefing session after all focus group discussions. Field notes were written after each focus group discussion.

Participant characteristics

In total, 15 persons living with dementia, 16 family caregivers and 46 healthcare professionals participated. Demographic characteristics of the participants are shown in Table 2 and Table 3. Since family caregivers were not necessarily related to the participating person living with dementia, demographic characteristics of the people living with dementia being cared for by the family caregivers are also shown. The moderator and observer had no relation to participants before study commencement. One member of the advisory expert team did participate and was therefore known beforehand. No participants dropped out of the study.

Data analysis

Transcripts of the focus group discussions were entered into Atlas.ti (version 8.4.15). Inductive thematic analysis was used (Elo and Kyngas, 2008), in which common themes and categories were identified using inductive reasoning and constant comparison, which means no theoretical perspective guided the coding or interpretation. Coding was done separately by two researchers (CvC and MW). We developed a coding system by using open codes to describe all relevant aspects raised by participants (Hsieh and Shannon, 2005). Codes referring to the same phenomenon were grouped into categories and these categories were grouped into higher-order themes. For example, the statement "I think it is important that you know how someone has lived at home [before moving to a nursing home], and try to maintain that as much as possible"" was coded under the category "life history and habits". This category was later linked to the category "Being the person you have always been" and merged together with another category into the theme "having a sense of personal identity". Consensus meetings with the research team and the advisory expert team were held to reach agreement on coding and interpretation, and together themes were defined. Based on these identified themes, we developed a framework in which all the themes were incorporated. The consolidated criteria for reporting qualitative research (COREQ) were followed in this article (Tong et al., 2007).

Ethical considerations

The study was conducted in accordance with Dutch law and the Declaration of Helsinki. The study protocol was reviewed by the local Medical Ethics Review Committee "CMO Regio Arnhem Nijmegen" (number 2018-4101), which stated that the study was not subject to the Medical Research Involving Human Subjects Act. Verbal and/or written informed consent was obtained from all participants before the start of the focus group discussion or interview. People living with dementia were approached to participate a week beforehand by a healthcare professional familiar to them. At the time of the focus group discussion or interview, they were asked again if they were willing to participate. During the focus group discussion or interview, the interviewer and observer monitored the participants' engagement and their willingness to participate remained high. For people living with dementia residing in a psychogeriatric nursing home unit, next to verbal consent of the person with dementia, written consent was also obtained from the family caregiver.

Table 2. *Demographic characteristics of participating people living with dementia, and family caregivers and their family member with dementia*

	Participating person living with dementia (n = 15)	**Participating family caregivers**	
		Family caregiver (n=16)	**Family member living with dementia** (n=16)
	Mean (SD) or n (%)	*Mean (SD) or n (%)*	*Mean (SD) or n (%)*
Mean age (years)	83.3 (9.8)	65.6 (10.7)	-
Sex (% female)	12 (80.0)	14 (87.5)	-
Marital status			
Married	3 (20.0)	-	-
Divorced	1 (6.7)	-	-
Widow(er)	10 (66.7)	-	-
Single	1 (6.7)	-	-
Educational level			
Low	12 (79.9)	5 (31.2)	-
Middle	1 (6.7)	7 (43.8)	-
High	2 (13.4)	4 (25.0)	-
Living status			
Living alone	5 (33.3)	-	-
Living with others	3 (20.0)	-	10 (62.5)
Nursing home (somatic)	3 (20.0)	-	-
Nursing home (psychogeriatric)	4 (26.7)	-	6 (37.5)
Relation with PwD			
Married/Partner	-	9 (56.3)	-
Child	-	5 (31.3)	-
Child-in-law	-	2 (12.5)	-
Living with PwD (% yes)	-	8 (50.0)	-
Dementia type[a]			
Alzheimer’s disease	7 (46.7)	-	8 (50.0)
Vascular dementia	2 (13.3)	-	4 (25.0)
Combination AD VD	2 (13.3)	-	3 (18.8)
Combination VD FTD	1 (6.7)	-	-
Unknown	2 (13.3)	-	-
Stage of dementia[b]			
Mild	4 (26.7)	-	2 (12.5)
Average	9 (60.0)	-	9 (56.3)
Severe	2 (13.3)	-	5 (31.3)
Caregiver burden[c]	-	4.9 (2.7)	-

PwD = person living with dementia

[a] One missing PwD, one missing for family caregivers, AD = Alzheimer’s disease, FTD = frontotemporal dementia, VD = vascular dementia

[b] Indication of healthcare professional (participating PwD) or family caregiver (family member living with dementia)

[c] Rating on a scale from 0 (low caregiver burden) to 10 (high caregiver burden)

Table 3. *Demographic characteristics of healthcare professionals.*

	Healthcare professional working with PwD residing at home (n = 19) *Mean (SD) or n (%)*	**Healthcare professional working with PwD residing in a nursing home** (n = 27) *Mean (SD) or % (n)*
Mean age (years)	50.3 (10.5)	46.2 (11.9)
Sex (% female)	19 (100)	26 (96.3)
Educational level		
Low	1 (5.3)	-
Middle	5 (26.3)	18 (66.7)
High	13 (68.4)	9 (33.3)
Years of working experience		
With support or care for PwD	17.7 (11.3)	15.7 (10.5)
Current position[a]		
Care assistant	-	1 (3.7)
Nurse assistant	3 (15.8)	9 (33.3)
Nurse	1 (5.3)	7 (25.9)
Specialist nurse	-	1 (3.7)
Elderly care physician	-	1 (3.7)
Activity therapist	2 (10.5)	4 (14.8)
Psychologist	-	1 (3.7)
District nurse	4 (21.1)	-
Case Manager	10 (52.6)	-
Occupational therapist	1 (5.3)	1 (3.7)
Other[b]	4 (21.1)	2 (7.4)
Field of work[c]		
Somatic department nursing home	-	7 (25.9)
Psychogeriatric depart. nursing home	2 (10.5)	20 (74.1)
Small-scale living unit	-	12 (44.4)
Home care	7 (36.8)	-
Case management	10 (52.6)	-
Day care	5 (26.3)	-
Other[d]	4 (21.1)	3 (11.1)

PwD = person living with dementia

[a] Percentages add up to more than 100 percent, because six participants reported two positions

[b] Healthcare professional in nursing home: living room staff member, team leader. Healthcare professional at home: elderly consultant, coordinator day care, and district coach

[c] Percentages add up to more than 100 percent, because seven participants reported two positions and five participants reported three positions

[d] Field of work in nursing home: Alzheimer organization Gelderland, center for the deaf-blind, private occupational therapist practice. Healthcare professional at home: mental healthcare, psychiatry district coach team (twice)

Results

Based on the perspectives of people living with dementia, family caregivers, and healthcare professionals, we were able to identify four themes considered as important aspects of empowerment: (1) having a sense of personal identity, (2) having a sense of choice and control, (3) having a sense of usefulness and being needed, and (4) retaining a sense of worth. Table 4 shows an overview of the codes, categories and themes. Saturation was established as no new categories or themes emerged after the twelfth focus group discussion. Based on the four themes, we developed a conceptual framework as displayed in Figure 1.

Table 4. *Overview of codes, categories and themes.*

Themes (heading) and categories	Codes
Having a sense of personal identity	
Being the person you have always been	*Know the person: life history and habits*
Being the person you are now	*Know the person: wishes and needs*
Having a sense of choice and control	
Making own choices	*Making your own choices, freedom in choices*
Choices are accepted and respected	*Accept choice of person living with dementia, nothing is mandatory*
Making choices is supported when needed	*Maintain autonomy with support*
Having a sense of usefulness and being needed	
Doing what you can, want, and are used to for as long as possible	*Don't take over tasks, start with new habits in good time*
Being activated and challenged	*Involve person living with dementia in daily tasks, try what activates someone*
Retaining a sense of worth	
Feeling valued	*Retain sense of worth, dignity*
Being heard and seen	*Talk to the person living with dementia*
Participating in society	*Dementia-friendly society, knowledge about dementia*

Theme "having a sense of personal identity"

One of the key themes that emerged from the analysis was the importance of identity, being both personal identity from the past and what this is now. This theme was mostly addressed by healthcare professionals and family caregivers. People living with dementia did not explicitly mention this theme. However, one woman living with dementia residing in a nursing home showed many of her personal belongings during the interview, which could be seen as the importance of her personal identity.

Being the person you have always been

Healthcare professionals and family caregivers mentioned the importance of knowing the life history of the person living with dementia. It was stated that through this, healthcare professionals gained insight into a person's motivations, and received explanations for certain behaviors, so they could adjust their approach specifically to that person. Healthcare professionals reported being able to provide better support in this way, to adjust activities to the individual, and consequently empower a person living with dementia by connecting to who a person has always been:

> *A man came here at the day care center who had always been a concierge at a school. That's why we made a badge for him with "concierge" on it. But he found it odd that he never got paid, so every Friday we gave him an envelope with 20 euro. On Mondays, his daughter returned the same envelope with the 20 euro to us. But we said to him "thank you for working here, there you go, see you next week" (healthcare professional, working at a day care center, H29)*

To connect to who a person has always been, some examples were given about staying engaged in activities someone did for a long time. A healthcare professional mentioned an example of a woman who was able to stay in her bridging club, with the help of a friend, despite her cognitive impairment. She could remain the person who she had always been: someone who enjoys bridge.

Being the person you are now

Healthcare professionals and family caregivers mentioned the relevance of recognizing and supporting who the person is at this moment. They stated that individual preferences may change over time. A healthcare professional described the example of a man who liked to do the gardening at the day care center. His daughter was surprised, since he had never shown any interest in gardening before. It was mentioned that such interests in new activities should be supported and encouraged to connect to who a person is now.

Differences in living situation and/or severity

The importance of having a sense of personal identity was mentioned more often for nursing home residents than for people living with dementia residing at home. First of all, healthcare professionals and family caregivers mentioned the difficulty of having a sense of personal identity within the group dynamics of the nursing home. Some healthcare professionals mentioned they tried to overcome this by giving individual attention to each individual, even when together in a group. Furthermore, healthcare professionals and family caregivers mentioned experiencing difficulties with connecting to the person, when people with more progressed dementia are disorientated in time and think they are in an earlier life phase. This makes it more challenging to connect to their world and the person they are at that moment, since they provide less information on what they like and wish, and what is important for them. Healthcare professionals and family caregivers mentioned they tried to overcome this by obtaining information about a person's life story (including their former preferred interests, roles, habits, routines, values, and norms), but also by trying different activities and attitudes, thereby observing behaviors of the person living with dementia.

Theme "having a sense of choice and control"

The second key theme that emerged from the data was the importance of people living with dementia having a sense of choice and control. This theme was mentioned by people living with dementia, family caregivers and healthcare professionals. This included people living with dementia making their own choices, choices being accepted by the people around them, and support in making choices being provided when necessary.

Making own choices

People living with dementia, family caregivers and healthcare professionals both mentioned the importance of making their own choices and feeling in control. A participant living with dementia said:

> *If you are capable of making choices yourself, then you want to keep control over your own life, right? Otherwise you are just a number. (person living with dementia, residing at home, D14)*

It was emphasized that no activities or choices should be mandatory, and individuals should always have the possibility to say "no". Examples included providing choices around daily activities: which activities are preferred, routine of daily activities, and habits in personal care. Other examples included making choices on what to eat or drink, or to include a person in choosing what to wear that day. Also, the freedom to go where you want to go (at home and within the nursing home) was mentioned by people living with dementia, family caregivers and healthcare professionals as an example of choice and control.

Furthermore, people living with dementia, family caregivers and healthcare professionals indicated that it is important that people living with dementia don't feel controlled by their environment. A healthcare professional working in a nursing home stated:

> *Sometimes [a sensor alarm] is used, but the resident finds it really annoying. But family members go so far that they want the sensor alarm at any cost, because someone once had a fall, and suppose it happens again and they are left lying on the ground for an hour. The residents state every time: "why are you here?", "You're checking up on me", "I really won't do anything wrong", and "I will not fall again". (healthcare professional, working in a nursing home, H20)*

Choices are accepted and respected

Healthcare professionals and family caregivers indicated that empowerment includes choices being accepted and respected, even if one wouldn't make that same choice for oneself. For example, when a person chooses to not engage in activities, or when a person decides to make an "extraordinary" combination of foods, you should give people that space and accept their choice:

> *When people make the choice to not want something, or not to go into conversation with you [...], then I also call that empowerment, because someone states: "I don't feel good, I don't want this and just leave me for the moment". The art of giving the other person that space is then also simply accepting. (activity therapist, working in a nursing home, H17)*

> *My father-in-law could put things on his sandwich that actually didn't match at all, for example cold cuts with chocolate sprinkles. But yeah, if he likes it, there's no harm, so we let it be and don't say anything about it. You will only hurt his feelings, and for what? What does it matter if he eats like this? (family caregiver of a person living with dementia residing in a nursing home, I09)*

For people living with dementia themselves, it seemed more obvious that they can choose what they want and that their choices are accepted. For example, when asked if her choices were accepted, a woman living with dementia said "of course" with no doubt, as if another option did not even occur to her.

Making choices is supported when needed

Healthcare professionals and family caregivers mentioned that empowerment also means supporting choices when needed. People living with dementia did not mention this theme. Since decision-making becomes more difficult as dementia progresses, caregivers suggested there could be too many options to oversee, which may lead to feelings of insecurity or distress. Caregivers can help with narrowing down those options. Furthermore, it was noted that the initiative of the person living with dementia may be reduced, so caregivers can encourage people living with dementia to make their own choices:

> *And sometimes it takes a while, because there are so many possibilities that the resident will not come to a choice or cannot say for himself "I want to come", so you provide a bit of direction. (activity therapist, working in a nursing home, H15)*

Differences in living situation and/or severity

Healthcare professionals and family caregivers reported that the type and amount of choices and level of control may vary in different stages of dementia, and therefore in the two different settings. Choices made by a person living with early dementia residing at home will be different from choices of a person living with advanced dementia residing in a nursing home. Even though choices may differ, it may lead to the same *feelings* of choice and control. At home, examples mentioned by people living with dementia and caregivers were choices about future care, while in a nursing home, examples included choices about what to wear that day.

Theme "having a sense of usefulness and being needed"

The importance of having a sense of usefulness and being needed was the third key theme to emerge from the analysis. This theme was mentioned by people living with dementia, family caregivers and healthcare professionals. This included doing what you can, want and were used to, for as long as possible, and being activated and challenged.

Doing what you can, want, and were used to, for as long as possible

The majority of people living with dementia, family caregivers and healthcare professionals agreed on the importance for people living with dementia to use their existing abilities and talents for as long as possible, and, thus, feel useful and needed. It was suggested that healthcare professionals and family caregivers should be careful when taking over tasks, and leave them to people living with dementia according to their competencies. One person living with dementia mentioned the importance of doing things herself in and around the house, and stated "*I won't let them take work off my* *hands*". Her husband confirmed this importance of not taking over the tasks in and around the house:

Family caregiver (I15):	*But it is also important, if she wants something, also let her do it by herself, and not start by saying …*
Person living with dementia (D13):	*"I will do that"*
Family caregiver (I15):	*Automatically you will do that sometimes, but in general you try as much as possible for herself, independence.*

To help preserve abilities and talents for as long as possible, healthcare professionals and family caregivers emphasized the need to anticipate to coming changes early on. This can be done by making use of existing abilities and by learning new skills or habits. As one dementia case manager explained:

> *Like you were saying, with hanging the laundry, that you see that someone is hesitating with the clothespin […]. I agree with you: repetition, repetition, repetition, so things can become engrained again. (healthcare professional, working at home, H25)*

Being activated and challenged

Healthcare professionals and family caregivers mentioned the importance of challenging and activating a person. People living with dementia did not mention this theme. Since loss of initiative is often a characteristic of dementia, healthcare professionals and family caregivers described addressing feelings of usefulness and being needed by activating or challenging a person to undertake activities. These activities mainly included household activities or personal care activities, such as folding laundry or dressing oneself. Another example was asking for help from a person living with dementia with specific expertise, for example with knitting:

> *For me, it is not about knitting an enormous scarf, but there were three ladies fussing over me, how I should knit a certain stitch. "Yeah, that's how you do it, girl". But you see with these ladies, at first, they are like: my fingers are stiff and I have rheumatism, everything squeaks and creaks. But gradually you see the ladies growing in helping me. (activity therapist, working in a nursing home, H15)*

The other examples were mainly focused on activating and challenging a person living with dementia to take part in pleasurable activities. In particular family caregivers stressed the importance of engaging a person living with dementia in meaningful activities during the day:

> *If my mother doesn't get any support, she just sits there and does nothing. (family caregiver of person living with dementia residing in nursing home, I06)*

To find out which activities suit someone best, healthcare professionals and family caregivers mentioned the power of trying, by offering different activities and observing which activities a person living with dementia enjoys.

Differences in living situation and/or severity

Healthcare professionals and family caregivers argued that the practical implications of feeling useful and being needed may differ at home and in nursing homes. They reported that a person living with advanced dementia residing in a nursing home may not be as useful and needed as before, but sufficiently so for that phase of dementia, and, thus, still feel useful and needed.

Theme "retaining a sense of worth"

The last key theme to emerge from the analysis was the importance to retain a sense of worth. This theme was mentioned by people living with dementia, family caregivers and healthcare professionals. This included feeling valued, being heard and seen, and participating in society.

Feeling valued

Both people living with dementia, family caregivers and healthcare professionals stressed the importance of feeling valued. Some people living with dementia, family caregivers and healthcare professionals suggested that dementia can compromise this feeling: people can get insecure, because things don't work out anymore, or because people around them start to treat them differently:

> *Sometimes I find it harrowing to see how insecure people can be, because they know: it is not going well, but they cannot place it, what is exactly not going well? And that can eat away at self-worth. (healthcare professional, working in a nursing home, H40)*

As a person with dementia at home mentioned:

> "*I am just treated like a child. 'Oh, she is starting to get demented, so …' " (person living with dementia, residing at home, D14)*

To feel valued, people living with dementia, family caregivers and healthcare professionals mentioned the importance of focusing on abilities the person still has, instead of focusing on lost abilities. Furthermore, healthcare professionals and family caregivers mentioned the importance of letting a person try first, before someone in the environment takes over. The wife of a man with aphasia due to dementia mentioned:

> *If he can't work it out for himself [find the words], then, […] sometimes it just takes too long and I try to help. But then he says: "No, don't". So that is self-worth, he has to try to remember the words for himself. Nowadays I say "I don't know, just keep trying". And then he tries to think of something to work it out. (family caregiver of a person living with dementia residing at home, I16)*

It was suggested by healthcare professionals and family caregivers that someone might not be able to complete the task themselves entirely, but can still complete sub-tasks. Recognizing those smaller abilities was reported to contribute to the sense of worth. For example, an occupational therapist argued that when the cooking process becomes too complex, a sense of worth is retained when someone still does the preparations, while a caregiver completes the meal, instead of completely taking over.

Being heard and seen

People living with dementia, family caregivers and healthcare professionals mentioned that to retain a sense of worth, it is important to be heard and seen, and be treated as an equal:

> *I do notice it […], because, yeah, sometimes you tell a story or say something, but then you can tell from someone's face that they are not interested at all. (person living with dementia, residing at home, D06)*

When asked about being heard and seen, people living with dementia, family caregivers and healthcare professionals expressed the value of talking to the person living with dementia, instead of *about* the person living with dementia:

> *Then they say: "you just see me as a normal person. Normally, this and that gets decided for me. And now we're talking to each other as two adults, that makes me feel good, you know." (healthcare professional, working at a daycare center, H31)*

Participating in society

To retain a sense of worth, people living with dementia, family caregivers and healthcare professionals said that it is imperative that people can participate in society for as long as possible and are seen as a full member of society. To them, this means that people in society need to have knowledge about dementia and adjust services so that people living with dementia can participate for as long as possible. Examples included dementia-friendly supermarkets or soccer clubs making an effort to include people living with dementia. Some people living with dementia said they experienced a barrier to participate in society, because unfamiliarity with the disease can cause stigma. As one person mentioned:

> *You're also afraid that people think you're insane. […] Sometimes I am looking for something and someone asks: "where did you put it then?" Yeah, I don't remember anymore, but then I get nervous and I definitely won't know it (person living with dementia, residing at home, D14)*

Different perspectives on empowerment

The various groups of participants differed in their perspective on empowerment. People living with dementia mainly mentioned needs and wishes regarding empowerment, for example "*I just want to live my own life and do the things I want*" (person living with dementia, D04). Caregivers, on the other hand, often indicated what the environment could do to support empowerment for people living with dementia. As a result, themes regarding support were not always mentioned by people living with dementia themselves. Furthermore, children (in law) tended to focus more on the practical support *for* the person living with dementia and what they could do to help their parent to live their best life. On the other hand, partners tended to focus more on how to communicate and live *with* the person living with dementia. For example, a daughter-in-law of a man living with dementia (I09) said:

> *You have to make use of what is still there […]. You just have to start on time, in my experience, for example with a week planner. […] Then they get used to it, and it will continue to work for a long time.*

While the partner of a man living with dementia (I12) said:

> "*What is very important, it that you keep figuring out the best way to respond*".

Interviews with people living with dementia provided different information than focus group discussions. It was more difficult for them to talk about what they found important in their support, but they communicated what was important to them otherwise, for example, by showing personal belongings such as pictures and souvenirs, or talking about the activities they engaged in.

Conceptual framework of empowerment

Based on the four themes, we developed a conceptual framework (Figure 1), incorporating all different perspectives on needs and wishes regarding empowerment, and perspectives on how to support this empowering process. The framework also incorporates the finding that all themes are important both at home and in nursing homes, and for different stages of dementia. We did not find some themes being more important than others. The conceptual framework shows that empowerment takes place within the person living with dementia, but is achieved through interaction between the individual and their environment. Healthcare professionals consistently mentioned the significance of communication and interaction with the person living with dementia. As a participating psychologist mentioned, the right approach can empower a person living with dementia. A nursing assistant explained:

> *That's the most important thing, that you really should make a connection. (healthcare professional, working in a nursing home, H13)*

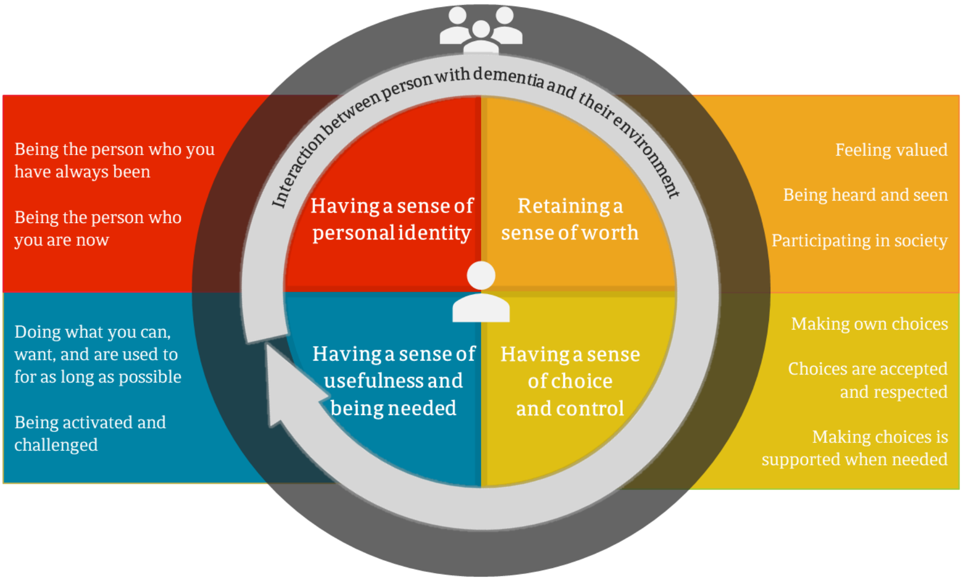

Figure 1. *Conceptual framework of empowerment in people living with dementia.*

Discussion and implications

The study revealed four themes of empowerment: (1) having a sense of personal identity, (2) having a sense of choice and control, (3) having a sense of usefulness and being needed, and (4) retaining a sense of worth. The four themes seem to be important both at home and in nursing homes, and in different stages of dementia. However, practical detailing of support differed. We have integrated the themes in a framework that can be used for implementing empowerment in daily practice.

Our results show some overlap with the definition of empowerment formulated by McConnell and colleagues, based on the perspectives of nine persons living with dementia. They defined empowerment as "people living with dementia are respected, have a voice and are heard" and "are involved in making decisions about their life", which corresponds to our themes *retaining a sense of worth* and *having a sense of choice and control* respectively. In our focus group discussions, the last component of their definition "create change through access to appropriate resources" was not mentioned, and perhaps reflects the activist mentality of the people living with dementia co-producing this definition of McConnell and colleagues. As new themes, we found *having a sense of personal identity* and *having a sense of usefulness and being needed*. These were not reflected in McConnell's definition. Perspectives of family caregivers and healthcare professionals contributed to the identification of these themes.

While information on the concept of empowerment in people living with dementia is limited, research has been focusing on the specific themes of empowerment. Our first theme *having a sense of personal identity* is consistent with previous studies, which demonstrate the importance of acknowledging the person behind the dementia (Cohen-Mansfield et al., 2006, Surr, 2006). People living with dementia do not associate their illness with their perception of "self", but their sense of self is based on current roles and roles no longer played (Macrae, 2010), being the same and a different person simultaneously (Skaalvik et al., 2016). For this reason, to empower the person living with dementia, (in)formal caregivers may benefit from addressing previous and current roles in their support and acknowledge who a person has always been in the past and who a person is now.

Regarding the second theme *having a sense of choice and control*, previous literature supports this finding, as a sense of choice is found to be related to well-being (Kloos et al., 2019). This suggests that people living with dementia must be included in decision-making processes as much as possible. (In)formal caregivers can provide support or adjust the number of choices to individual capabilities. Bhatt and colleagues add that a person living with dementia is in a better position to contribute to the decision-making process if they are informed, being listened to, have the ability to express their opinion, have time for reflection and there is reversibility of choice (Bhatt et al., 2018). These elements provide further directions for the development of empowerment interventions for people living with dementia.

Having a sense of usefulness and being needed was found as third theme of empowerment. This is in line with previous studies, which suggest that engagement in meaningful occupations can enhance the well-being of people living with dementia. When someone feels useful and needed as a result of engaging in these occupations, it gives purpose to their lives, enhances physical and mental health and promotes self-confidence (Du Toit et al., 2019). People living with dementia need opportunities to experience continued development to feel a sense of control and experience purposeful lives (O'Sullivan, 2013). This relates to the importance of *retaining a sense of worth*, which this study identified as the fourth theme of empowerment. The general importance of retaining a sense of worth for people living with dementia is often mentioned in earlier research. These studies encouraged supporting a sense of worth by life storytelling and reminiscence, and by helping to find meaning in life through enriching activities (Heggestad and Slettebo, 2015, Tranvag et al., 2016). In the development of empowerment interventions, emphasis is needed on providing knowledge and tools for (in)formal caregivers on how to support the sense of worth and feelings of usefulness.

The conceptual framework brings the four themes together, stressing the centrality of interaction for the concept of empowerment. Several studies support the importance of relation-centeredness (Clarke et al., 2020, Machiels et al., 2017, Nolan et al., 2004, Yu et al., 2018). For example, the relationship between the person living with dementia and caregiver appeared to be one of the main elements for maintaining autonomy (Boumans et al., 2018). For this reason, to empower a person living with dementia, a focus is needed on communicating with a person living with dementia about their needs and wishes. Whether this also means that the relative importance of themes or their interrelation should be considered in this communication, is not yet clear.

The concept of empowerment contributes to the shift from task-oriented care, with a focus on the illness, to person-centered care (Kitwood, 1997) and relationship-centered care (Nolan et al., 2004): approaches that focus on the whole person and the care relationship. An empowering approach encourages the person living with dementia to be a person with individual talents and capabilities and may contribute to reciprocity in relationships (Vernooij-Dassen et al., 2011, Westerhof et al., 2014). It helps to focus on what is possible, instead of what is no longer possible. People living with dementia should be able to live with a sense of worth and dignity. This way of thinking also shows overlap with, for instance, the concept of social health (Droes et al., 2017, Stiekema et al., 2018, Vernooij-Dassen and Jeon, 2016). Empowerment can add to these approaches as it helps to specify ways of interaction between the person living with dementia and their environment. It provides concrete opportunities for healthcare professionals and family caregivers to address and support strengths.

Strengths and limitations

A key strength of this study is the participation of all stakeholders involved: people living with dementia, their family caregivers and healthcare professionals with a broad range of occupations. Participants were included from both settings: living at home and living in a nursing home. This guarantees that multiple perspectives are taken into account. Another strength of this study is that all analyses were conducted separately by two researchers, who had regular discussions with each other, with the research team and advisory expert team. This is important to increase the trustworthiness of the results (Graneheim and Lundman, 2004). Although it would be best to confirm our findings with participants, we chose not to do this, to minimize the load of the study for participants. Instead findings were confirmed by their representatives from the advisory expert team. Furthermore, a limitation of this study is the potential selection bias towards motivated and enthusiastic participants, since recruitment was done by invitation. However, current participants facilitated a rich discussion about empowerment. Given the heterogeneity of our participants, we assume our study population reflects the wide range of people living with dementia and their caregivers in different settings.

Conclusion

Based on the perspectives of people living with dementia, their family caregivers and healthcare professionals, we can conclude that to empower a person living with dementia, it is important that they have a sense of personal identity, can make their own choices, that their capabilities are addressed, and that they can experience a sense of worth. The four themes of empowerment seem to be important both at home and in nursing homes, and in different stages of dementia. However, support must be adjusted to the personal situation and individual capabilities, and, therefore, practical detailing of support differs. Our empowerment framework provides a basis for developing interventions to empower people living with dementia and to support (in)formal caregivers in this empowerment process.

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Additional file 1. Interview guide

This interview guide presents the topics that were covered in the focus group discussions. The order of the topics discussed may differ, and not all questions were necessarily answered during all focus group discussions. The moderator used probing questions.

1. Definition of empowerment

- First associations with the word empowerment
- Perspective on the definition of empowerment
- Empowerment in different stages of dementia

Examples of questions asked:

- *What comes to mind when you hear the word "empowerment"?*
- *When dementia progresses, do different things become important for empowerment?*

2. Current care and support regarding empowerment

- The current level of empowerment of people with dementia
- The importance of empowerment in the daily lives of people with dementia
- Results and consequences of empowerment
- When it is difficult to feel empowered/support the empowerment process
- People involved in empowerment
- Support for informal caregivers

Examples of questions asked:

- *Do you feel empowered? Why? (people with dementia)*
- *How important do you think empowerment is in the daily lives of people with dementia? (caregivers)*
- *What happens when you feel empowered? What is the result? (people with dementia)*
- *In which situations is it difficult to empower a person with dementia? (caregivers)*
- *What can persons with dementia do themselves to feel empowered? Do they need support?*
- *How can informal caregivers best be supported to empower a person with dementia? (caregivers)*

3. What can be changed to empower people with dementia

- Points of improvement in care and support regarding empowerment
- Communication about the needs and wishes of people with dementia

Examples of questions asked:

- *What could be changed to make you feel more empowered? (people with dementia)*
- *Which improvements can be made in the care and support for people with dementia to make them feel empowered? (caregivers)*

Chapter 3

Empowerment for people living with dementia: an integrative review

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Abstract

Background and objectives: Although the concept of empowerment seems useful for good care and support for people living with dementia, there is a lack of understanding of the process of empowerment. Therefore, more insight is needed into the concept of empowerment, and the environment's role in the empowerment process.

Research design and methods: We performed an integrative literature review (PubMed, CINAHL, PsychINFO), including studies that addressed empowerment for people living with dementia in their title or abstract. Using qualitative data analysis software ATLAS.ti, we applied open codes to describe all relevant aspects of included articles. Common themes and categories were identified using inductive reasoning and constant comparison.

Results: Sixty-nine articles were included. We identified four themes: (1) description of the state of being empowered, (2) the process of empowerment, (3) contribution of the environment to the empowerment process, and (4) effects on other variables. We combined these results with the conceptual framework of our previous qualitative study on the definition of empowerment for people living with dementia based on stakeholders' perspectives into a revised conceptual framework. Subsequently, the combined information of both studies was visualized in a revised conceptual framework.

Discussion and implications: This literature review provides more details as to the role of the environment for empowerment of people living with dementia and suggests that empowerment can be considered a dynamic process, taking place through interaction between the person living with dementia and their environment. Our revised conceptual framework of empowerment can serve as a basis for future studies on empowerment for people living with dementia, and to support (in)formal caregivers in the empowerment process.

Introduction

The concept of empowerment has received increasing attention across a growing number of contexts (Hage and Lorensen, 2005). In the context of healthcare, empowerment contributes to the shift from task-oriented care, with a focus on the illness, to person-centred care with an emphasis on the whole person (Holmstrom and Roing, 2010). The World Health Organization defines it as a process through which people gain greater control over decisions and actions affecting their health (World Health Organization, 1998). However, definitions of empowerment may differ depending on the population in which it is applied (Tengland, 2008). For example, for people living with a chronic illness, empowerment occurs when patients come to terms with their threatened security and identity, not only with their health (Aujoulat et al., 2008). Furthermore, it can be argued that empowerment for people living with dementia differs from empowerment for those without dementia, considering the cognitive impairment and behavioral changes that may affect control over decisions and actions. The concept of empowerment seems useful in providing care and support for people living with dementia, for example through being involved in decision-making, improved relationships and interaction, and the use of advance directives for future medical care (Hill et al., 2018, McConnell et al., 2018, Prato, 2018, Shelton et al., 2018). However, literature on what empowerment means for people living with dementia remains scarce. A clear definition may contribute to better communication on empowerment, and, therefore, to the development of interventions aimed at promoting empowerment for people living with dementia. To optimally contribute to good care and support for people living with dementia, specific research about the concept and process of empowerment is needed.

In our recent qualitative study, we proposed a conceptual framework of empowerment for older people living with dementia based on the perspectives of people living with dementia themselves, their family caregivers and health care professionals (van Corven et al., 2021). We were able to identify four themes surrounding what it means to be empowered: having a sense of personal identity, having a sense of choice and control, having a sense of usefulness and being needed, and retaining a sense of worth. The four themes seemed to be as important for people living with dementia residing at home, as for those residing in a nursing home, and was evident across different stages of dementia. However, empowerment may not only be defined by its state, but also by its process (Richardson, 2002), and much less is known about how empowerment works. An important step in advancing understanding is to review existing literature with the aim of gaining insight into the process of empowerment, how empowerment can be supported by others, and subsequently placing our stakeholder perspective's framework of empowerment in the broader perspective of the literature.

To our knowledge, McConnell et al. (2019) are the only researchers who have reviewed the literature on empowerment for people living with dementia (McConnell et al., 2019). In their scoping review, they identified ten articles that presented concepts or constructs regarding empowerment for people living with dementia. As these articles did not provide definitions of empowerment, McConnell et al. extracted the implied definitions of empowerment from these research papers. This resulted in a list of constructs and terms associated with empowerment: choice, control, autonomy, agency, involvement, participation, decision-making, active, self-determination, using abilities, creating change, advocacy and confidence. To advance knowledge, a more extensive literature review seems valuable, also addressing how empowerment works within specific contexts, such as empowerment taking place in society, or taking place in the interaction with the direct environment. Also, investigating how empowerment can affect other variables, for example well-being, seems valuable. A better understanding of the process of empowerment is needed to promote and support empowerment for people living with dementia. To expand on previous research, and to obtain a broader understanding of the concept of empowerment for people living with dementia, an integrative review (Whittemore and Knafl, 2005) is a valuable asset through the combination of a wide range of literature on empowerment for people living with dementia.

The purpose of this study was to explore the empowerment process for people living with dementia by reviewing how empowerment is used within the literature, and to integrate this knowledge with the themes from our recently developed conceptual framework based on stakeholder perspectives. In this way, we hope to contribute to a basis for developing interventions that support empowerment for people living with dementia.

Methods and design

We used the integrative literature review method. Integrative literature reviews are the broadest type of review methods and enable various perspectives to be identified. An integrative review follows a systematic process, but is more inclusive than a systematic review as a wide range of study types are included. It follows the steps of problem identification, literature search, data evaluation, data analysis, and presentation (Whittemore and Knafl, 2005). Subsequently, we further integrated the results of this literature review into our empirically-based conceptual framework on empowerment for people living with dementia (van Corven et al., 2021).

Literature search

We retrieved scientific publications on empowerment for people living with dementia by searching the current literature for explicit use of the concept “empowerment”. This systematic search was conducted across PubMed, PsycINFO and CINAHL in November 2020. MeSH terms (Pubmed), Thesaurus terms (PsycINFO, CINAHL) and free text words in either the title and/or abstract were used. These terms included (“empower*” or “disempower*”) combined with (“Alzheimer*” or “CADASIL” or “Creutzfeldt-Jakob” or “Dementia*” or “Diffuse Neurofibrillary Tangles with Calcification” or “Frontotemporal Dementia” or “Frontotemporal Lobar Degeneration” or “Huntington” or “Kluver-Bucy” or “Lewy Body” or “Pick” or “Picks” or “Primary Progressive Aphasia” or “Primary Progressive Nonfluent Aphasia”). The search was limited to English and Dutch publications and there was no limit on publication year. Studies were included if they addressed empowerment for people living with dementia in their title or abstract. Studies were excluded if they addressed the empowerment of (in)formal caregivers without any relation to the specific empowerment of people living with dementia. All publication types were included (e.g., editorials, study protocols, theoretical and empirical research papers, both qualitative and quantitative), books or book chapters were excluded.

After reading the full-texts, we formulated three additional exclusion criteria: (1) authors only used empowerment in the form of “empower to …” and never as a construct on its own, (2) the word empowerment was only mentioned in the title or abstract, and not in the full-text, or (3) authors only addressed disempowerment for people living with dementia and did not mention empowerment.

Data evaluation

First, all of the titles and abstracts were screened independently by two researchers (CvC and MW) taking into consideration the exclusion criteria. Any discrepancies were resolved by consensus meetings between the two reviewers. For the screening of the full-texts for remaining references, 20 full-texts were selected for inclusion and studied independently by two researchers (CvC and AB). After discussion of any discrepancies within the first ten full-texts, no further discrepancies occurred in the following ten full-texts. Therefore, the remaining full-texts were screened for inclusion by one researcher (CvC), who only consulted the other reviewer (AB) when in doubt. This researcher also assessed the quality of the included studies using the Joanna Briggs critical appraisal for systematic reviews (Aromataris et al., 2015) and the Mixed Methods Appraisal Tool (MMAT Tool) for all other articles (Pace et al., 2012). We did not use these quality assessment methods as inclusion criteria, as we considered it important to include the widest range of possible articles in the analysis.

Data extraction and analyses

Baseline characteristics were extracted by the first author (CvC): publication (authors, year, country), study design, and study setting. Furthermore, we appraised how the concept of empowerment was used in the article: did authors provide empirical evidence, or did they, for instance, only use the word empowerment in the introduction without any elaboration on the topic.

The texts of all papers were entered into the qualitative data analysis software ATLAS.ti (version 8.4.15). The first author (CvC) applied open codes to describe all information on empowerment of included articles, which led to the subsequent development of a coding system. Codes referring to the same phenomenon were grouped into categories and these categories were grouped into higher-order themes. Using inductive reasoning and constant comparison, common categories and themes were identified (Braun and Clarke, 2006). For example, the statement “Empowerment may be translated into practice when people with dementia have more autonomy” was coded under the broader category “choice, control and autonomy”. This category was later linked to the theme “description of the state of being empowered”. The research team held consensus meetings to refine and consolidate the coding and interpretation.

Thereafter, we combined the results of this integrative review with the themes presented in our conceptual framework, visualizing the combined information of both studies in a revised conceptual framework.

Results

The systematic searches identified 990 potentially eligible articles. The flow diagram in Figure 1 illustrates the number of articles assessed, excluded and included at each stage of the selection process (Moher et al., 2009). In total, 69 articles were selected. Types of included articles were qualitative (n=23), quantitative (observational n=2 or intervention studies n=3) and mixed methods empirical research articles (n=7), review articles (n=7), discussion papers (n=13), papers describing an intervention (n=6), commentaries (n=2), feasibility or pilot studies (n=2), study protocols (n=2), an editorial (n=1), and a participatory action research article (n=1). The methodological quality of all included articles was satisfactory to good (Additional File 1). Articles originated from 16 countries.

Most articles came from the United Kingdom (n=26), followed by the United States (n=12), Australia (n=5), Canada (n=5), the Netherlands (n=5), Sweden (n=4), Japan (n=2) and Norway (n=2). One article originated from each of the following countries: Austria, Belgium, Brazil, China, France, Ireland, Israel, and Italy. The main reason for exclusion was that the word empowerment was not used with regard to people living with dementia.

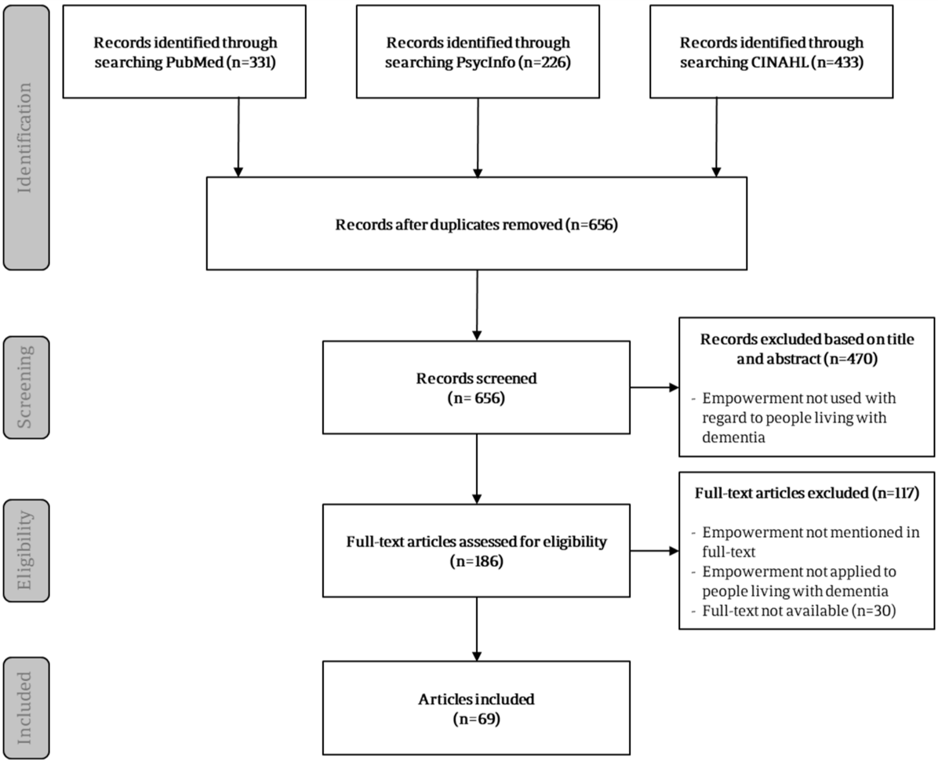

Figure 1. *PRISMA flow diagram.*

Use of empowerment in included studies

Articles reported specifically on people living with dementia who resided at home (n=35), in a nursing home (n=10) or both (n=11). Ten articles did not mention the setting, while three articles reported on the hospital setting. The use of the concept of empowerment in the articles differed: empowerment as a main topic of the article (n=3), empowerment as a qualitative theme in the results section (n=15), a particular care practice discussed as a means for empowerment (n=6), empowerment as target or as module of an intervention (n=18), empowerment as a word used in the results or discussion section (n=20), or other usage (n=7). All information was qualitative, as none of the identified articles presented quantitative data on empowerment. Also did none of the included articles, except one (McConnell et al., 2019), provide a specific definition of empowerment for people living with dementia. In all of the other included articles, authors used the word empowerment without a clear definition of the concept for people living with dementia.

Several of these articles presented empirical evidence on empowerment, for example due to the fact that empowerment emerged as a theme in the results section of a qualitative article (Alsawy et al., 2019, Han and Radel, 2017, Hobden, 2018, Hung and Chaudhury, 2011, Kannaley, 2018, Manthorpe and Samsi, 2013, Mmako et al., 2020, Parveen et al., 2017, Prato, 2018, Ryan et al., 2009, van 't Leven et al., 2018), or because effects of an empowerment intervention were studied (Chung, 2001, Nomura et al., 2009, Passmore et al., 2007). Nevertheless, the use of the word empowerment was not always explained or defined properly. For example, Passmore and colleagues investigated the effects of community-based recreation groups called “empowerment groups” (Passmore et al., 2007). They found that participants reported increased feelings of usefulness after one year. Why these groups were called “empowerment groups” or why these groups were considered empowering is not mentioned. Another example is the article of Kannaley and colleagues in which they qualitatively analyzed blog narratives written by people living with dementia (Kannaley, 2018). One of the resulting themes of the study was “advocacy and empowerment”. Within the paragraph, the authors summed up multiple subcategories, but did not elaborate on empowerment, or its relationship with advocacy.

The word “empowerment”

How authors used the word empowerment varied. Most authors either used the noun “empowerment”, the present participle “empowering” as a verb or adjective, or the gerund noun “empowering”. Furthermore, “empower to […]” is used by thirty-two articles. Some examples include “empower to communicate” (Alsawy et al., 2019, Parke, 2016), “empower to access treatment” (Keenan et al., 2016), “empower to participate in society” (Sixsmith and Gibson, 2007), or “empower to make positive changes in life” (Carpenter et al., 2002). Furthermore, seventeen authors used, next to empowerment, the word “disempowerment” or “disempowering” in their article.

The word empowerment was often used in combination with another construct. For example, the theme “Approach and empowerment” as a result of a qualitative study (Bielsten et al., 2018) or within an enumerated list, such as in the sentence “Dementia Friendly Initiatives generally share an individualized and holistic approach that promotes dignity, empowerment, engagement, and autonomy” (Hebert and Scales, 2017). All identified constructs used in combination with the word empowerment can be found in Additional File 2. Lastly, empowerment is used as a prepositive adjective to describe something (an intervention, approach, etc.) as positive or to characterize a quality, for example an “empowering hospital experience” (Prato, 2018).

Overview of articles

Based on all of the included articles in this integrative literature review, we were able to identify four themes: (1) description of the state of being empowered, (2) the process of empowerment, (3) contribution of the environment to the empowerment process, and (4) effects on other variables. An overview of the articles can be found in Table 1. Table 2 shows an overview of the codes, categories and themes.

Table 1. *Overview of included articles and the identified categories and themes.*

Author (year)	Article type	Setting and country	Empowerment	Description of the state of being empowered	Process of empowerment	Contribution of the environment to the empowerment process	Effects on other variables
Hallberg et al. (1995)	Qualitative research article	Nursing home, Sweden	Not primary theme, empowerment used to interpret results	-	(1) Relationships and social interaction	(1) Attitudes of family caregivers and healthcare professionals	-
Martin and Younger (2000)	Mixed methods research article	Nursing home, United Kingdom	Empowerment as main topic	(1) Choice, control and autonomy	(1) Relationships and social interaction	(1) Attitudes of family caregivers and healthcare professionals	-
Chung (2001)	Qualitative research article	Home, China	Evaluation of empowerment intervention	-	(1) Relationships and social interaction	-	(1) Improved relationships
Proctor (2001)	Qualitative research article	Hospital, United Kingdom	Empowerment in disability research used to shape methods	(1) Self-worth and confidence	-	-	-
Wilkinson (2001)	Discussion paper	Home and nursing home, United Kingdom	Empowerment as target of intervention	(1) Choice, control and autonomy	-	(1) Attitudes of family caregivers and healthcare professionals	-

Author (year)	Article type	Setting and country	Empowerment	Description of the state of being empowered	Process of empowerment	Contribution of the environment to the empowerment process	Effects on other variables
Carpenter et al. (2002)	Intervention paper	Nursing home, United States	Empowerment as component of intervention	(1) Choice, control and autonomy, (2) Sense of self-worth and confidence	(1) Relationships and social interaction	(1) Attitudes of family caregivers and healthcare professionals	(1) Confidence, self-esteem and dignity
MacKinlay (2002)	Qualitative research article	Nursing home, United States	Disempowerment as theme in results section	-	-	(1) Attitudes of family caregivers and healthcare professionals, (2) Dementia friendliness, inclusion and low stigma	(1) Quality of life and wellbeing
Nolan et al. (2002)	Discussion paper	Not specified, United Kingdom	Not primary theme, empowerment as a word used in discussion	-	(1) Relationships and social interaction	-	-
Kümpers et al. (2005)	Mixed methods research article	Home and nursing home, the Netherlands	Not primary theme, empowerment used to describe results	-	-	(1) Care approaches	-

Author (year)	Article type	Setting and country	Empowerment	Description of the state of being empowered	Process of empowerment	Contribution of the environment to the empowerment process	Effects on other variables
Ramos et al. (2005)	Discussion paper	Not specified, Brazil	Technology is mentioned as means for empowerment	-	-	(1) Dementia friendliness, inclusion and low stigma	(1) Participation in society
Passmore et al. (2007)	Quantitative research article	Home, United States	Evaluation of empowerment intervention	-	(1) Relationships and social interaction	-	-
Ready (2007)	Commentary	Not specified, United States	Not primary theme, empowerment as a word used in commentary	(1) Self-worth and confidence	-	(1) Care approaches	-
Gould et al. (2008)	Intervention paper	Home, United States	Empowerment as target of intervention	-	-	(1) Attitudes of family caregivers and healthcare professionals	(1) Sense of control
Beard et al. (2009)	Qualitative research article	Home, United States	Not primary theme, empowerment as a word used in discussion section	-	-	(1) Professional care, (2) Dementia friendliness, inclusion and low stigma	-

Author (year)	**Article type**	**Setting and country**	**Empowerment**	**Description of the state of being empowered**	**Process of empowerment**	**Contribution of the environment to the empowerment process**	**Effects on other variables**
Nomura et al. (2009)	Qualitative research article	Home, Japan	Evaluation of empowerment intervention	(1) Use of abilities and being active	(1) Relationships and social interaction	(1) Attitudes of family caregivers and healthcare professionals	(1) Confidence, self-esteem and dignity
Paradise et al. (2009)	Quantitative research article	Not specified, United Kingdom	Not primary theme, empowerment as a word used to name relevance	-	-	(1) Knowledge about dementia trajectory by PwD and family caregiver	-
Ryan et al. (2009)	Qualitative research article	Home and nursing home, Canada	Theme in results section	(1) Choice, control and autonomy, (2) Self-worth and confidence	(1) Relationship and social interaction	-	(1) Confidence, self-esteem and dignity
Young and Manthorp (2009)	Discussion paper	Home and nursing home, United Kingdom	Empowerment as component of code of practice	-	(1) Relationships and social interaction	-	-
Carr et al. (2010)	Intervention paper	Home, United States	Not primary theme, empowerment as a word used in discussion section	-	-	(1) Dementia friendliness, inclusion and low stigma	-

Author (year)	**Article type**	**Setting and country**	**Empowerment**	**Description of the state of being empowered**	**Process of empowerment**	**Contribution of the environment to the empowerment process**	**Effects on other variables**
Genoe (2010)	Discussion paper	Home and nursing home, Canada	Leisure is mentioned as means for empowerment	(1) Self-worth and confidence	-	-	(1) Sense of self
Pierce (2010)	Discussion paper	Not specified, United Kingdom	Advance directives are mentioned as means for empowerment	-	-	(1) Care approaches	-
Wolfs et al. (2010)	Quantitative research article	Home, the Netherlands	Empowerment used to interpret results	(1) Choice, control and autonomy	-	(1) Knowledge about dementia trajectory by PwD and family caregiver	-
Hung and Chaudhury (2011)	Qualitative research article	Nursing home, Canada	Theme in results section	-	-	(1) Attitudes of family caregivers and healthcare professionals	(1) Confidence, self-esteem and dignity
Young et al. (2011)	Intervention paper	Home and nursing home, United Kingdom	Empowerment as component of intervention	-	(1) Relationships and social interaction	(1) Attitudes of family caregivers and healthcare professionals, (2) Care approaches	(1) Confidence, self-esteem and dignity, (2) Sense of self

Author (year)	Article type	Setting and country	Empowerment	Description of the state of being empowered	Process of empowerment	Contribution of the environment to the empowerment process	Effects on other variables
Pearce et al. (2012)	Intervention paper	Home, United Kingdom	Empowerment as target of intervention	-	-	(1) Care approaches	-
Manthorpe and Samsi (2013)	Qualitative research article	Home and nursing home, United Kingdom	Theme in results section	-	-	(1) Knowledge about dementia trajectory by PwD and family caregiver	-
Span et al. (2013)	Review article	Home and nursing home, the Netherlands	Not primary theme, empowerment as a word used in discussion section	-	-	(1) Dementia friendliness, inclusion and low stigma	(1) Quality of life and wellbeing, (2) Sense of control
Di Fiandra et al. (2015)	Commentary	Home and nursing home, Italy	Empowerment mentioned as objective to improve quality of life	-	(1) Relationships and social interaction	(1) Professional care, (2) Information about dementia trajectory by PwD and family caregiver	(1) Quality of life and well-being

Author (year)	**Article type**	**Setting and country**	**Empowerment**	**Description of the state of being empowered**	**Process of empowerment**	**Contribution of the environment to the empowerment process**	**Effects on other variables**
Olsen et al. (2015)	Qualitative research article	Nursing home, Norway	Empowerment used to interpret results	(1) Use of abilities and being active, (2) Self-worth and confidence	-	(1) Care approaches	-
Willemse et al. (2015)	Mixed methods research article	Nursing home, the Netherlands	Not primary theme, empowerment as a word used in discussion section	(1) Use of abilities and being active	-	-	(1) Quality of life and wellbeing
Keenan et al. (2016)	Discussion paper	Home, United Kingdom	Not primary theme, empowerment as a word used in discussion	-	-	(1) Care approaches	(1) Sense of control
Parke et al. (2016)	Qualitative research article	Hospital, Canada	Empowerment as working mechanisms of intervention	-	(1) Relationships and social interaction	-	-

Author (year)	Article type	Setting and country	Empowerment	Description of the state of being empowered	Process of empowerment	Contribution of the environment to the empowerment process	Effects on other variables
Poland and Birt (2016)	Editorial	Not specified, United Kingdom	Not primary theme, empowerment as a word used in discussion section	-	-	(1) Dementia friendliness, inclusion and low stigma	-
Burholt et al. (2017)	Quantitative research article	Home, United Kingdom	Not primary theme, empowerment as a word used in discussion section	-	(1) Relationships and social interaction	-	-
Di Lorito et al. (2017)	Review article	Not specified, United Kingdom	Theme in results section	-	-	(1) Dementia friendliness, inclusion and low stigma	-
Han and Radel (2017)	Qualitative research article	Home, United States	Theme in results section	(1) Choice, control and autonomy	(1) Relationships and social interaction	(1) Care approaches	-

Author (year)	Article type	Setting and country	Empowerment	Description of the state of being empowered	Process of empowerment	Contribution of the environment to the empowerment process	Effects on other variables
Hebert and Scales (2017)	Review article	Home, United States	Empowerment as target of reviewed intervention	-	-	(1) Care approaches, (2) Dementia friendliness, inclusion and low stigma	(1) Quality of life and well-being
Kenigsberg et al. (2017)	Discussion paper	Home, France	Technology is mentioned as a means for empowerment	(1) Choice, control and autonomy, (2) Use of abilities and being active	(1) Relationships and social interaction	1) Attitudes of family caregivers and healthcare professionals, (2) Dementia friendliness, inclusion and low stigma	(1) Quality of life and wellbeing, (2) Confidence, self-esteem and dignity
Mahieu et al. (2017)	Discussion paper	Nursing home, Belgium	Empowerment used to interpret results	-	-	(1) Care approaches	-
Parveen and Oyebode (2017)	Qualitative research article	Home, United Kingdom	Theme in results section	(1) Choice, control and autonomy	(1) Relationships and social interaction	(1) Knowledge about dementia trajectory by PwD and family caregiver	(1) Quality of life and wellbeing

Author (year)	Article type	Setting and country	Empowerment	Description of the state of being empowered	Process of empowerment	Contribution of the environment to the empowerment process	Effects on other variables
Read et al. (2017)	Qualitative research article	Home, Australia	Not primary theme, empowerment as a word used in discussion section	-	-	(1) Knowledge about dementia trajectory by PwD and family caregiver	(1) Sense of control
Smith et al. (2017)	Mixed methods research article	Home, United Kingdom	Empowerment of person living with dementia as aim of professional caregiver intervention	(1) Choice, control and autonomy	(1) Relationship and social interaction	(1) Attitudes of family caregivers and healthcare professionals	-
Swall et al. (2017)	Qualitative research study	Nursing home, Sweden	Empowerment as target of intervention	-	-	-	(1) Confidence, self-esteem and dignity
Auckland (2018)	Discussion paper	Not specified, United Kingdom	Advance directives are mentioned as means for empowerment	-	-	(1) Professional care	-

Author (year)	**Article type**	**Setting and country**	**Empowerment**	**Description of the state of being empowered**	**Process of empowerment**	**Contribution of the environment to the empowerment process**	**Effects on other variables**
Bielsten et al. (2018)	Mixed methods research article	Home, Sweden	Theme in results section	-	-	(1) Attitudes of family caregivers and healthcare professionals	-
Clarke et al. (2018)	Qualitative research article	Home, United Kingdom	Study on determinants of empowering relationships	(1) Choice, control and autonomy	(1) Relationships and social interaction	(1) Professional care	-
Giguere et al. (2018)	Study protocol for RCT	Home, Canada	Empowerment as aim of intervention	-	-	(1) Care approaches	-
Harris and Caporella (2018)	Qualitative research article	Home, United States	Empowerment as target of intervention	-	-	(1) Dementia friendliness, inclusion and low stigma	-
Hobden et al. (2018)	Qualitative research article	Home, United Kingdom	Theme in results section	(1) Use of abilities and being active	-	-	-

Author (year)	Article type	Setting and country	Empowerment	Description of the state of being empowered	Process of empowerment	Contribution of the environment to the empowerment process	Effects on other variables
Kannaley et al. (2018)	Qualitative research article	Home, United States	Theme in results section	-	(1) Relationships and social interaction	-	-
van 't Leven et al. (2018)	Qualitative research article	Home, the Netherlands	Theme in results section	(1) Use of abilities and being active, (2) Self-worth and confidence	-	(1) Attitudes of family caregivers and healthcare professionals	-
McConnell et al. (2018)	Qualitative research article	Home, United Kingdom	Empowerment as main topic	(1) Choice, control and autonomy, (2) Use of abilities and being active, (3) Self-worth and confidence	(1) Relationships and social interaction	(1) Attitudes of family caregivers and healthcare professionals, (2) Dementia friendliness, inclusion and low stigma, (3) Knowledge about dementia trajectory by PwD and family caregiver	(1) Quality of life and wellbeing, (2) Confidence, self-esteem and dignity, (3) Sense of control, (4) Improved relationships, (5) Participation in society

Author (year)	Article type	Setting and country	Empowerment	Description of the state of being empowered	Process of empowerment	Contribution of the environment to the empowerment process	Effects on other variables
Phillipson et al. (2018)	Quantitative research article	Home, Australia	Empowerment as target of intervention	-	-	(1) Attitudes of family caregivers and healthcare professionals, (2) Dementia friendliness, inclusion and low stigma	(1) Confidence, self-esteem and dignity
Prato et al. (2018)	Qualitative research article	Hospital, United Kingdom	Theme in results section	(1) Choice, control and autonomy	(1) Relationships and social interaction	(1) Care approaches	-
Shelton et al. (2018)	Discussion paper	Not specified, United States	Empowerment mentioned as means to avoid unwanted medical care	-	-	(1) Knowledge about dementia trajectory by PwD and family caregiver	-
Alsawy et al. (2019)	Qualitative research article	Home, United Kingdom	Theme in results section	(1) Sense of self-worth and confidence	(1) Relationships and social interaction	(1) Attitudes of family caregivers and healthcare prof., (2) Professional care, (3) Dementia friendliness, inclusion and low stigma	-

Author (year)	Article type	Setting and country	Empowerment	Description of the state of being empowered	Process of empowerment	Contribution of the environment to the empowerment process	Effects on other variables
Lee et al. (2019)	Mixed methods research article	Home, Canada	Theme in results section	-	-	(1) Care approaches	-
McConnell et al. (2019)	Mixed methods research article	Not specified, United Kingdom	Empowerment as main topic	(1) Choice, control and autonomy, (2) Use of abilities and being active, (3) Self-worth and confidence	(1) Relationships and social interaction	(1) Attitudes of family caregivers and healthcare professionals, (2) Dementia friendliness, inclusion and low stigma	-
Plunger et al. (2019)	Intervention paper	Home, Austria	Not primary theme, empowerment one of the aims of the intervention	-	-	(1) Care approaches, (2) Dementia friendliness, inclusion and low stigma	-
Teng et al. (2019)	Review article	Home to nursing home, Australia	Theme in results section	-	(1) Relationships and social interaction	-	-

Author (year)	Article type	Setting and country	Empowerment	Description of the state of being empowered	Process of empowerment	Contribution of the environment to the empowerment process	Effects on other variables
Watt et al. (2019)	Discussion paper	Nursing home, Australia	Empowerment as target of intervention	-	-	(1) Knowledge about dementia trajectory by PwD and family caregiver	-
Bhatt et al. (2020)	Feasibility study of intervention	Home, United Kingdom	Empowerment as aim of intervention	(1) Choice, control and autonomy	-	-	-
Dassa et al. (2020)	Pilot study of intervention	Home, Israel	Not primary theme, empowerment as a word used in results section	-	(1) Relationships and social interaction	-	-
Hicks et al. (2020)	Participatory action research article	Home, United Kingdom	Empowerment as an approach in action research	-	(1) Relationships and social interaction	-	-
Husebo et al. (2020)	Study protocol for RCT	Home, Norway	Empowerment as a component of intervention	-	-	(1) Care approaches	-

Author (year)	**Article type**	**Setting and country**	**Empowerment**	**Description of the state of being empowered**	**Process of empowerment**	**Contribution of the environment to the empowerment process**	**Effects on other variables**
Maki et al. (2020)	Discussion paper	Home, Japan	Dementia-friendly communities are mentioned as a means for empowerment	(1) Use of abilities and being active	-	(1) Dementia friendliness, inclusion and low stigma	-
Mmako et al. (2020)	Review article	Home, Australia	Theme in results section	(1) Choice, control and autonomy	(1) Relationships and social interaction	-	-
Parker et al. (2020)	Review article	Home, United Kingdom	Not primary theme, empowerment as a word used in discussion section	-	-	(1) Dementia friendliness, inclusion and low stigma	-
Whelan et al. (2020)	Review article	Home and nursing home, Ireland	Not primary theme, empowerment used to describe results	(1) Self-worth and confidence	-	--	(1) Confidence, self-esteem and dignity

PwD = person living with dementia, RCT = randomized controlled trial

Description of the state of being empowered

One of the themes that emerged from the analysis is the description of the state of being empowered. This included choice, control and autonomy, the use of abilities and being active, and self-worth and confidence (see Tables 1 and 2).

Choice, control and autonomy

Several authors mentioned choice (Clarke et al., 2018, Martin and Younger, 2000), control (Carpenter et al., 2002, McConnell et al., 2018, Ryan et al., 2009, Wilkinson, 2001) and autonomy (Kenigsberg, 2017, McConnell et al., 2018, Wilkinson, 2001) as aspects of the state of being empowered.

Authors emphasized the importance of independence (Smith et al., 2017), self-determination (Wilkinson, 2001), and involvement within the decision-making process (Martin and Younger, 2000, McConnell et al., 2018, McConnell et al., 2019, Prato, 2018), for example by having a choice over their activities (Han and Radel, 2017, Mmako et al., 2020, Parveen et al., 2017), actively deciding on care interventions (Wolfs et al., 2010), or making decisions about the disclosure of their dementia diagnosis (Bhatt et al., 2020). To illustrate:

> *"[...] empowerment involved being consulted, heard and actively involved in decision making." (McConnell et al., 2018)*

McConnell and colleagues concluded in their empirical study that the person living with dementia should have the opportunity to create change (McConnell et al., 2019). However, Wilkinson and colleagues highlighted that at some point the risk associated with some decisions may be too high. Facilitation and support from others is then required (Wilkinson, 2001).

Use of abilities and being active

Other authors found or suggested the use of abilities (McConnell et al., 2018, McConnell et al., 2019, van 't Leven et al., 2018) and being active (Maki et al., 2020, McConnell et al., 2019) as the core description of the state of being empowered:

> *"We identified 'empowerment' as the core theme in the stories of our participants, e.g. focusing on remaining capacities, searching for strengths that could compensate for limitations, and increasing self-confidence without denying limitations." (van 't Leven et al., 2018)*

Some authors also highlighted the importance of maximizing skills, or acquiring new skills (Kenigsberg, 2017, McConnell et al., 2018). To illustrate, Nomura and colleagues named regaining procedural skills as a strategy to support empowerment for a person living with dementia (Nomura et al., 2009). Being active was further characterized as being able to make a contribution through helping others (Hobden, 2018, Olsen et al., 2015) and meeting requirements for occupation (Willemse et al., 2015). For example, in the qualitative study of Hobden and colleagues, a participant described how he is normally shy and reserved, but being actively engaged in swimming sessions gave him the opportunity to develop his confidence and to help other participants with their swimming (Hobden, 2018).

Table 2. *Overview of codes, categories and themes.*

Themes (heading) and categories	Codes
Description of the state of being empowered	
Choice, control and autonomy	*Independence, choice over activities*
Using abilities and being active	*Meeting needs for occupation, learning new skills*
Self-worth and confidence	*Being heard, sense of belonging*
Process of empowerment	
Relationships and social interaction	*Meaningful communication, intimate family relationships*
Contribution of the environment to the empowerment process	
Attitudes of family caregivers and healthcare professionals	*Giving adequate time, respect and value to interests*
Care approaches	*Person-centered care, service planning*
Dementia friendliness, inclusion and low stigma	*Dementia friendly initiatives, changing perceptions, co-production*
Knowledge about the dementia trajectory by people living with dementia and their family caregiver	*Awareness of treatment options, awareness of available services*
Effects on other variables	
Quality of life and well-being	*Quality of life, well-being*
Confidence, self-esteem and dignity	*Being aware of capabilities, sense of competence*
Sense of self	*Affirmed identity, diminished loss of valued roles*
Sense of control	*Involved in decision making*
Improved relationships	*Reduced isolation*
Participation in society	*Social inclusion, shared social identity*

Self-worth and confidence

Authors used a sense of self-worth (Proctor, 2001) and confidence (McConnell et al., 2019, van 't Leven et al., 2018) to define the state of being empowered. They found or suggested that a sense of self-worth or confidence can be experienced by being heard (Alsawy et al., 2019, McConnell et al., 2019), being invested in (Olsen et al., 2015) and feeling respected

(McConnell et al., 2019). Furthermore, authors mentioned the importance of a sense of belonging (McConnell et al., 2018, Whelan et al., 2020), a sense of pride, and a positive self-image (Proctor, 2001). They argued that feelings of accomplishment and purpose are important for a person living with dementia to feel empowered (Ryan et al., 2009), together with the growing realization that there is more to dementia than cognitive and functional impairments (Ready, 2007). Genoe and colleagues argued that being empowered is associated with the ability to define oneself rather than accepting the definitions provided by others (Genoe, 2010). Examples included reviewing past successes (Carpenter et al., 2002), and using abilities to show your worth (Genoe, 2010).

Process of empowerment

The second theme that emerged from the analysis was the process of empowerment. This included relationships and social interaction (see Tables 1 and 2).

Relationships and social interaction

Authors suggested that empowerment is promoted through meaningful communication (Alsawy et al., 2019, Martin and Younger, 2000, Prato, 2018, Smith et al., 2017, Young and Manthorp, 2009, Young et al., 2011), for instance by sharing experiences (Alsawy et al., 2019, McConnell et al., 2018) and striving for equal partnership (Clarke et al., 2018, Hicks et al., 2020, Martin and Younger, 2000, McConnell et al., 2019, Nolan et al., 2002, Prato, 2018, Ryan et al., 2009). Furthermore, authors implied that the relationships between the person living with dementia and their family caregivers (Parke, 2016, Prato, 2018) and healthcare professionals (Hallberg, 1995, Martin and Younger, 2000) make up the empowerment process. Positive caregiving from family caregivers (Chung, 2001, Parveen et al., 2017) and intimate family relationships (Chung, 2001, Nomura et al., 2009) were ways to promote empowerment. As Nomura and colleagues (2009) wrote:

> *"As both people with dementia and caregivers feel the loss of the family relationship, improving the family relationship itself can result in empowering both of them." (Nomura et al., 2009)*

It was argued that promoting strategies of personal and familial engagement may promote empowerment for people living with dementia (Dassa et al., 2020, Di Fiandra et al., 2015, Teng et al., 2019). In the relationship with healthcare professionals (mostly working in the nursing home or hospital), Prato and colleagues observed communication and behaviors endorsing empowerment when ward-based staff focused on developing an empathic relationship with trust and friendship. They emphasized that staff making decisions in conjunction with people living with dementia and their relatives contributes to establishing empowerment (Prato, 2018). In contrast, Carpenter and colleagues reasoned from the perspective of the person living with dementia, and argued that interventions focusing on empowerment involve exploring fears about raising issues with staff, and engaging in role-playing exercises for people living with dementia such as when learning how to approach staff and communicate their requests (Carpenter et al., 2002). Furthermore, authors suggested that empowerment may be encouraged through regular social activity (Burholt et al., 2017, Kenigsberg, 2017, Passmore et al., 2007), but also through peer support and a shared social identity with other people living with dementia (Kannaley, 2018, McConnell et al., 2018, Mmako et al., 2020, Nomura et al., 2009, Passmore et al., 2007).

Contribution of the environment to the empowerment process

The third theme that emerged from the analysis was the contribution of the environment to the empowerment process. This included the attitudes of family caregivers and healthcare professionals, care approaches, dementia friendliness, inclusion and low stigma, and knowledge about the dementia trajectory by people living with dementia and their family caregiver (see Tables 1 and 2).

Attitudes of family caregivers and healthcare professionals

Authors mentioned that the attitudes of family caregivers and healthcare professionals to people living with dementia influences the empowerment process for people living with dementia. As MacKinlay and colleagues wrote:

> *"We can empower the person with dementia by our attitudes and actions and listening to their voice. If we view someone as being special, unique, and valuable, we will relate to the person in that way, and the person will respond positively. They will flourish." (MacKinlay, 2002)*

Generally, giving adequate time, being patient, being emphatic (Smith et al., 2017) and providing positive feedback (Nomura et al., 2009) were mentioned by authors as promoting empowerment. More specifically, authors noted that acknowledging the potential of the person living with dementia (Bielsten et al., 2018, Carpenter et al., 2002, Nomura et al., 2009) and addressing their capabilities (Carpenter et al., 2002, Kenigsberg, 2017, van 't Leven et al., 2018) as important aspects contributing to the empowerment process. They argue that people living with dementia should be encouraged to use existing skills and learn new skills (McConnell et al., 2018), and it was found that necessary resources should be provided to facilitate their skills (McConnell et al., 2019). Authors argued that family caregivers and healthcare professionals should support what people wish and are able to do for as long as possible (Hung and Chaudhury, 2011, van 't Leven et al., 2018, Wilkinson, 2001).

Furthermore, authors mentioned that to promote empowerment for people living with dementia, a person's life history, beliefs, values, and individual preferences have to be central (Kenigsberg, 2017, Young et al., 2011). They identified the importance of listening to their experiences (McConnell et al., 2019) and suggested that respecting and valuing their interests has a significant impact (Han and Radel, 2017, Nomura et al., 2009, Smith et al., 2017). Therefore, authors said exploring personal preferences (Carpenter et al., 2002) and activity needs are critical for promoting empowerment (van 't Leven et al., 2018).

Moreover, authors stated that an approach in which family caregivers and healthcare professionals increase choice (Kenigsberg, 2017, Martin and Younger, 2000), control (Hallberg, 1995, Martin and Younger, 2000), and involvement of people living with dementia in decision-making (Alsawy et al., 2019, McConnell et al., 2018, Wilkinson, 2001) contributes to empowerment, with assistance in the decision-making process as and when it is needed (Carpenter et al., 2002, Gould et al., 2008). Authors also suggested that to encourage people living with dementia they should see themselves as effective, powerful people (Carpenter et al., 2002), with others listening to their voice (MacKinlay, 2002) and recognizing their rights (Phillipson et al., 2018, Wilkinson, 2001).

Care approaches

Many authors indicated that empowerment can be promoted through care provision (Clarke et al., 2018, Mahieu et al., 2017, Prato, 2018), especially person-centered care (Alsawy et al., 2019, Han and Radel, 2017, Hebert and Scales, 2017, Keenan et al., 2016, Kümpers, 2005, Lee et al., 2019, Plunger et al., 2019, Ready, 2007, Young et al., 2011):

> *A person-centered approach that empowers the individual with dementia is fundamental to best practice. (Keenan et al., 2016)*

Involvement in service planning or decision making (Di Fiandra et al., 2015, Giguere et al., 2018, Kümpers, 2005, Lee et al., 2019, Olsen et al., 2015), and advanced directives in which wishes for the future are documented were demonstrated to contribute to feelings of empowerment (Auckland, 2018, Beard et al., 2009, Husebo et al., 2020, Pierce, 2010). Pearce and colleagues advocated for giving people living with dementia a voice in anticipation of when they are no longer able to articulate their views, and the opportunity to record their views on aspects of their life that they feel are important to them (Pearce et al., 2012). Keenan and colleagues mentioned that early diagnosis is beneficial to give people living with dementia the opportunity to plan and prepare for these future needs (Keenan et al., 2016).

Dementia friendliness, inclusion and low stigma

Authors mentioned that dementia friendliness facilitates the empowerment process within society (MacKinlay, 2002) as well as in the community (Harris and Caporella, 2018, Hebert and Scales, 2017, Maki et al., 2020, Parker et al., 2020, Phillipson et al., 2018). The same goes for dementia friendly initiatives in general (Hebert and Scales, 2017), such as dementia friendly swimming sessions (Hobden, 2018). Reducing stigma and changing the perceptions of dementia was said to promote empowerment for people living with dementia (Beard et al., 2009, McConnell et al., 2018, Poland and Birt, 2016). As Phillipson and colleagues wrote:

> *"Low levels of public understanding can contribute to the fear, stigma and social exclusion associated with living with dementia. Dementia friendly communities aim to address this by empowering people with dementia and increasing their social inclusion." (Phillipson et al., 2018)*

Carr and colleagues mentioned that staying in the community rather than having to move to a nursing home can be considered empowering (Carr et al., 2010), and Kenigsberg and colleagues stated that this also reduced isolation and disconnection from personal and social communities (Kenigsberg, 2017). Ramos and colleagues noted the use of digital devices as important for maintaining independence, autonomy and maximal social integration (Ramos et al., 2005).

Moreover, authors noted that involvement in research (Di Lorito et al., 2017, Span et al., 2013) and co-design (Alsawy et al., 2019) as ways to contribute to the empowerment of people living with dementia. For example, involvement in the co-design of technology (Kenigsberg, 2017, Span et al., 2013) and in the development of dementia-friendly pharmacies (Plunger et al., 2019). It was found that co-production promotes empowerment for people living with dementia by facilitating agency and listening to their experiences (McConnell et al., 2019). McConnell and colleagues argued that empowerment driven organizations should be committed to involving people living with dementia in lead roles and key decision making moments (McConnell et al., 2018).

Knowledge about the dementia trajectory by people living with dementia and their family caregiver

Furthermore, people living with dementia and their family caregivers having knowledge about dementia may promote empowerment. This knowledge includes awareness of treatment options (Watt et al., 2019, Wolfs et al., 2010), recognition of available services (Di Fiandra et al., 2015) and information about the dementia trajectory (Di Fiandra et al., 2015, McConnell et al., 2018, Paradise et al., 2009, Parveen et al., 2017, Read et al., 2017, Shelton et al., 2018). Many authors describe the important role that healthcare professionals play in providing this information to people living with dementia and their family caregivers (Read et al., 2017, Wolfs et al., 2010). Gould and colleagues suggest that people living with dementia may feel empowered by having the most relevant information at the time when it is most needed; this could avoid hasty decisions that might be regretted in the future (Gould et al., 2008). Many authors note the importance of knowledge and information for making informed choices and planning for the future (Manthorpe and Samsi, 2013, Read et al., 2017).

Effects on other variables

The last theme that emerged from the analysis was effects of empowerment on other variables. This included quality of life and well-being, confidence, self-esteem and dignity, sense of self, sense of control, improved relationships, and participation in society (see Tables 1 and 2).

Quality of life and well-being

Authors argued that empowerment in people living with dementia results in positive changes in their quality of life (Di Fiandra et al., 2015, Kenigsberg, 2017, McConnell et al., 2018, Parveen et al., 2017) and well-being (Hebert and Scales, 2017, Kenigsberg, 2017, McConnell et al., 2018, Span et al., 2013, Willemse et al., 2015). In the words of MacKinlay and colleagues: *"They will flourish." (MacKinlay, 2002).* Parveen and colleagues wrote about their information program for families:

> *"The program had an indirect impact on the quality of life of those with dementia, as families now offered choice and focused on empowerment." (Parveen et al., 2017)*

Confidence, self-esteem and dignity

Possible results of empowerment in a person living with dementia include confidence, self-esteem and dignity (Carpenter et al., 2002, Hung and Chaudhury, 2011, Kenigsberg, 2017, McConnell et al., 2018, Nomura et al., 2009, Ryan et al., 2009, Whelan et al., 2020), as well as people living with dementia becoming aware of their capabilities (McConnell et al., 2018). Lastly, empowerment was mentioned to promote a sense of competence (Young et al., 2011), feelings of being respected (Phillipson et al., 2018), and a sense of being important, needed and meaningful (Swall et al., 2017).

Sense of self
One of the effects of empowerment was people living with dementia having a sense of self (Swall et al., 2017, Young et al., 2011), an affirmed identity, and a diminished loss of valued roles (Genoe, 2010).

Sense of control
Having an enhanced sense of control was also mentioned as an effect of empowerment (Span et al., 2013), as people living with dementia can be more involved in decision making related to their future needs (Gould et al., 2008, Keenan et al., 2016, McConnell et al., 2018, Read et al., 2017).

Improved relationships
Other effects of empowerment in people living with dementia were improved relationships (Chung, 2001, McConnell et al., 2018), reduced isolation, and the confidence to disclose their diagnosis to family and friends (McConnell et al., 2018).

Participation in society
On a societal level, authors described greater social inclusion (McConnell et al., 2018), participation in society (Ramos et al., 2005), and reduced stigma (McConnell et al., 2018) as possible effects of empowerment in people living with dementia. As Ramos and colleagues mentioned:

> *"The core objective is to [...] empower cognitively impaired people and Alzheimer´s patients, enabling them to exercise their citizenship, participate and share with their community their life experiences and aspirations." (Ramos et al., 2005)*

Furthermore, McConnell and colleagues suggested the effect of empowerment as having a shared social identity, a sense of collective strength, and the confidence to speak out on issues that affect them, becoming active co-producers of policy and service development (McConnell et al., 2018).

Revising the conceptual framework of the process of empowerment

We combined the results of this integrative review with the conceptual framework from our previous qualitative study on the definition of empowerment for people living with dementia based on stakeholders' perspectives (van Corven et al., 2021). This resulted in a revised conceptual framework of empowerment for people living with dementia, as presented in Figure 2.

In our previous qualitative study, through focus group discussions with people living with dementia, their family caregivers and healthcare professionals, four themes of empowerment were identified. These themes concerned what it means for a person living with dementia to be empowered and were considered central domains of empowerment: having a sense of personal identity, having a sense of choice and control, having a sense of usefulness and being needed, and retaining a sense of worth (van Corven et al., 2021). These domains correspond to the theme 'description of the state of being empowered' found in this literature review, namely being choice, control and autonomy, using abilities and being active, and a sense of self-worth and confidence. The importance of having a sense of personal identity was not distinctly present in the current literature review. It follows that empowerment can be described as a state, where a person living with dementia feels empowered when the four domains of empowerment are attained and present within their daily lives. In the revised conceptual framework, this is represented by the colored middle visualizing what it means for a person living with dementia to feel empowered.

Furthermore, the findings of this integrative literature review help us to understand the process of empowerment, and the role of the surrounding social environment in this empowerment process. A high number of included articles, with all satisfactory to good methodological quality, highlighted the role of the social environment and the importance of relationships and social interaction for empowerment of people living with dementia. Although the included articles do not provide clear information as to whether they consider empowerment as a state or as a process, by emphasizing the importance of the interaction between the person living with dementia and their environment, they in this way describe empowerment as a process. In the revised conceptual framework, the process of empowerment is represented by the light grey circle. The dark grey boxes show how the environment can promote empowerment, and how this effect can be attributed to either the direct, organizational and societal environments. The process of empowerment can be initiated by either the person living with dementia themselves or their environment, which may depend on individual and contextual differences, such as setting and stage of dementia.

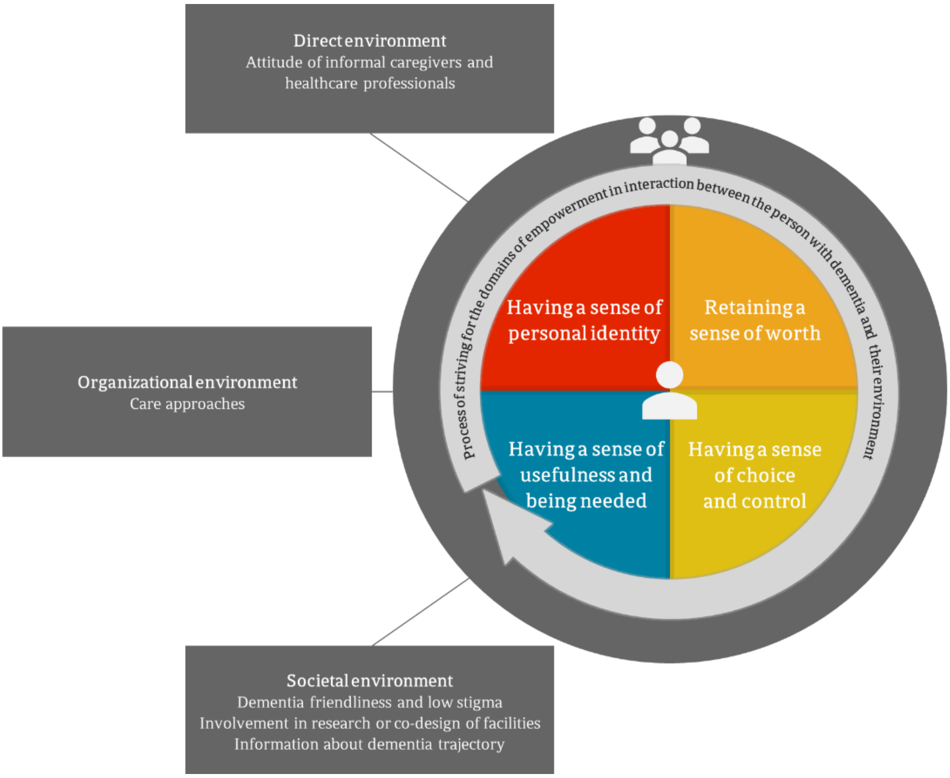

Figure 2. *Revised conceptual framework of the process of empowerment for people living with dementia.*

Discussion

This extensive review of the literature identified four themes for empowerment: (1) description of the state of being empowered, (2) the process of empowerment, (3) contribution of the environment to the empowerment process, and (4) effects on other variables. We presented a revised conceptual framework of empowerment for people living with dementia, combining the results of this integrative review with the results from our previous qualitative study on defining empowerment for people living with dementia (Figure 2). The majority of included articles was published in the last 10 years, which highlights the growing interest for empowerment. Our findings show that the empowerment of people living with dementia can be considered a dynamic process, with empowerment taking place within the interaction of, and relationship between, the person living with dementia and their environment. In particular, it is the result of striving for the four domains of empowerment in this interaction. This literature review elucidated the process of empowerment and added more details as to the role of the environment. Implications for practice are that the social environment of people living with dementia should be made aware of their role in the empowerment process and be supported by knowledge and tools on how to promote empowerment for people living with dementia. More empirical research is needed to provide clarity on the role of the social environment.

In the revised conceptual framework, the names of the domains are used that describe the state of being empowered as found in our qualitative study, for the domains to be as recognizable for people living with dementia, their family caregivers, and healthcare professionals. Furthermore, the revised conceptual framework does not include the effects on other variables identified in this integrative review. Relations to other variables were not well described in the identified papers, not empirically studied, and in our view, several of the mentioned effects on other variables seem to constitute only one part of the process, instead of being fixed outcomes of the empowerment process. For example, the identified effects on the variables *confidence, self-esteem and dignity* could be seen as an interaction around sense of worth. Furthermore, we argue that other effects on variables such as *quality of life and well-being* are not a direct outcome of the empowerment process, as suggested by authors from included articles, but that the empowerment process itself may *contribute* to increasing quality of life and well-being. Additional research is needed to provide more clarity about the relationship between empowerment, quality of life and well-being.

The relevance of having a sense of personal identity was not distinctly present in the current literature review, although it was found as one of the themes of empowerment in our recent qualitative study (van Corven et al., 2021). Articles included in this review suggest that the attitudes of family caregivers and healthcare professionals, knowing a person's life history, beliefs, values, preferences and individual needs are important in the empowerment process. Authors categorized this sense of self as an effect of the empowerment process. Therefore, we did not adjust the revised conceptual framework and kept the domain of a sense of personal identity. Previous literature also described the priority of person-centred care, emphasized the need to know and understand the person living with dementia (Fazio et al., 2018, Kitwood, 1997), and supported the importance of personhood and identity for people living with dementia (Brown, 2017, Paddock et al., 2018). For this reason, although literature didn't specifically highlight striving for a sense of personal identity, more research seems to be needed into the role of personal identity in the empowerment process. It seems valuable for future empowerment interventions to explicitly address the person behind the dementia. Our findings highlight the importance of the four themes of empowerment in care and support for people living with dementia.

Results of this integrative review should be interpreted cautiously, as substantive literature on what empowerment means and includes for people living with dementia is scarce, and therefore it was not possible to base our analysis on extensive empirical research. Most findings of this integrative review were merely suggested, proposed or implied by authors of the included articles. Only one of the 69 included articles provided extensive empirical evidence on empowerment for people living with dementia (McConnell et al., 2019). The evidence of other empirical articles is minimal or ambiguous, as authors used the word empowerment in contexts where it was possibly not always the most suitable concept. For example when empowerment is used as theme in a qualitative study, but without explanation or elaboration as to the concept, or the reason as to why the word was used to describe a particular result. This contributes to confusion about the concept. Nevertheless, we saw reason to revise the conceptual framework, as many authors highlighted the environment's role in the empowerment process and the importance of relationships and interaction, and these articles were of satisfactory to good methodological quality. It is an important issue for future research to provide clarity on the concept of empowerment. This will improve communication on empowerment and may thus contribute to the development of interventions aimed at empowerment for people living with dementia and to support (in)formal caregivers in the empowerment process.

As the results of this integrative literature review indicate, there is an overlap between the description of the state of being empowered, the process of empowerment, contribution of the environment to the empowerment process, and effects on other variables. One clear example is choice and control. Articles included in this review suggest that an attitude from (in)formal caregivers that provides choice, control and inclusion in the decision making process are environmental factors that contribute to the empowerment process. Moreover, having choice and control was both mentioned as a way to describe the state of being empowered, and as being an effect of empowerment. This same phenomenon can be noticed with the theme low stigma. This may be caused by authors using the word empowerment where it may not be suitable, or may confirm empowerment as a dynamic process.

Strengths and limitations

To our knowledge, this is the first study performing an extensive review of the literature regarding empowerment for people living with dementia, including all articles that used the word empowerment in their title or abstract. A strength of this study is the solid performance of the search, selection and analysis of scientific articles. The use of the qualitative data analysis software ATLAS.ti ensured systematic data analysis. This integrative literature review contributes to an understanding of the process of empowerment, but also highlights the existing confusion and inconsistencies. A limitation of this study is the search restriction to articles in English and Dutch. The majority of articles are from the United Kingdom, the United states and other western countries, while only a few articles originated from outside Europe or Northern America, such as China, Israel or Brazil. This possibly impacts the global generalizability of our results, since other interpretations of empowerment for people living with dementia may exist in other cultures. Furthermore, some articles were excluded since the full-text was not available, which could have biased results. Lastly, the interpretation of the results of this integrative review could be influenced by ideas from the development of the conceptual framework of empowerment for people living with dementia from our previous qualitative study.

Articles were not analyzed specifically for different settings or stages of dementia. Nevertheless, we assume that our integrative literature review reflects a wide range of settings and stages, as all of the themes surrounding empowerment appeared in articles addressing the home, hospital and nursing home settings. As seen in our previous qualitative study, the results showed that support must be adjusted to the personal situation and individual capabilities (van Corven et al., 2021), and therefore practical details of how to support empowerment for a person living with dementia may differ across various settings. Future empowerment interventions should have the possibility to be tailored to each individual.

Conclusion

This integrative literature review provides an insight into the process of empowerment for people living with dementia. Our revised conceptual framework of empowerment can serve as a basis for future studies on the process of empowerment for people living with dementia, and develop interventions to support (in)formal caregivers in the empowerment process.

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Additional file 1. Methodological quality of included articles

Table 1. *Mixed methods appraisal tool of qualitative studies.*

Authors	Year	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	1.1. Is the qualitative approach appropriate to answer the research question?	1.2. Are the qualitative data collection methods adequate to address the research question?	1.3. Are the findings adequately derived from the data?	1.4. Is the interpretation of results sufficiently substantiated by data?	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
Hallberg et al.	1995	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Chung	2001	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Proctor	2001	Yes	Yes	Yes	Yes	Yes	Yes	Yes
MacKinlay	2002	Yes	Yes	Yes	Yes	No	Yes	Yes
Beard et al.	2009	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Nomura et al.	2009	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Ryan et al.	2009	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hung and Chaudhury	2011	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Manthorpe and Samsi	2013	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Olsen et al.	2015	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Parke et al.	2016	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Han and Radel	2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Authors	Year	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	1.1. Is the qualitative approach appropriate to answer the research question?	1.2. Are the qualitative data collection methods adequate to address the research question?	1.3. Are the findings adequately derived from the data?	1.4. Is the interpretation of results sufficiently substantiated by data?	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
Parveen and Oyebode	2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Read et al.	2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Swall et al.	2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Clarke et al.	2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Harris and Caporella	2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hobden et al.	2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Kannaley et al.	2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes
van 't Leven et al.	2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes
McConnell et al.	2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Prato et al.	2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Alsawy et al.	2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Dassa et al.	2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hicks et al.	2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Table 2. *Mixed methods appraisal tool of quantitative non-randomized studies.*

Authors	Year	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	3.1. Are the participants representative of the target population?	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?	3.3. Are there complete outcome data?	3.4. Are the confounders accounted for in the design and analysis?	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?
Passmore et al.	2007	Yes	Yes	Not known	Yes	Yes	No	Yes

Table 3. *Mixed methods appraisal tool of quantitative descriptive studies.*

Authors	Year	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	4.1. Is the sampling strategy relevant to address the research question?	4.2. Is the sample representative of the target population?	4.3. Are the measurements appropriate?	4.4. Is the risk of nonresponse bias low?	4.5. Is the statistical analysis appropriate to answer the research question?
Paradise et al.	2009	Yes	Yes	Yes	Yes	Yes	Not mentioned	Yes
Wolfs et al.	2010	Yes	Yes	Yes	Yes	Yes	Not mentioned	Yes
Burholt et al.	2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Phillipson et al.	2018	Yes	Yes	Yes	No	Yes	No	Yes

Table 4. *Mixed methods appraisal tool of mixed methods studies.*

Authors (year)	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	5.2. Are the different components of the study effectively integrated to answer the research question?	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?
Martin and Younger (2000)	Yes	Yes	Yes	Yes	Yes	Yes	No
Kümpers et al. (2005)	Yes	Yes	Yes	Yes	Yes	Not applicable	No
Willemse et al. (2015)	Yes	Yes	Yes	Yes	Yes	Not applicable	Yes
Smith et al. (2017)	Yes	Yes	Yes	Yes	Yes	Not applicable	Yes
Bielsten et al. (2018)	Yes	Yes	Yes	Yes	Yes	Yes	No
Lee et al. (2019)	Yes	Yes	Yes	Yes	No	Not applicable	Yes
McConnell et al. (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Table 5. *Mixed methods appraisal tool of studies on which the quality appraisal is not applicable.*

Authors	**Year**	**S1. Are there clear research questions?**	**S2. Do the collected data allow to address the research questions?**
Wilkonson	2001	No	-
Carpenter et al.	2002	No	-
Nolan et al.	2002	No	-
Ramos et al.	2005	No	-
Ready	2007	No	-
Gould et al.	2008	No	-
Young and Manthorp	2009	No	-
Carr et al.	2010	No	-
Genoe	2010	No	-
Pierce	2010	No	-
Young et al.	2011	No	-
Pearce et al.	2012	No	-
Di Fiandra et al.	2015	No	-
Keenan et al.	2016	No	-
Poland and Birt	2016	No	-
Kenigsberg et al.	2017	No	-
Mahieu et al.	2017	No	-
Auckland	2018	No	-
Giguere et al.	2018	No	-
Shelton et al.	2018	No	-
Plunger et al.	2019	No	-
Watt et al.	2019	No	-
Bhatt et al.	2020	No	-
Husebo et al.	2020	No	-
Maki et al.	2020	No	-

Table 6. *Joanna Briggs critical appraisal for systematic reviews checklist.*

	Span et al. (2013)	Di Lorito et al. (2017)	Hebert and Scales (2017)	Teng et al. (2019)	Mmako et al. (2020)	Parker et al. (2020)	Whelan et al. (2020)
1. Is the review question clearly and explicitly stated?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2. Were the inclusion criteria appropriate for the review question?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3. Was the search strategy appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
4. Were the sources and resources used to search for studies adequate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
5. Were the criteria for appraising studies appropriate?	Yes	No	Yes	Yes	No	Yes	Yes
6. Was critical appraisal conducted by two or more reviewers independently?	Yes	Yes	Yes	Yes	Not applicable	Yes	Yes

	Span et al. (2013)	**Di Lorito et al. (2017)**	**Hebert and Scales (2017)**	**Teng et al. (2019)**	**Mmako et al. (2020)**	**Parker et al. (2020)**	**Whelan et al. (2020)**
7. Were there methods to minimize errors in data extraction?	Yes	Not mentioned	Not mentioned	Yes	No	Yes	Not mentioned
8. Were the methods used to combine studies appropriate?	Yes	Yes	No	Yes	Yes	Yes	Yes
9. Was the likelihood of publication bias addressed?	No	No	No	No	No	No	No
10. Were recommendations for policy and/or practice supported by the reported data?	Yes	Yes	No	Yes	Yes	Yes	Yes
11. Were the specific directives for new research appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Additional file 2. Overview words used simultaneously with empowerment

Table 3. *Overview of words used simultaneously with the word empowerment for people living with dementia.*

Words	# articles	Words	# articles
Autonomy	9	Inclusive	1
Independence	6	Informed	1
Choice	5	Inspire	1
Confidence	5	Integrity	1
Control	4	Motivation	1
Engagement	4	Opportunities for inclusion	1
Involvement	4	Partnership	1
Support	4	Person-centered	1
Agency	3	Person-centered care	1
Dignity	3	Personhood	1
Enabling	3	Positive caregiving culture	1
Self-management	3	Positively going forward into future	1
Social inclusion	3	Protect	1
Self-efficacy	2	Recognize his/her full potential	1
Stigma reduction	2	Reinforcement of identity	1
Supported and included in society	2	Safeguarding	1
Achievement	1	Safety	1
Advocacy	1	Satisfaction	1
Approach	1	Secure	1
Awareness	1	Sense of accomplishment	1
Belonging	1	Social change	1
Care for	1	Social justice	1
Clarity	1	Strengthen sense of self	1
Competent	1	Understand his/her rights	1
Emancipation	1	Understanding for person with dementia	1
Facilitate	1	Uplifting	1
Feel valued and heard	1		
Feeling comfortable	1		
Inclusion	1		

Chapter 4

Family caregivers' perspectives on their interaction and relationship with people living with dementia in a nursing home

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Abstract

Background: Social interactions are important for people living with dementia in a nursing home. However, not much is known about interactions and relationships between residents and family caregivers and related experiences of family caregivers. We aim to advance the knowledge on how family caregivers interact with people living with dementia in a nursing home and how they maintain or redesign a meaningful connection.

Methods: Qualitative research using interviews with family caregivers (n=31) to explore perspectives on their interaction and relationship with the person living with dementia. Interviews were held during the reopening of nursing homes after the first COVID-19 lockdown in the Netherlands. In this situation, family caregivers became more aware of their interaction and relationship with the resident, which provided a unique opportunity to reflect on this. The interviews explored the interaction and relationship in a broad sense, not specifically for the COVID-19 situation. Thematic analysis was performed to analyze the data.

Results: We were able to identify three key themes reflecting the experiences of family caregivers: (1) changes in the interaction and relationship, (2) strategies to promote connection, and (3) appreciation of the interaction and relationship. From the viewpoint of family caregivers, the interaction and relationship are important for both the resident living with dementia and for themselves, and family caregivers have different strategies for establishing a meaningful connection. Nevertheless, some appear to experience difficulties with constructing such a connection with the resident.

Conclusions: Our results provide a basis for supporting family caregivers in perceiving and establishing mutuality and reciprocity so that they can experience togetherness.

Background

For people living with dementia, interactions and relationships with their family and friends are especially important as these help them to fulfil their potential, live their lives with the highest possible degree of independence, and participate in social activities (Droes et al., 2017, Vernooij-Dassen and Jeon, 2016). The significance of these social interactions has been highlighted for people living with dementia in a nursing home as well (Jao et al., 2018, Mabire et al., 2018). Specifically, relationships within families are imperative aspects of well-being in the everyday life of residents (Cronfalk et al., 2018), and social interactions are associated with fewer neuropsychiatric symptoms (Arai et al., 2021) and positively affecting the person living with dementia (Jao et al., 2018). It was also found that support from family promotes adjusting to life in the nursing home (Davison et al., 2019). The recent COVID-19 pandemic highlighted the importance of social interactions, as meaningful connections came under pressure due to restrictive visiting policies (Koopmans et al., 2021, Verbeek et al., 2020). Furthermore, research on empowerment for people living with dementia, which includes a sense of identity, usefulness, control, and self-worth, showed that empowerment takes place within the interaction between the person living with dementia and their environment (van Corven et al., 2021). Loved ones of people living with dementia in a nursing home (called family caregivers in this article) could play an important role in this.

Nevertheless, not much is known about the interactions and relationships between people living with dementia in a nursing home and their family caregivers and related experiences of those family caregivers. They may experience challenges in connecting with the person living with dementia (Duggleby et al., 2013), as dementia causes loss of abilities across cognitive, functional, and behavioral domains. Preserving a sense of togetherness, for example feeling "one" as a couple, may be challenging (Førsund et al., 2016, Swall et al., 2020). Previous research found that strong ties in the relationship are helpful in creating new ways of communication, for example, using body language when verbal communication becomes difficult (Cronfalk et al., 2018), or developing strategies to preserve continuity in the relationship, such as scheduling visits for periods when residents are more alert and capable of interacting (Førsund et al., 2016). Nevertheless, such studies on the perspectives and experiences of family caregivers on interaction and relationships in the nursing home remain scarce, as research regarding family caregivers mostly focuses on caregiving for people living with dementia at home (Lloyd et al., 2016, Marques et al., 2021, Yu et al., 2018), or on family caregivers' functional involvement in the nursing home, such as communicating with staff or making decisions on care and support (Hoek et al., 2020, Tjia et al., 2017). To support family caregivers in establishing a meaningful connection with the resident, more understanding on the perspectives and experiences of family caregivers appears valuable.

In this study, we aim to explore the perspectives of family caregivers on their interaction and relationship with the person living with dementia in a nursing home. We aim to advance the knowledge on how family caregivers interact with people living with dementia in a nursing home, their related experiences, and how they construct a meaningful connection.

Methods

Design

We performed a longitudinal qualitative study, interviewing family caregivers of people living with dementia residing in a nursing home in two stages. Data collection took place in the Netherlands from May 2020 to February 2021.

Setting and participants

Family caregivers of residents living with dementia in a psychogeriatric unit from five nursing homes participated. Data collection was coordinated by the local university networks for long-term care in the regions of Amsterdam, Groningen, Maastricht, Nijmegen, and Tilburg. These local university networks are alliances between a university and multiple care organizations in the region. For each local university network, one nursing home participated in this study, each with 21 to 163 people living in psychogeriatric nursing home units. We interviewed a convenience sample of family caregivers in two stages. The consolidated criteria for reporting qualitative research (COREQ) were followed in this article (Tong et al., 2007).

Stage 1

Nursing homes in the Netherlands closed their doors to visitors on March 20th 2020, as obliged by law, to prevent and control COVID-19 infections. This meant that family caregivers were unable to visit residents. After two months of lockdown, nursing homes in the Netherlands were cautiously reopened for visitors during a pilot, with strict guidelines, including one designated visitor being allowed per resident, and visits took place at least at 1.5 meters distance (Koopmans et al., 2021, Verbeek et al., 2020). A convenience sample of family caregivers who participated in the pilot in one of the five participating nursing homes, and thus visited their loved one in May 2020, were asked by a contact person of the nursing home to participate in a telephone interview on their experience of the visit. All interviews took place in May 2020. It is not known how many participants were asked to participate in the interview.

Stage 2

The interviews from stage 1 provided interesting information on interactions and relationships between family caregivers and residents, but data saturation regarding overall experiences was not reached in this first stage, as the interviews focused on the impact of COVID-19 restrictions. Therefore, a second stage was added, in which a purposive sample of 20 participants were asked after four to nine months (September 2020 – February 2021) for a follow-up interview to collect more information on the overall interaction and relationship the resident. In approaching participants for the follow-up interview, we considered sex, relation to the resident, length of stay in residential care, and the region in the Netherlands to achieve variation in participant characteristics (Moser and Korstjens, 2018). During these follow-up interviews, guidelines for visitations were still in effect, including one visitor at a time (from a few designated visitors per resident) and at least 1.5 meters distance between the family caregiver and resident. However, not all dyads kept this 1,5 meters distance.

Data collection

To conduct the interviews in stage 1, the researchers (CvC, AB, DG) developed an interview guide, as shown in Additional file 1. Questions aimed to investigate general experiences with the first visit to the nursing home after it reopened for visitors after the first COVID-19 lockdown in the Netherlands, and were aimed at three topics: (1) organization of the visit, (2) impact on the family caregiver, and (3) impact on the resident living with dementia in the nursing home. General experiences regarding the visits are described in the article of Verbeek et al. (2020) (Verbeek et al., 2020). As these interviews also revealed interesting information on interactions and relationships between family caregivers and residents in general, the interview guide was rigorously adapted (Additional file 1) for a second round of interviews (stage 2). Questions in these stage 2 interviews specifically aimed to investigate the overall interaction and relationship between family caregivers and people living with dementia in the nursing home and further explored information already given by family caregivers in the first round of interviews. Data collection continued until saturation was reached. The focus of this article is the overall interaction and relationship between family caregivers and residents living with dementia of nursing homes.

The researcher of the local university network for long-term care called the participant to make an appointment for the interview. In all interviews, open-ended questions were asked, followed by questions on themes that were introduced by participants. No pilot was done before data collection took place. Semi-structured interviews were done via telephone and lasted between 12 and 68 minutes for stage 1, or between 16 and 38 minutes for stage 2. Interviews were performed by seven interviewers (CvC, AB, IL, EdV, EvV, MJ, CB) in stage 1, and by the first author (CvC) in stage 2. All interviewers were female and had experience with conducting interviews. Before starting the interview, interviewers introduced themselves and explained the aim and reason for the study. Participants were given the opportunity to ask questions, and provided oral consent. Interviews were tape-recorded and transcribed verbatim. Transcripts were not returned to participants for comments or correction. Field notes were written after each interview.

Data analysis

Firstly, transcripts of the interviews from stage 1 regarding visiting guidelines were entered into Atlas.ti (version 8.4.15). Thematic analysis was used (Braun and Clarke, 2014), in which common themes and categories were identified using inductive reasoning and constant comparison, which means that no theoretical perspective guided the coding or interpretation. We developed a coding system by using open codes to describe all relevant aspects raised by participants (Hsieh and Shannon, 2005). Thematic analysis was also used for the follow-up interviews. As open codes were used to describe all new relevant aspects raised by participants, the coding system was rigorously adapted for follow-up interviews in stage 2. Coding of the interview transcripts from stages 1 and 2 was done separately by two researchers (CvC and MW). Codes referring to the same phenomenon were grouped into categories, and these categories were grouped into higher-order themes. Consensus meetings with the research team were held to reach agreement on coding and interpretation, and categories and themes were defined together.

Results

Participant characteristics

In total, 31 family caregivers participated in this qualitative study – 30 family caregivers participated in an interview in stage 1, and 13 participated in a follow-up interview in stage 2. Twenty caregivers were asked to participate in the follow-up interview (considering variation in participant characteristics), six of whom did not participate: three did not respond, two did not provide a reason for not wanting to participate, and one did not participate since the resident had died since the first interview. One family caregiver only participated in the follow-up interview. Characteristics of the participants are shown in Table 1. For two family caregivers participating in both interviews, both parents resided in the nursing home – either both or one parent living in a psychogeriatric nursing home unit. For two family caregivers, the resident had died at the time of the follow-up interview. Interviewers did not have any relationship with participating family caregivers prior to study commencement.

Table 1. *Characteristics of participating family caregivers.*

	All participating family caregivers (n=31)	**Family caregivers participating in follow-up interview** (n=14)
	Mean (SD) or n (%)	Mean (SD) or n (%)
Mean age (years)	63.3 (9.9), range 48 – 84 [b]	65.7 (7.9), range 56 -78 [b]
Sex (% female)	24 (80.0)	11 (78.6)
Relationship to resident		
Married / partner	5 (16.7)	3 (21.4)
Child (in-law)	19 (63.3)	8 (57.1)
Brother or sister	1 (3.3)	1 (7.1)
Niece or nephew	4 (13.3)	1 (7.1)
Other	1 (3.3)	1 (7.1)
Travel time to nursing home (minutes)	17.0 (16.4), range 0 – 75 [b]	15.4 (14.2), range 5 - 60
Average number of visits [a]		
(Almost) every day	6 (20)	2 (14.2)
A few times per week	16 (53.3)	10 (71.6)
Once per week	5 (16.7)	1 (7.1)
Less than once per week	2 (6.7)	0 (0.0)
Average visiting time [a]		
Approximately half an	0 (0.0)	0 (0.0)
hour	9 (30)	4 (28.6)
Approximately an hour	17 (56.7)	9 (64.3)
More than one hour		
Length of stay of resident in nursing home (years)	3.1 (3.0), range 0.5 – 15 [b]	2.8 (1.6), range 1 - 6

[a] Before the start of the COVID-19 pandemic

[b] One missing for age, average number of visits and number of years living in nursing home, four missing for average time of visit for all family caregivers, one participating in the follow-up interview

Findings of the interviews

Based on the perspectives of family caregivers, we were able to identify three themes in the interaction and relationship between people with dementia living in a nursing home and their family caregivers: (1) changes in the interaction and relationship, (2) strategies to promote a connection, and (3) appreciation of the interaction and relationship. Table 2 shows an overview of the codes, categories and themes. Saturation was reached; none of the categories or themes emerged after analysis of the second follow-up interview, and after the twelfth follow-up interview no new relevant codes emerged.

Table 2. *Overview of themes, categories and codes.*

Themes (heading) and subthemes	Codes
Changes in the interaction and relationship	
Changes in communicative abilities of the resident	*Resident shows no initiative, cognitive abilities vary*
Quality of the changed interaction and relationship	*Relationship has improved, making a connection is not possible*
Experiences with the changes in interaction and relationship	*Visit feels as long, difficult to lose connection*
Strategies to promote connection	
Verbal interaction	*Chatting together, family caregivers learn suitable attitudes over time*
Undertaking activities	*Going outside together, preserving interests of resident*
Physical interaction	*Physical interaction is essential in interaction, caregiving promotes intimacy*
Just being there	*Visiting so residents 'feel' their presence, nursing home feels as home for family caregiver*
Contextual strategies	*Visiting at 'the right time' of the day*
Appreciation of the interaction and relationship	
Appreciation by residents living with dementia	*Family caregivers cannot be replaced by healthcare professionals, resident smiles when seeing the family caregiver*
Appreciation by family caregivers	*Supporting during the last life phase is fulfilling, family caregiver is happy when the resident is happy*

Theme "Changes in the interaction and relationship"

One of the key themes that emerged from the analysis regarded changes that occurred in the interaction and relationship between the resident and the family caregiver. This included changing communicative abilities of the resident, the subsequent influence on the quality of the interaction and relationship, and pertaining experiences of these changes by family caregivers.

Changes in communicative abilities

Family caregivers reported that the resident's dementia changed their interaction and relationship. They stated that the resident's communicative abilities decreased, mostly describing the decrease in verbal interaction. Examples ranged from decreased cognitive abilities limiting in-depth conversations to residents who did not respond to family caregivers or showed no signs of recognition. Many family caregivers mentioned that the residents' initiative in interaction disappeared and that conversations (if there were any) were more and more about the past:

> *My mother doesn't say much. If you ask my mother: how are you doing? Then she just smiles and nods, but says nothing. [...] She is just very withdrawn at the moment, very much in her own little world. [...] That is probably the deterioration in her condition. But she does recognize me, and she knowns exactly who I am, but she just doesn't have anything to say anymore. (daughter, P43)*

They stated that on some days the resident was more in their own world, confused, "far away", or showed few emotions. A daughter explained that due to this fluctuation, the interaction with her father differs between visits:

> *If he is in that fantasy world, well, then he tells me that he went shopping everywhere by car. But yeah, I know that is not true at all. He is caught up in the story and the experience. I just let him be. I don't tell him: that's not right. Then I ask more questions, but these are, of course, pointless conversations, because I actually know that these things didn't happen at all. If he is having a good day, then you can also talk with him about my nephew or about my partner or about our house we built. If he Is having a good day he knows all of this again. (daughter, P26)*

Barriers for interaction that were mentioned included sadness in the resident, anger, tiredness, or moments of distraction. Furthermore, family caregivers mentioned barriers to interaction such as physical discomfort, drowsiness due to medication use, or limited hearing.

Quality of the changed interaction and relationship

Although all respondents stated that the resident's communicative abilities had changed, their experiences with the quality of their interaction and relationship with the resident differed considerably. Many family caregivers stated they generally succeed in connecting with the resident. Several interviewees stated that good interaction with the resident is self-evident, as there had always been a strong relationship. As the partner of a resident stated:

> *Interviewer: Did you have the feeling you could make a connection as usual with your husband?*
> *Family caregiver: Yes, but that makes sense, we'll be married 55 years next week. (wife, P01)*

Some family caregivers mentioned that the interaction and relationship with the resident had improved as dementia progressed. A son explained:

> *My father was always a very independent man. Actually, the contact with my father was never very intimate, but towards the end he surrendered completely to me. I arranged everything for him. I just noticed that he was glad when I was there, and that he also kind of put the responsibility entirely with me. (son, P09)*

Others stated that the quality of the interaction and relationship with the resident decreased as the dementia progressed. Several family caregivers reported the interaction had become more superficial over time. Others mentioned they failed to connect with the resident.

> *Making a connection is very difficult anyway. You can't go through everyday things with her anymore, because it is all just too much for her. (husband, P32)*

Experiences with the changes in interaction and relationship

Many interviewees reported experiencing the changes in interaction as difficult. They reported struggling when seeing cognitive abilities decrease, or with the feeling of losing connection with the resident.

> *That is difficult, if you notice that the connection is getting worse. And the idea that he will no longer recognize you, that is difficult. (brother, P40)*

Many family caregivers reported challenges when visiting the resident, although related experiences were different. Some family caregivers stated *it takes a certain type of character* to connect with people living with dementia, which some say comes naturally to them.

> *I think you have to be a certain type of person for that, and I am. Even if I don't get an answer, I still sit with him and grab his hand. I talk to him, and so he will hear me talk. And then, yes, he gives a reaction. I try to do it that way. (daughter, P46)*

Other family caregivers explained that a visit to the nursing home sometimes feels quite long. They reported that having a conversation was challenging and stated preferring to have some distractions during the visit. They mentioned examples such as having the television playing, undertaking activities, or having other people to talk to, such as other family or friends, other residents, or healthcare professionals. This view was not shared by all participants, as some family caregivers mentioned that a connection was established best when they were alone with the resident.

> *If my sister or my brother is there, and we go for a walk, then it breaks the visit so to speak. It's a little hard when she doesn't talk. Well, sometimes a healthcare professional walks in, and then you usually have a chat. Or someone from the cleaning service, who also chats a bit. That breaks the visit for a short moment. (daughter, P34)*
>
> *Because she, of course, says the same thing a hundred times, and at some point, I don't really know what to say anymore. (friend, P16)*

Some family caregivers mentioned having accepted the changes in the interaction or relationship or having got used to them.

> *We do have a conversation, but he often just replies yes or no, you know. [...] That's not nice, but, of course, I've accepted that for a while now. I'll live with that. So yeah, as long as I'm there, you know, that he feels that I am there. (daughter, P46)*
>
> *If I know he is feeling good at that moment, [...] then I actually feel just as good. I think it is also a bit of resignation, like, this is how it is and now we should try to be happy. (wife, P01)*

A daughter explained she had accepted her father's dementia with the accompanying changes in interaction. Nevertheless, situations in which her father talked about her mother as if she was still alive kept feeling confrontational to her.

> *When he makes up those stories that he's been out and about, I find it very easy to say: oh yeah and was it fun? I don't have a problem with that. But when it comes to my mother, it feels much more complicated. [...] For me, my mother has died of course, and for him she hasn't. (daughter, P26)*

Theme "Strategies to promote connection"

The second key theme that emerged from the analysis comprised strategies family caregivers use to connect with the resident. These included verbal interaction, undertaking activities, physical interaction, 'just being there', and contextual strategies.

Verbal interaction

With regard to verbal interaction, some family caregivers mentioned having learned the right approach to connect with the resident over time, for example, not asking difficult questions or not correcting the resident. Family caregivers also noted that using humor may help to distract from dreariness and that laughing together brings joy.

Several family caregivers mentioned that verbal interaction with the resident improved if other people were present. For example, a daughter mentioned that if a healthcare professional joined the conversation, she could also interact with the healthcare professional, which was favorable for her mother, as she heard the chitchat and felt she was part of the conversation. On the other hand, one family caregiver emphasized the importance of involving her mother in the interaction when her sisters were also present. She named the pitfall that the sisters only talked to each other while their mother was not involved in the conversation.

Undertaking activities

Many family caregivers reported undertaking activities to connect with the resident. They mentioned activities including going outside, going for a walk, drinking coffee, and reminiscing, for example, by looking at pictures. Moreover, family caregivers mentioned connecting activities such as singing, listening to music, watching television, but also activities such as re-organizing the wardrobe together. Some family caregivers mentioned trying to undertake activities to connect to the person someone always used to be.

> *Then you just see that she is happy, when I do that, do a bit of laundry with her. Because that used to be her thing. So, I just involve her. (friend, P16)*

Furthermore, a family caregiver mentioned that the caregiving task of helping with eating was a way for her to interact with the resident.

> *Lately, I often visited around dinner time, so I could help her eat, or at least offer her food. I thought that was a nice thing to do, because you have some kind of connection. […] If you helped her eat, you could say something like: here's another bite. Then she would open her mouth and sometimes she would say: nice. Or that I saw that she was thirsty and I asked: do you want some more water? So, there was still some form of communication possible. […] Helping her eat has really become a form of communication for me. (daughter, P18)*

Family caregivers noted that they distracted the resident from depressed moods by undertaking activities.

> *When I arrive at my mother's room, she is often quite depressed, but you can easily distract her by taking her downstairs for a while, drinking a cup of coffee, and then she will have forgotten all about it. (daughter, P44)*

Interviewees mentioned that possibilities for activities had decreased over time due to their own decreased physical health (e.g., not being able to push a wheelchair anymore), or the resident's decreased cognitive abilities or physical health.

Physical interaction

Many family caregivers reported on the importance of physical interaction for connecting with the resident, and to have missed this when it was not allowed due to COVID-19 restrictions. Although this importance differed between family caregivers, many family caregivers considered physical interaction essential. Some family caregivers mentioned that they increased physical interaction as dementia progressed, thus replacing verbal interaction. Interviewees also mentioned that residents appreciate physical contact, and it can fill silences.

> *Oh, she was so happy. Yes, she was so happy. Touching me all the time. And she said: oh I haven't touched you for so long. Yes, that's really the most important thing for her. (daughter P02)*

> *At times when the conversation normally stops for a while, then you stroke his head, or … Then you actually fill it up with physical contact and a little hug. (daughter, P22)*

Some family caregivers stated that physical interaction during caregiving tasks may increase feelings of connection to the resident.

> *If we go to a restaurant and she has to go the bathroom, I help to get down her stockings. We are then in that toilet together. I don't mean that it is nice to be in the toilet with someone, but you know what I mean, then you just have some kind of intimate connection. (niece, P45)*

On the other hand, other family caregivers stated that physical interaction is not important in their relationship with the resident. Mostly, these family caregivers mentioned that physical interaction had never been important, even before dementia onset.

'Just being there'

Some family caregivers mentioned connecting to the resident by 'just being there'. As a son said about the interaction with his parents:

> *There are also people, for example, who don't like silences if they are visiting somewhere. I don't feel that way at all. I can sit down with my parents and say nothing for half an hour, and then there is still a feeling of connection. [...] That's just the warmth you give each other. (son, P09)*

These family caregivers reported being part of the daily routine of the resident, and feeling at home in the nursing home. As the partner of a resident mentioned:

> *When I do the laundry, he usually comes to watch and help. And otherwise he just sits comfortably in the chair. He has a relaxing chair, and he just sleeps for a bit. And I'll just do my thing. [...] It's feels a bit like a home life. (wife, P01)*

Contextual strategies

Family caregivers mentioned that contextual strategies promoted interaction with the resident, including the strategy to visit during "the best time of the day of the resident", and to visit at a place with which the resident is familiar.

> *She's often more confused after 3 pm, so I prefer to go early in the afternoon. (daughter, P02)*

Theme "Appreciation of the interaction and relationship"

The third key theme that was identified is the appreciation of the interaction and relationship by people living with dementia and family caregivers.

Appreciation of the interaction and relationship for residents living with dementia

Family caregivers reported that their visits mostly had a positive impact on the resident. They stated that they saw the resident enjoying their visit, feeling at ease, their mood improving, looking happy, or smiling. One family caregiver also mentioned that her dad said he enjoyed her visit.

> *He does mention that. He has some very good moments, and then he says: oh I'm so glad you're here. (daughter, P26)*

Furthermore, a family caregiver mentioned that the resident liked her visits, because they break up his day. Another interviewee mentioned that the resident liked that she brings him in contact with the world outside of the nursing home. Also, one family caregiver mentioned that her husband was more willing to accept care when she is around. Moreover, family caregivers reported that the resident apparently liked their visits, since the resident became grumpy when they leave, or asked healthcare professionals many times for them. One family caregiver stated that for these benefits of visiting, it did not matter who was visiting, but it had to be someone familiar for her dad.

> *If it is me or my sister, you know, that won't make much difference. But in any case, there's someone whose name he recognizes and who is here. (daughter, P18)*

Multiple interviewees mentioned that their visits support the resident's cognitive or functional abilities, and that these abilities would decline if they did not visit the resident. They did this by undertaking extra activities with the resident, or talking to them while incorporating their life history into the conversations, which healthcare professionals cannot.

> *Talking to my mother is mainly based on memories, you see. How things used to be, bringing things up: do you remember this and this? And healthcare professionals cannot do that, of course. That's why it seems she is just nodding off a bit. (son, P09)*

Some family caregivers also mentioned that they see the resident enjoying the visit, but stated they think that the resident would not notice if they would stop visiting. Other family caregivers added they questioned whether the visit sticks with the resident.

> *She was very happy. But who visited on Mondays, for her that's of course... So yeah, she was very happy and she really enjoyed it [...], but I don't know if it actually sticks. (daughter, P35)*

On the other hand, several interviewees mentioned that their visit could be tiring for the resident, or they wondered whether the resident always appreciated the visit.

Appreciation of the interaction and relationship for family caregivers

Family caregivers reported that the interaction and relationship with the resident gave them satisfaction, as they supported their last life phase and having a good farewell. Nevertheless, they stated this was not always easy.

> *For me it's a form of saying goodbye in a good way. Suppose she doesn't wake up at some point or a different situation arises, then I'll still have the feeling that I did everything, I gave her what she longed for. (son, P09)*

> *It may not be a nice time for him, I am very aware of that. Because he sometimes makes it clear that he doesn't want to live anymore. When he is not feeling well, or is in pain, or nothing is going his way. Then it's not fun, not even for me, because then I think: yeah, I can't do anything about it, I can only try to make things nice and try to give attention and also ask the healthcare professionals if they want to do that. You know, that he can make his way through life a little. (daughter, P46)*

Moreover, family caregivers mentioned interaction with the resident gave them energy, or they enjoyed hearing stories about the past. Some family caregivers mentioned they enjoyed the interaction most when they saw the resident was thankful for their presence.

> *My father is sometimes very grateful. He then takes me by the shoulders and rubs my shoulders. He smiles at me, and I just know that he is very happy and that gives me so much energy. Then I just want to put him in a little box and take him home (daughter, P29)*

Interviewees mentioned being grateful when the resident made a compliment, showed appreciation, or recognized the family caregiver.

> *Because if he says to you, well, that you look nice, when I was wearing a new blouse... So, something like that, I like, yes. That he says that. That he notices that I'm wearing something new, or something like that. (wife, P30)*

Some family caregivers stated it was important for them to take care of practical matters, such as finances, the laundry or to monitor physical health. Interviewees reported that COVID-19 visiting policies restricted this.

> *I am very happy that we can visit. But I'd really like to do something too. Id' like to clean up some stuff in my dad's closet or whatever. [...] Staff don't have the time for that, and I think: I would like to do that. (daughter, P29)*

Moreover, family caregivers reported they continued to visit and benefited from the visit, even though they found it difficult to interact, since "*it is your father*" or "*you just do it*". As family caregivers said:

> *Interviewer: What does the interaction with your father bring you?*
> *Family caregiver: That's a difficult question. I think it mainly has to do with him just being my father, and of course he has done a lot for me in my life. That I also want to give him something back. But in terms of the conversation, it is a rarity that you can really discuss something of added value with him. Those occasions are exceptions. (daughter, P26)*

Discussion

Three themes were found that reflected perspectives of family caregivers on their interaction and relationship with their loved one living with dementia in a nursing home: (1) changes in the interaction and relationship, (2) strategies to promote connection, and (3) appreciation of the interaction and relationship. Our results show that some family caregivers experience difficulties in making a meaningful connection with the resident, while others succeed in constructing togetherness despite decreased communicative abilities of the person living with dementia, for example, by undertaking activities or by *just being there*. Nevertheless, all family caregivers experienced benefits of their interaction and relationship with their loved ones in the nursing home.

This study confirms the importance of a meaningful connection between people living with dementia in the nursing home and their family caregivers, as family caregivers reported benefits for both. For people living with dementia, this included enjoyment and improved mood, and for family caregivers, this included feelings of satisfaction and fulfillment. Nevertheless, we found great diversity in the day-to-day visiting experiences of family caregivers. For some, establishing or maintaining a meaningful connection with the resident came naturally, while others experienced difficulties, such as decreasing mutuality and reciprocity in the relationship. A previous study among family caregivers of people living with dementia in the community has shown that perceiving mutuality by family caregivers requires them to direct additional attention to subtle positive responses from the person living with dementia (Yu et al., 2018). Family caregivers in the nursing home may also benefit from acknowledging such responses as conveying affection or appreciation. It appears valuable for future research to explore how to support family caregivers in perceiving mutuality and reciprocity.

Furthermore, family caregivers applied different strategies to construct a meaningful connection with their loved one living with dementia, including verbal interaction, undertaking activities, physical interaction, 'just being there', and contextual strategies. These results are in line with previous research. For example, a recent study found that physical proximity and peaceful silence helps to reach emotional connectedness with the person living with dementia (Levy-Storms and Chen, 2020). Nevertheless, the identified strategies for constructing togetherness do not appear to differ between family caregivers who succeed and those who experience difficulties in connecting with the resident. For example, going for a walk may help in interacting and connecting for one family caregiver, but may be a way to avoid interaction for others. The used strategies, therefore, do not guarantee a meaningful connection but are a useful starting point for supporting family caregivers in establishing a meaningful interaction and relationship, and so promote positive experiences (Hado and Friss Feinberg, 2020, Walmsley and McCormack, 2018). Strategies need to be tailored to the needs and wishes of people living with dementia and their family caregivers, and to their personal context.

Moreover, supporting a meaningful connection is expected to not only benefit family caregivers but also be beneficial for people living with dementia, as meaningful interaction can be empowering. Meaningful interaction with family caregivers may promote a sense of identity, usefulness, control, and self-worth (van Corven et al., 2021), which are central to empowerment. It requires family caregivers to be aware of their role and corresponding attitude in the empowerment process (Morris et al., 2020, Thompson et al., 2020). An empowering approach encourages the person living with dementia to be a person with individual talents and capabilities and may contribute to reciprocity in relationships (Vernooij-Dassen et al., 2011). The results of our study provide more details on barriers family caregivers experience and strategies they apply in establishing meaningful interaction. It provides a basis for supporting family caregivers to promote empowerment for people living with dementia in a nursing home.

It is interesting to note that in the interviews with family caregivers on the COVID-19 visiting policies, family caregivers highlighted the importance of not being able to act as caregiver, including household activities or checking finances, whereas in follow-up interviews asking specifically what made their interaction and relationship with the person living with dementia meaningful, this role of caregiving was rarely mentioned. Previous research showed that caregivers indeed wanted to continue having an active role in caring after nursing home admission (Bramble et al., 2009). They gained from the caring itself, including satisfaction, emotional reward, and personal growth, but also from the interaction between the family caregiver and the person living with dementia, including relationship gains and satisfaction in reciprocity (Lloyd et al., 2016). Future research should be undertaken to explore the possibly stimulating role of caregiving for family caregivers of people living with dementia in a nursing home, as this may help family caregivers being meaningfully included in the nursing home life of their loved one

(Boumans et al., 2018, Puurveen et al., 2018, Ryan and McKenna, 2015), and being perceptive to the positive aspects of their interaction and relationship with the person living with dementia. These positive caregiving experiences can increase caregivers' well-being (Quinn and Toms, 2019).

Strengths and limitations

To our knowledge, this is the first study to explore the perspectives of family caregivers on their interaction and relationship with their loved ones living with dementia in a nursing home. A key strength of this study is the timing of the interviews, as the lockdown and subsequent visiting guidelines facilitated family caregivers in reflecting on their interaction with the resident and their pertaining visiting routines, since these guidelines had hindered their usual ways of face-to-face interaction. Family caregivers appeared to become more aware of what made their interaction with the resident meaningful (Koopmans et al., 2021, Verbeek et al., 2020). Another strength of this study is the investigator triangulation, as multiple researchers were involved in conducting the first-stage-interviews (Carter et al., 2014). All interviewers worked at a university network for long-term care, and therefore had experience and knowledge regarding the topic of our study. The relevance of our topic was confirmed as in the interviews of every interviewer interesting information came up about the interaction and relationships between family caregivers and residents. Also, were multiple researchers involved all analyses, having regular discussions with each other, so reaching agreement on the different themes. Last, all coding was conducted separately by two researchers, who had regular discussions with each other and the research team, and many discussions about the analyses were held with the research team, which increases the trustworthiness of the results (Graneheim and Lundman, 2004).

A limitation of this study is the potential selection bias towards involved family caregivers visiting the nursing home often, as participants were a convenience sample from family caregivers who visited soon after the reopening of nursing homes after the first COVID-19 lockdown. Furthermore, given their heterogeneity, we think our study population reflects a wide range of family caregivers. A second limitation may be that some themes may have been overemphasized, such as the importance of a physical connection, because of the COVID-19 situation at the time of interviewing.

Conclusion

Based on the perspectives of family caregivers, we conclude that the interaction and relationship between family caregivers and their loved ones living with dementia in a nursing home are important for both and that family caregivers apply different strategies for constructing togetherness. Nevertheless, some family caregivers appear to experience difficulties in establishing a meaningful connection with the resident. Our results provide a basis for tailoring interventions aimed at supporting family caregivers in perceiving mutuality and reciprocity in the interaction and relationship with the resident, by supporting family caregivers to understand and come to terms with changes that threaten the maintenance or establishment of a meaningful connection. This may help them to have a positive attitude, so maintaining or improving the quality of the relationship between family caregivers and residents living with dementia.

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Additional file 1. Interview guide

Topic guide first interview

1. Organization

Planning the visit

- How did you experience the information prior to the visit? How did you know visitors were allowed back into the nursing home?
- To which extent were you able to decide when you wanted to visit?
- Did you know what to expect during the visit?
- Did you know what was expected of you during the visit? For example, wearing a protective face covering.

Allowing visitors back into the nursing home

- How do you feel about being allowed back into the nursing home as visitor?
- To what extent was it difficult to decide who was allowed to visit your loved one?
- What do you think of this way of visiting?

Visiting guidelines

- What did you think of the guidelines for the visit?
- How was your contact with healthcare professionals during the visit?
- Was it difficult for you to comply with the guidelines? If yes, in which way?
- Did the guidelines affect the contact with the resident in the nursing home? If yes, in which way?
- Did you experience any barriers due to the guidelines? If yes, which barriers?

Points for improvement

- Is there anything you would like to be different on your next visit?

2. Impact on the family caregiver

- How did you experience the visit?
- Did you have any doubts about visiting? If yes, about what?
- Did the visit meet your expectations? Why?
- Was it of added value to see the resident of the nursing home in person? If yes, in which way?
- What made this visit different than visits before the COVID-19 pandemic?
- How did you keep in touch with the resident in the nursing home when visitors were not allowed? How did this visit differ from those alternative ways?

3. Impact on the well-being of the resident living with dementia

- Were you able to interact meaningfully with the resident? If yes, how did you meaningfully interact? What this different from visits before the COVID-19 pandemic? If yes, why?
- According to you, did the resident realize you had not seen each other for a long time?
- Did the resident seem different to you than during visits before the COVID-19 pandemic?
- According to you, how did the resident experience the visit?
- Was the resident sad during the visit? If yes, how did you notice?
- Was the resident happy during the visit? If yes, how did you notice*?*
- Was the resident anxious during the visit? If yes, how did you notice*?*

- Was the resident confused during the visit? If yes, how did you notice?
- Did the resident laugh during the visit?
- Was the resident enthusiastic during the visit? If yes, how did you notice?
- Were these emotions different than during visits before the COVID-19 pandemic?
- Did the resident feel at ease? If yes, how did you notice?

Topic guide follow-up interview

Meaningful interaction and relationship

- How would you describe the relationship with the resident?
- What does a typical visit generally look like?
- In what way do you meaningfully interact with the resident?
- What makes you feel that you have meaningfully interacted with the resident?
- According to you, how does the resident experience your visits? How do you notice?
- In which situations do you succeed in interacting meaningfully?
- In which situations do you not succeed in interacting meaningfully? How do you cope when this happens?

Presenting the results of the first interviews

Participants mentioned that meaningful interaction can be established by (1) verbal interaction, (2) physical interaction, and (3) undertaking activities together.

- Are there other ways in which you meaningfully interact? According to you, what is the most important for meaningfully interaction?
- To what extent has meaningful interaction changed since the resident was diagnosed with dementia or moved to a nursing home?

Chapter 5

Empowering interventions for people living with dementia: a European survey

Revisions undergoing review

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Abstract

Aims: We aim to identify existing empowerment interventions for people living with dementia and to explore which used interventions and projects are considered empowering and why.

Design: An online survey.

Methods: We conducted an online survey between May 2018 and July 2018 among professionals interested in dementia care in Europe. Interventions were clustered within the ecological model for health promotion. Reasons from respondents as to why they considered interventions to be empowering were analysed and structured according to a recently developed conceptual framework of empowerment for people living with dementia.

Results: Seventy-three respondents from 23 countries together mentioned 98 interventions or projects, of which 90 were unique. Interventions focused on the (inter)personal (n=54), organisational (n=15), communal (n=6) and societal (n=15) levels. A broad range of interventions were considered empowering, but no interventions were specifically developed for, nor aimed at, empowerment. Reasons as to why respondents considered these interventions as empowering fitted the framework's domains.

Conclusion: This European survey provides insights into interventions considered empowering for people living with dementia. An important step that needs to be taken is to develop and test interventions that specifically aim to promote empowerment for people living with dementia.

Impact: Empowerment may encourage people with dementia to live the life they choose, and focus on what is possible, instead of what is no longer possible. Many interventions are considered as empowering for people living with dementia, however no interventions could be identified that were specifically developed for or aimed at empowerment. This study shows that for promoting empowerment, it is necessary to develop and test interventions that specifically aim for empowerment, do this in collaboration with relevant stakeholders, and in this way support people living with dementia to live according to their competencies, talents and wishes.

Introduction

The concept of empowerment contributes to the shift from task-oriented care, with a focus on the illness, to person-centred care, with an emphasis on the whole person (Holmstrom & Roing, 2010). Empowerment has received increasing attention, also for people living with dementia (Morris et al., 2020; Prato, 2018; Shelton et al., 2018). To encourage them to live the life they choose and focus on what is possible, instead of what is no longer possible, it is considered important to encourage empowerment for people living with dementia (Hage & Lorensen, 2005; Tengland, 2008). Therefore, interventions that promote empowerment for people living with dementia, and that support (in)formal caregivers in this empowerment process, are valuable for care and support.

Background

Over recent decades, several interventions or projects for people living with dementia addressing the concept of empowerment have been described in the literature (Bhatt et al., 2020; Gould et al., 2008; Pearce et al., 2012). Furthermore, it is possible that additional empowering interventions for people living with dementia may already exist, but cannot be found in the literature as they may only be used in practice without description in the scientific literature, or because they did not specifically use the word “empowerment”. Nevertheless, there is a lack of clarity around the concept. Literature on what empowerment means and includes for people living with dementia remains scarce, and most literature surrounding empowerment lacks a clear definition or explanation of the concept (van Corven et al., 2021b). Perspectives on empowerment of people with dementia were therefore evaluated and described elsewhere (van Corven et al., 2021a). To gain an overview of empowering interventions for people living with dementia, and thus find opportunities to improve current care and support, a review of scientific literature may not be the best method as this could possibly overlook many empowering interventions.

Therefore, in this study, we performed a European survey aiming to identify existing empowerment interventions for people living with dementia and to find out which applied interventions and projects are considered empowering and why. Results may direct further work on empowerment interventions, and thus provide a basis to promote empowerment for people living with dementia, and to support (in)formal caregivers in this empowerment process.

The study

Aims

We aim to identify existing empowerment interventions for people living with dementia and to explore which used interventions and projects are considered empowering and why.

Design and procedure

We performed an online survey between May 2018 and July 2018 among professionals interested in dementia care across Europe. The survey was hosted online using the online survey tool, Limesurvey.

The European Working Group of People With Dementia (EWGPWD) was consulted on the relevance and design of the survey, leading to further specification of the aim and adaptations in terminology. The EWGPWD was set up by Alzheimer Europe in 2012. The group is composed entirely of people living with dementia, who are nominated by their national Alzheimer Association. They work in collaboration with Alzheimer Europe, contributing towards their work and supporting research projects (Alzheimer Europe, 2020).

Participants

This survey targeted European dementia researchers and healthcare providers for people living with dementia residing at home and in nursing homes. The survey was distributed in a variety of ways. First of all, the survey was distributed via several networks and channels of Alzheimer Europe (e.g., its 37 national Alzheimer associations from 33 countries, newsletter and social media). Second, the survey was distributed to people presenting at the Alzheimer Europe conferences of 2017 and 2018 with the word "empowerment" in their abstract. Third, the survey was distributed to all members of the pan-European, multi-professional clinical research network INTERDEM (Timely Detection and Intervention in Dementia), the United Kingdom's Older People Network, and the pan-European Community Occupational Therapy for people with dementia (COTiD) network. Lastly, we sent the survey to Dutch dementia researchers in the professional network of the authors. Respondents were asked to forward the survey to other relevant people in their network or country.

Data collection

To identify existing empowerment interventions for people living with dementia in Europe, a specific survey was developed, including both open format and multiple-choice questions. Questions covered basic information about the intervention, its goals, target population, involved healthcare professionals, information on the development, evaluation and implementation, and why respondents considered the intervention to be empowering. The questions of the survey can be found in Additional File 1. Respondents could choose between two languages of preference: English or Dutch. If respondents were not aware of the details of the intervention, they could answer some basic questions, only covering the aim of the intervention, a general description and why they considered the intervention to be empowering (see Additional File 1).

Ethical considerations

The study was conducted in accordance with Dutch law and the Declaration of Helsinki. The study protocol was not reviewed by the local Medical Ethics Review Committee, since the participating professionals were not subjected to actions nor were rules of behavior imposed on them. By filling in the survey, professionals in dementia care gave their consent for participation.

Data analysis

Interventions were clustered within the ecological model for health promotion on the (inter)personal, organisational, communal and societal levels (McLeroy et al. 1988). Interventions on the (inter)personal level included all interventions regarding the person living with dementia and/or their social environment. Therefore, these interventions were further clustered based on the person who was targeted (person living with dementia, family caregiver, formal caregiver or a combination). Information about interventions which were mentioned more than once was combined. For each cluster of interventions, all qualitative data was summarised. The quantitative data of the multiple-choice questions was analysed using descriptive statistics (absolute frequency and relative frequency).

The reasons as to why respondents of this survey considered interventions to be empowering are structured according to the conceptual framework of empowerment for people living with dementia, based on stakeholder perspectives and the scientific literature. This conceptual framework includes: (1) the state of being empowered, (2) the process of empowerment, and (3) contribution of the environment to the empowerment process.

Validity, reliability and rigour

For this study, a specific English survey was developed by the authors. The survey was piloted by three member associations of Alzheimer Europe (i.e., the national Alzheimer associations of Ireland, Italy and Finland), leading to textual changes of questions (e.g. specification of multiple choice options), and increased readability and clarity of the introduction text. Afterwards, the survey was also translated to Dutch by the first author (CvC), which was checked by two other authors (AB, DG).

Results

In total, 73 people participated in the study. Their responses mentioned a total of 98 interventions that they considered to be empowering. There were 90 unique instances of interventions, as some interventions were mentioned more than once. Detailed questions about the intervention were answered for 69 interventions, while for 21 interventions, only basic information was provided.

Respondent characteristics

Table 1 presents the various methods of survey distribution, the number of people who received the survey (either sent by us, or forwarded by respondents), the number of people who completed the survey, and the number of interventions mentioned.

Respondents of the survey had a range of occupations, with employment at research universities (n=22), Alzheimer or other patient organisations (n=17), health care organisations (n=13), universities of applied sciences (n=9), university medical centres (n=9), governmental organisations (n=2), or other employment (n=9), including consultancy, information research organisations, knowledge centres, national centres for research, education and service development, NGOs, professional scientific societies, research and engagement programs and research institutes. These numbers add up to more than the total number of respondents as some were employed at multiple organisations.

The respondents were from 23 countries. An overview of the number of participants and interventions per country can be found in the Additional File. Three respondents filled in the survey, but indicated that empowering interventions or projects might exist, but that they or their organisation did not know this information (n=2), or indicated that to the best of their knowledge this type of intervention or project did not exist in their country (n=1). These respondents came from Finland, Greece and Bulgaria.

Table 1. *Characteristics of survey distribution*

Way of distribution	**Survey sent**	**Survey forwarded**	**Number of people receiving the survey**	**Completed surveys**	**Mentioned interventions**
Alzheimer Europe network	45	24	69	18	27
Interdem network[a]	174	16	173	41	55
COTiD network	18	7	25	5	7
UK Older People Network[b]	3	0	2	0	0
Professional network of authors	31	4	35	9	9
Total	**271**	**51**	**304**	**73**	**98**

[a] 17 non-responses because of invalid e-mail address (n=14), retirement (n=1), or research outside Europe (n=3)

[b] 1 non-response because of invalid e-mail address.

Empowering interventions

Baseline characteristics

Baseline characteristics were provided for 69 interventions. Interventions targeted people living with dementia residing at home (n=58, 84%), attending a day care centre (n=31, 45%), or in a care home or nursing home (n=35, 51%). Percentages add up to over 100% as some interventions were applied in multiple settings. The majority of the interventions did not specify age of dementia onset (n=56, 81%), however some interventions were specifically for people living with young onset dementia (n=3, 4%) or late-onset dementia (n=10, 15%). Furthermore, the majority of interventions targeted all types of dementia (n=66, 96%), whereas some interventions specifically targeted Alzheimer's disease (n=3, 4%). Most interventions were specifically for people living with mild (n=35, 51%) or moderate (n=23, 33%) dementia. Three interventions were tailored to people living with severe dementia (4%). Severity was not specified for the other interventions (n=30, 44%). These percentages add up to over 100% as some interventions focused on multiple categories of dementia severity.

A diverse range of healthcare professionals were involved in the interventions: elderly care physicians, geriatricians, general practitioners, psychiatrists, psychologists, dementia case managers, nurses, nursing assistants, care assistants, social workers, physiotherapists, occupational therapists, speech therapists, volunteers and many more.

Table 2. Types of interventions that were considered empowering, and their effective or useful elements

Intervention types	Intervention goal
Interpersonal (n=54)	
The person living with dementia	
Physical health	
Cognitive rehabilitation or stimulation (n=4)	To achieve personally meaningful goals.
Management of medication (n=1)	-
Nutritional guidance (n=1)	To improve health-related quality of life.
Physical activity (n=2)	To enable people with dementia to participate in physical activities and to benefit from physical activity.
Health coach (n=1)	To improve health-related quality of life.
Experiences	
Music (n=2)	To create an inclusive participatory music environment, and focus on the person behind the dementia.
Art (n=2)	To touch people through art and to share experiences.
Reminiscence (n=3)	To gain insight into life stories and positive memories, and to increase well-being.
Peer support or education for people living with dementia (n=2)	To inform people about living with dementia, provide a sense of community, and find ways to live with dementia.
Physical environment	
Mobility (n=3)	To maintain mobility.
Assistive technologies at home (n=6)	To turn the home of the person living with dementia into a personalised “coaching assistant”, to support memory and structure in everyday life, and to support social participation, self-management and independence.
Interaction	
Communication with caregivers (n=2)	To support the dialogue with (in)formal caregivers, assist in creating better insight into what support is needed to uphold independent living, and support the needs and wishes of the person living with dementia.
Promotion of social contacts (n=1)	To promote social networks, improve skills, and obtain support for regular activities.

Intervention types	Intervention goal
Person living with dementia and their family caregiver	
Peer support (n=2)	Aims for social activation, new friendships, mastery over one's own life, to share experiences, improve quality of life, and raise awareness about dementia.
Multicomponent interventions (n=10)	Aims for active aging, reducing neuropsychiatric symptoms, retaining independence, participating in meaningful activities, improving quality of life, reducing burden on the family caregiver, providing individual counselling, give direction in care pathways, and seek possibilities to adapt the environment or activities.
Promote interaction between person living with dementia and their family caregiver (n=1)	To make contact, improve comfort, improve or preserve quality of life, and increase the positive experiences of the family caregiver.
Family caregiver	
Education (n=2)	To provide better support in caring for the person living with dementia, and improving self-management of the family caregiver to stay in balance.
Care relief (n=5)	To delay long-term institutionalisation, prevent overload and increase social support.
Healthcare professional (and family caregiver)	
Education (n=4)	To provide a practical approach to communication, that helps caregivers pause, reflect and connect to people living with dementia, teaches general practitioners on communicating about what is important for people living with dementia and their family caregiver, improve quality of communication about end-of-life care and care wishes.
Organisation (n=15)	
Care approach (n=5)	To engage in activities that fit personal wishes and ideas, provide a home, provide help in summarising thoughts about end-of-life care, create a culture of palliative care, and promote respect for dignity.
Day support facilities (n=10)	To slow down the process of dementia, provide some structure to the day, promote coping, train cognitive or physical functioning, provide psychological support, information about the disease, meaningful daytime activities, support in one place, and cater to varied needs of people living with dementia.

Intervention types	Intervention goal
Community (n=6)	
Dementia friendly community (n=6)	To increase community awareness and understanding of dementia, turn places into a memory-friendly areas, reduce barriers, and involve people living with dementia in their communities, so they have the opportunity to continue to engage in their usual activities.
Society (n=15)	
Dementia friendly society (n=6)	To raise awareness of dementia, share stories, run national campaigns, and bring together national organisations to connect and take practical action on dementia.
Research and policy involvement (n=4)	To stimulate people with dementia to talk about what they need and want.
Knowledge generation (n=5)	To gain knowledge about living with dementia and appropriate care and support, and to support autonomy and agency.

The reach of the interventions ranged from regional (n=25, 36%), national (n=28, 41%) and international (n=15, 22%), with the range of one intervention marked as unknown (1%). Most interventions had benefited between 1 to 100 people living with dementia (n=28, 41%), others indicated having benefited 100-500 (n=12, 17%), 500-2,000 (n=7, 10%), or more than 2,000 people (n=8, 12%). For fourteen interventions (20%), respondents indicated that they did not know how many people living with dementia had benefited from the intervention so far.

Description of empowering interventions

The four levels of the ecological model (McLeroy et al., 1988) for health promotion were represented: interventions were on either an (inter)personal (n=54), organisational (n=15), communal (n=6) or societal (n=15) level. Interventions on an (inter)personal level targeted the person living with dementia (n=30), the person living with dementia and their family caregiver (n=13), the family caregivers (n=7), or the healthcare professional (n=4). Lastly, interventions for people living with dementia regarded a range of categories, such as physical health (n=9), music and art (n=9), interaction (n=9), or physical environment (n=3). Table 2 displays the clustering of interventions, an overview of the type of interventions and their effective or useful elements.

Reasons for interventions to be considered empowering

The reasons as to why respondents considered interventions as empowering were clustered according to the domains of a recently developed framework of empowerment for people living with dementia (van Corven et al., 2021b). The total amounts to more than the number of interventions, as some respondents mentioned multiple reasons as to why they considered an intervention to be empowering. However, none of the interventions focused on all of the domains of empowerment.

The state of being empowered

Firstly, corresponding to the empowerment theme "having a sense of personal identity", respondents considered interventions as empowering when the intervention was person-centred, and focused on the needs and wishes of the person living with dementia and their family caregivers (n=25). Secondly, in line with the theme "having a sense of choice and control", interventions that promoted choice, control and autonomy were considered to be empowering (n=28), which also included promoting independence and exerting an influence on everyday life activities. Thirdly, fitting into the theme "using abilities and being needed", interventions were considered empowering by respondents if people living with dementia were encouraged to stay active, take part in activities, and had the opportunity to make a contribution (n=22). Moreover, interventions enabling the person living with dementia to actively live in the community for a longer period were mentioned (n=8), or if they focused on remaining or preserving abilities (n=11), for example by training cognitive abilities. Lastly, fitting with the empowerment theme "retaining a sense of worth", respondents considered interventions empowering if these promoted self-worth and confidence (n=12). This included people living with dementia being considered as resourceful human beings and being proud of themselves.

The process of empowerment

Corresponding to the process of empowerment, which takes place within the interaction of the person living with dementia and their environment, respondents designated interventions as empowering if they improved relationships or social participation, actively involved familial caregivers, or improved communication between the person living with dementia and their family caregiver or healthcare professionals (n=17).

Contribution of the environment to the empowerment process

A number of respondents noted that they considered interventions to be empowering when they focused on the contribution of the environment to the empowerment process. Firstly, on an (inter)personal level, interventions were thought to be empowering by respondents if they trained and informed healthcare professionals and family caregivers on different topics of dementia, and on how to communicate with the person living with dementia (n=4). In this way, family caregivers could provide better care and support for the person living with dementia.

Secondly, on an organisational level, several care approaches were thought to be empowering by respondents (n=3) as they offered solutions before moving to a nursing home, such as respite care for informal caregivers.

Thirdly, on a societal level, dementia friendliness, low stigma, participation in society, and social inclusion were mentioned by respondents as contributions from the environment to the empowerment process (n=16). They argued that people living with dementia would feel more integrated and could remain included in society. It was thought to be empowering by respondents to create communities where there is complete acceptance and inclusion of people living with dementia, and where people living with dementia are supported to continue to live fulfilling lives for as long as possible. This necessitates a community that is aware of the challenges faced by people living with dementia and their partners, families and close friends. Moreover, respondents considered an intervention that promoted advocacy for people living with dementia as empowering (n=1), for example the opportunity to be a spokesperson for people living with dementia. In other interventions, people living with dementia could share their story (n=3), for example in a film or outreach campaign, and, through this, give a face to dementia. In these interventions, people living with dementia were encouraged to speak openly about their condition. Furthermore, respondents thought that generating knowledge about the condition and providing information about available services was empowering (n=6). Lastly, it was considered empowering by respondents for people living with dementia to have a leading role in research projects or the design of services (n=7).

Effects of empowerment on other variables

Some of the mentioned reasons as to why an intervention was considered empowering could not be clustered to the domains of the empowerment framework. This entailed that there were possible effects of empowerment on other variables. Multiple respondents considered various interventions designed for people living with dementia as empowering when they aimed to improve the quality of life, mood or well-being of people living with dementia, or supported people to have a good life alongside their dementia (n=23).

Discussion

This European survey gave an interesting overview of interventions for people living with dementia that were considered to be empowering by different stakeholders in dementia care and research. It showed that many different types of interventions, with wide-ranging aims, are considered empowering by professionals interested in dementia care. Yet, most interventions appeared to fit within the conceptual framework of empowerment for people living with dementia. The majority of shared interventions (60%) focused on the (inter)personal level, i.e., the person living with dementia, their family caregivers or the healthcare professional.

Respondents of the survey suggested, proposed, or implied that interventions were empowering, but not one of the reported interventions specifically aimed to empower people living with dementia. Interventions identified in this survey may therefore contribute to good care and support for people living with dementia, but the question remains as to whether these are empowerment interventions, or interventions that may promote empowerment as a side effect. It could be, as seen in our integrative review, that people use the word “empowerment” in contexts where it is possibly not always the most suitable concept. An important step in promoting empowerment among people living with dementia is to develop and test interventions that specifically aim to promote empowerment, and to support (in)formal caregivers in this empowerment process. For this purpose, clarity around the concept of empowerment is needed. Our recently developed conceptual framework, based on stakeholders’ perspectives and the scientific literature (van Corven et al., in press), articulates the state of empowerment, the process of empowerment and the role of the environment therein, thus providing a structure for the development of effective interventions specifically aimed at promoting empowerment for people living with dementia. The framework suggests that empowering interventions should focus on a sense of identity, usefulness, control, and self-worth for people living with dementia, while supporting (in)formal caregivers in promoting the empowerment process (van Corven et al., in press).

Many of the reasons as to why respondents of this study considered interventions as empowering appeared to fit within the conceptual framework of empowerment (van

Corven et al., in press). Reasons that fell outside the framework's domains regarded the possible effects of empowerment on other variables, for example outcomes of empowerment. Several outcomes were also identified in our integrative literature review, but were subsequently not included in the framework as relationships of empowerment with the suggested outcomes were not well described nor empirically studied. Additional research is needed to provide more clarity as to the effects of empowerment on concepts such as a person's wellbeing.

Moreover, no new themes on the state of being empowered emerged from the current study, which further confirms the framework's relevance and appropriateness for professionals interested in dementia care. Some aspects of empowerment were more prominent in certain interventions than others. The sense of identity, usefulness and control were each addressed in about a quarter of the interventions, while much fewer interventions addressed a sense of self-worth. Furthermore, interventions which targeted the process of empowerment by improving interaction and relationships were scarce. We propose that all interventions may benefit from focusing on the four themes of empowerment for interaction. The fact that none of the interventions addressed all aspects of empowerment, and that the importance of interaction and relationships was not always highlighted, suggests the need for specific empowerment interventions. For example, an intervention which promotes feelings of usefulness may help the person to feel empowered, but may not be empowering on its own. Nevertheless, the interventions or projects identified by this survey add to practical details on how to promote the different aspects of empowerment, and may provide a basis for the development of interventions specifically aimed at empowerment.

Strengths and limitations

To our knowledge, this is the first study performing a European survey aimed at identifying existing interventions that are considered empowering for people living with dementia, and going beyond what can be found in the literature. In this way, we also identified interventions that do not specifically use the concept of empowerment, and interventions that are only used in applied practices. The results provide suggestions on how to promote empowerment for people living with dementia in Europe, and support (in)formal caregivers in this empowerment process.

A limitation of this study is that responding professionals and researchers suggested, proposed, or implied that interventions were empowering, but these effects on empowerment were not yet studied. We did not consult people living with dementia to validate if they found these interventions empowering. As the EWGPWD highlighted in their consultation, many services that might be described as empowering may not necessarily be considered as such by the people living with dementia. Therefore, it is important that people living with dementia are included in all phases of the development of interventions targeted specifically at empowerment. Furthermore, future studies on how the impact of empowerment can be measured would be valuable.

In addition, there could be a potential selection bias with motivated respondents who were willing to share their time and opinions by filling in the survey, who were familiar with English or Dutch, and who could be reached by addressing the networks of Alzheimer Europe, INTERDEM, COTiD, the UK's Older People Network, and the professional network of the authors. Moreover, as we included the professional network of the authors, there was an overrepresentation of Dutch interventions. It is possible that other empowering interventions exist that were not identified in this study. What may add to this is that the reliability and validity of the survey was not tested beforehand. Lastly, it would be interesting to involve people from various minority and marginalised groups in future discussions about what constitutes empowerment and what improvements are needed.

Conclusion

This European survey provides insight into interventions that are considered empowering for people living with dementia by different stakeholders in dementia care and research. A broad range of interventions were considered empowering, however none of the interventions were specifically developed for nor aimed at empowerment. An important step in promoting empowerment is to develop and test interventions that specifically aim to promote empowerment in collaboration with people living with dementia, and to investigate how to best measure their impact on feelings of empowerment.

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Additional file 1. Survey questions

We want to gain a broad overview of current empowerment interventions and projects across Europe. There are several definitions of empowerment, for example "A process through which people gain greater control over decisions and actions affecting their health". In the context of dementia, there have been many different approaches to empower people with dementia. In this project, we are interested in finding out about how empowerment is perceived and promoted in different countries and settings. We'd therefore like to know about any projects or interventions that are described as empowering or that (even if the term is not specifically used) you would consider as being empowering to people with dementia. We deliberately choose to use a broad concept of empowerment. We are interested in finding out which interventions and projects you consider empowering and why. We are open to different views on empowerment. We invite you to share all potentially relevant interventions or projects. Examples of interventions or projects considered empowering are interventions or projects that:

- aim to support people with dementia to stay active and involved as long as possible
- aim to enhance their ability to live well with dementia
- address individual needs and preferences

1. Are you familiar with an intervention or project as explained above?
    a. Yes
    b. No

2. If you answered no, can you explain why you are not familiar with an intervention or project as explained above?
    a. To the best of my knowledge, this type of intervention or project does not exist in my country.
    b. Such interventions of projects might exist, but I or my organisation cannot provide this information.

3. We would like to ask you some questions about the intervention or project. Can you answer some questions about the content of the intervention or project?
    a. Yes, I can answer questions about the intervention or project (see Detailed Questions)
    b. No, I only know basic information about the intervention or project (see Basic Information)

Detailed questions

What is the empowerment intervention or project about?

1. What is the name of the intervention?

2. What is the aim of the intervention?

3. Why do you consider this intervention or project to be empowering for people living with dementia?

4. What is the target population of the intervention or project?
    a. People with dementia living at home
    b. People with dementia attending day care centre
    c. People with dementia living in a care home or nursing home

    d. People with dementia living a special dementia care unit
    e. I don’t know
    f. Other

5. Please specify the onset of dementia of the target population
    a. Any age or age not specified
    b. Young-onset dementia (first symptoms before the age of 65 years)
    c. Late-onset dementia (first symptoms at the age of 65 years an over)
    d. Not applicable
    e. I don’t know

6. Please specify the dementia type of the target population
    a. All dementia types or type not specified
    b. Alzheimer’s disease
    c. Frontotemporal dementia
    d. Vascular dementia
    e. Dementia Lewy Bodies
    f. Not applicable
    g. I don’t know
    h. Other

7. Please specify the severity of dementia of the target population
    a. All severities or severity not specified
    b. Mild dementia
    c. Moderate dementia
    d. Severe dementia
    e. Not applicable
    f. I don’t know

8. Is the informal caregiver (e.g. relatives, friends, etc.) involved in the intervention or project? If yes, how are informal caregivers involved in the intervention or project?

9. Which health and social care professionals are involved in the intervention?
    a. Nursing home physician specialist
    b. Geriatrician
    c. General practitioner
    d. Psychiatrist
    e. Psychologist
    f. Case manager
    g. Nurse or nursing assistant
    h. Care assistant / auxiliary worker
    i. Social worker
    j. Physiotherapist
    k. Occupational therapist
    l. Speech therapist
    m. Volunteers
    n. None
    o. I don’t know
    p. Other

10. What is the duration of the intervention or project?
    - Average duration of one session (in minutes)
    - Number of sessions
    - Duration of intervention (in weeks)

11. Can you describe the intervention or project in a few sentences?

12. Do you have any additional comments on what the intervention or project is about, and the target population of the involvement of (in)formal caregivers?

Development of the intervention or project

13. When was the intervention or project developed?
    a. In the last 12 months
    b. 1-3 years ago
    c. 3-5 years ago
    d. 5-10 years ago
    e. More than 10 years ago
    f. I don't know

14. Who, or which organisation, developed the intervention or project?

Use of the intervention

15. Approximately how many people with dementia benefit or have benefited from the intervention or project since it started?
    a. 1-100 people with dementia
    b. 100-500 people with dementia
    c. 500-2,000 people with dementia
    d. More than 2,000 people with dementia
    e. I don't know

16. How would you describe the geographical spread of the intervention or project?
    a. Regional
    b. National
    c. International
    d. I don't know

17. Do you have any additional comments on how many people with dementia have used the intervention or the geographical spread?

Evaluation

18. What are (in your opinion) the most relevant elements of this intervention or project?

19. Has the project been evaluated?
    a. Yes, the intervention or project has been evaluated practice based
    b. Yes, it has been scientifically evaluated and a scientific article has been published
    c. The intervention or project is currently being evaluated
    d. No

20. If yes, what can you tell us about the results of the evaluation?

21. Do you have additional comments on the evaluation of the intervention or project?

Practicalities for implementation in a different setting

22. To implement this intervention or project in another country, what should be considered in terms of barriers and facilitators?

Basic information

1. What is the name of the intervention or project?

2. What is the aim of the intervention or project?

3. Can you describe the intervention or project in a few sentences?

4. Why do you consider this intervention or project to be empowering?

Additional file 2. Number of respondents and interventions per country

Table 1. *Number of respondents and mentioned interventions per country.*

Country	Number of respondents	Number of interventions
Netherlands	20	38
United Kingdom	11	11
Italy	8	9
Finland	5	7
Belgium	4	4
Germany	3	3
Denmark	2	4
Malta	2	2
Spain	2	2
Sweden	2	2
Greece	2	1
Czech Republic	1	3
Slovenia	1	3
Austria	1	1
France	1	1
Hungary	1	1
Ireland	1	1
Luxembourg	1	1
Norway	1	1
Portugal	1	1
Romania	1	1
Switzerland	1	1
Bulgaria	1	0

Additional file 3. Baseline characteristics of interventions

Table 2. *Baseline characteristics of the 69 interventions who provided this information.*

Characteristics	(n, %)
Setting[a]	
Home	n=58, 84%
Day care center	n=31, 45%
Nursing home	n=35, 51%
Age of dementia onset	
Not specified	n=56, 81%
Young-onset dementia	n=3, 4%
Late-onset dementia	n=10, 15%
Dementia type	
All types of dementia	n=66, 96%
Alzheimer's disease	n=3, 4%
Dementia stage[b]	
Not specified	n=30, 44%
Mild dementia	n=35, 51%
Moderate dementia	n=23, 33%
Severe dementia	n=3, 4%
Geographical spread	
Regional	n=25, 36%
National	n=28, 41%
International	n=15, 22%
Unknown	n=1, 1%
Reach of intervention thus far	
1-100 people	n=28, 41%
100-500 people	n=12, 17%
500-2000 people	n=7, 10%
More than 2000 people	n=8, 12%
Unknown	n=14, 20%

[a] Percentages add up to over 100% as some interventions were applied in multiple settings

[b] Percentages add up to over 100% as some interventions focused on multiple categories of dementia severity.

Chapter 6

Promoting empowerment for people living with dementia in nursing homes: development and feasibility evaluation of the WINC empowerment program

Revisions undergoing review

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Abstract

Objectives: This article describes the development and feasibility evaluation of an empowerment program for people living with dementia in nursing homes – the WINC empowerment program.

Methods: Development and feasibility evaluation of the empowerment program was guided by the British Medical Research Council's (MRC) framework. In the developmental phase, we used intervention mapping to develop the theory- and evidence-based intervention. During the feasibility phase, two care teams utilised the program from September to December 2020. We evaluated the feasibility in terms of demand, acceptability, implementation, practicality, integration and limited efficacy.

Results: This study showed that, according to healthcare professionals, the program was feasible for promoting empowerment for people living with dementia in a nursing home. Healthcare professionals mentioned an increased awareness regarding the four themes of empowerment (sense of identity, usefulness, control and self-worth), and greater focus on the small things that matter to residents. Healthcare professionals experienced challenges in involving family caregivers.

Conclusion: An important step is to take into account the implementation prerequisites that follow from our findings, and to further investigate feasibility, as the use of the program and data collection was hindered by the COVID-19 pandemic. Subsequent research could investigate the effects of the WINC empowerment program.

Introduction

Healthcare organisations continuously try to improve the quality of care for nursing home residents living with dementia. In recent decades, there has been a shift from task-oriented care, with a focus on illness, to person-centred (Edvardsson et al., 2008, Kitwood, 1997, McCormack et al., 2012, Simmons and Rahman, 2014) and relationship-centred care (Nolan et al., 2004). These are approaches that focus on the whole person and their relationship with caregivers. The concept of empowerment fits with this focus, as it promotes a sense of identity, usefulness, control and self-worth (van Corven et al., 2021, van Corven et al., 2021). These four domains of empowerment were identified using focus group discussions and interviews with people living with dementia, their family caregivers and healthcare professionals (van Corven et al., 2021). An extensive systematic literature review showed that empowerment is a dynamic process, taking place between the person living with dementia and their environment (van Corven et al., 2021). An empowering approach encourages the person living with dementia to be a person with individual talents and capabilities and may contribute to reciprocity in relationships (van Corven et al., 2021, Vernooij-Dassen et al., 2011, Westerhof et al., 2014).

Therefore, in nursing homes, the concept of empowerment has received growing attention (Carpenter et al., 2002, Hung and Chaudhury, 2011, Martin and Younger, 2000, Swall et al., 2017, Watt et al., 2019). Nevertheless, interventions that specifically aim at empowering people living with dementia in a nursing home are lacking (van Corven et al. submitted). Such interventions could be valuable as they may help to focus on what is possible, instead of what is no longer possible, by striving to achieve the four themes of empowerment (a sense of identity, usefulness, control and self-worth) in the interaction between people living with dementia and their environment (van Corven et al., 2021, van Corven et al., 2021). An important step in improving quality of care for people living with dementia is to develop and test interventions that specifically aim to promote empowerment for those people, and to support (in)formal caregivers in this process.

In this study, we develop such a program (the WINC empowerment program) for people living with dementia in a nursing home. The aim of the program is to reflect and act on the wishes and needs of people with dementia and their family caregivers regarding the four themes of empowerment (van Corven et al., 2021). It aims to provide concrete opportunities for healthcare professionals and family caregivers to address and support the strengths of the person with dementia, and through this, encourage the person with dementia to increase their sense of self-worth (W), identity (I), usefulness and being needed (N), and control (C). This article describes the development and feasibility evaluation of this WINC empowerment program.

Materials and methods

Design

The development and feasibility evaluation of the WINC empowerment program was guided by the British Medical Research Council's (MRC) framework on how to develop and evaluate complex interventions (Skivington et al., 2021), including four phases: (1) development or identification of the intervention, (2) feasibility, (3) evaluation, and (4) implementation. This article describes phases 1 and 2.

Phase 1 of MRC framework: intervention development

We used intervention mapping (IM) to develop the theory- and evidence-based intervention (Bartholomew et al., 2016). Intervention mapping consists of six different steps: (1) identification of potential improvements (needs assessment), (2) defining the behaviours and their determinants that are needed to reach the improvement goal, (3) selecting behaviour change techniques and ways to apply them, (4) designing the program, (5) specifying an implementation plan, and (6) generating an evaluation plan.

Phase 2 of MRC framework: feasibility

In this phase, we used the method described by Bowen et al. to evaluate the feasibility in terms of demand, acceptability, implementation, practicality, integration, and limited efficacy (Bowen et al., 2009). *Demand* is the extent to which the program is likely to be used; *acceptability* refers to suitability; *implementation* addresses the degree of delivery; *practicality* refers to the extent to which the program is carried out as intended; *integration* relates to the extent to which it can be integrated in existing systems, and *limited efficacy* addresses the promise the program shows of being effective.

Setting and participants

The program was developed by the project team, consisting of all authors, a quality assurance officer, an elderly care physician from the participating nursing home, and a nursing assistant. The European Working Group of People with Dementia (EWGPWD) and the Alzheimer Associations Academy (AAA) of Alzheimer Europe were consulted on the concept version. In this way, we aimed to ensure that the program reflects the priorities and views of all stakeholders, and that results would be applicable across Europe.

For the feasibility evaluation, we formed a local multidisciplinary working group within the participating nursing home before the start of the program, consisting of the quality assurance officer and elderly care physician (also participating in the project team), a psychologist, two nursing assistants, a specialist nurse, an activity therapist and a researcher (CvC). The contact person of the local multidisciplinary working group (quality assurance officer) approached six care teams from psychogeriatric nursing home units for participation in the study. Three teams were willing to participate. We chose two care teams from the same location for practical reasons, such as reducing travel time for participants and the project team. The three other teams who were not willing to participate did express their interest, but could not participate due to low staffing or high workload.

Data collection

Phase 1 of the MRC framework: intervention development

Between May 2018 and November 2020, we performed a needs assessment, using focus group discussions and interviews with stakeholders (van Corven et al., 2021), an integrative literature review (van Corven et al., 2021), and a European survey to identify existing empowerment interventions (van Corven et al., submitted). Between April and December 2019, regular meetings were held with the project team to discuss and interpret the results of the needs assessment, determine program objectives, and select behaviour change techniques that could be applied in nursing homes. These behaviour change techniques were extracted from the literature (Michie et al., 2011).

In December 2019, three researchers (CvC, AB, DG) joined the annual meetings of the EWGPWD and AAA to present the concept version of the program. Thereafter, we discussed its relevance, potential barriers and possible improvements for 30 minutes in subgroups.

Phase 2 of the MRC framework: feasibility

The study to evaluate the feasibility started in March 2020. The program stopped the same month due to the COVID-19 outbreak, but was restarted and ran between September and December 2020. We collected qualitative and quantitative data regarding feasibility.

Qualitative data collection regarding feasibility

We collected qualitative data using the field notes of all meetings with the local multidisciplinary working group, a focus group interview with healthcare professionals from both nursing home units and three members of the multidisciplinary working group (quality assurance officer and two nursing assistants), and telephone interviews with all other members of the multidisciplinary working group and two of the healthcare professionals from both nursing home units. Questions considered the program's acceptability (e.g., how did you appreciate the program?), implementation and practicality (e.g., what were the barriers and facilitators for using the program?), and limited efficacy (e.g., what did the program bring you and residents?). The focus group interview and individual interviews were moderated by the first author (CvC), tape-recorded and transcribed verbatim. They lasted one hour and between 10 to 30 minutes, respectively. Furthermore, the formulated objectives for each resident were collected from the residents' personal files.

Table 1. *Overview of quantitative data collection for healthcare professionals and family caregivers.*

#	Moment in time	Feasibility area of focus
Healthcare professionals		
T0	Before start (September 2020)	Overall demand, acceptability and limited efficacy
T1	After end (December 2020)	Overall acceptability, practicality, implementation and limited efficacy
Healthcare professionals proxy about resident living with dementia		
T0	Before start (September 2020)	Limited efficacy
T1	After end (December 2020)	Limited efficacy
Family caregivers		
T0	Before start (September 2020)	Overall demand, acceptability and limited efficacy
T1	After end (December 2020)	Overall acceptability, practicality, implementation and limited efficacy

Quantitative data collection regarding feasibility

An overview of the data collection by means of questionnaires is displayed in Table 1. Questionnaires included self-developed statements regarding demand, acceptability, implementation, practicality and integration (see Additional File 1). Participants responded to statements on a five-point Likert scale from 'totally disagree' to 'totally agree'. To assess the limited efficacy, we administered standardised questionnaires (see Additional File 2).

Data analysis

For all qualitative data, content analysis was used. Two authors (CvC, MW) coded the text, and constructed categories and themes based on consensus. For the quantitative data, we used medians and ranges to describe the baseline characteristics of participants and outcome measures. We used fractions to describe how many participants agreed with or totally agreed with the statements.

Ethical considerations

The study was conducted in accordance with Dutch Law and the Declaration of Helsinki. The study protocol was reviewed by the local Medical Ethics Review Committee 'CMO Regio Arnhem Nijmegen' (number 2018–4101), which stated that the study was not subject to the Medical Research Involving Human Subjects Act as the participants were not subjected to actions or behavioural rules that were imposed on them. We asked for verbal consent when consulting the EWGPWD and AAA. During the feasibility evaluation, we obtained prior written informed consent from all family caregivers and healthcare professionals. Family caregivers also provided written informed consent for residents living with dementia. The study was registered in the Dutch Trial Register (NTR), number NL8829

Results

Phase 1: intervention development

Following the first step of intervention mapping, which is identifying potential improvements, we found that for people living with dementia to feel empowered, a sense of identity, usefulness, control and self-worth are important. These four domains of empowerment followed from focus group discussions and individual interviews with people living with dementia (n=15), family caregivers (n=16) and healthcare professionals (n=46), exploring perspectives on empowerment, and needs and wishes regarding an empowerment intervention (van Corven et al., 2021). Moreover, an extensive systematic literature review showed that empowerment is a dynamic process, with it taking place within the interaction of the person living with dementia and their environment (van Corven et al., 2021). The European survey showed that stakeholders considered a broad range of interventions empowering in dementia care and research (van Corven et al., submitted). However, none of the available interventions in this survey were specifically developed for or aimed at empowerment. Therefore, the project team concluded that in order to promote empowerment, it is essential to develop and test interventions with a specific focus on empowerment.

Thereafter, for step 2, the project team identified the determinants of behaviours needed to promote empowerment, including knowledge (knowing how to promote empowerment), attitude (recognising the advantages of promoting empowerment), outcome expectations (expecting that promoting empowerment will increase well-being), skills (demonstrating the ability to promote empowerment) and self-efficacy (expressing confidence in the ability to promote empowerment), which is visualised in the model of change (see Additional File 3). The behaviour change matrix shows the specific behaviours that people living with dementia and their environment can perform to promote empowerment (see Additional File 3).

The selected behaviour change techniques, specified in step 3, included action planning, barrier identification, and focusing on past successes, among others. The techniques may promote the behaviours that people living with dementia and those in their environment can perform to promote empowerment. For example, we thought that healthcare professionals discussing the barriers to promoting empowerment, and ways of overcoming them during the Empowerment Café would be beneficial as it may increase the self-efficacy of the healthcare professionals to promote empowerment for residents, and their outcome expectations. An extensive overview of the behaviour change techniques, literature about these techniques, and how these are applied in the program can be found in Additional File 4.

For step 4, concerning design of the program, the project team specified the aim of the empowerment program, which is to enable professional caregivers to reflect and act on the wishes and needs of people with dementia and their family caregivers regarding the four themes of empowerment. An overview of the program is displayed in Figure 1.

Figure 1. *Visual representation of the modules of WINC.*

The project team ensured that the design was suitable for all stakeholders. Module 1 is a kick-off meeting (called the Empowerment Café) in which participating care teams discuss the themes of empowerment, experiences, benefits, barriers, and strategies to overcome these barriers to promotion of empowerment. Here, the project team explains the rest of the WINC empowerment program. For module 2, healthcare professionals work on two exercises for their own professional development. In the first exercise, each member of the care team joins a colleague for four hours to observe how they work with respect to empowerment. In the second exercise, each healthcare professional focuses on the themes of empowerment for all residents during their shifts. In the third module, which runs concurrently with the second module, healthcare professionals talk in a small multidisciplinary group about specific residents with the help of the WINC reflection cards, which contain questions about each theme of empowerment. These reflections result in goal setting for all residents, that will be discussed (and adjusted) with the family and the resident (when possible), and evaluated after six weeks. Module 4 is a final meeting (again called the Empowerment Café) to share experiences and evaluation of the program and its results, both for healthcare professionals and for residents, and make agreements as to how to continue, for example by repeating some of the modules of the program in the future.

For step 5, regarding specification of an implementation plan, we formed a local multidisciplinary working group within the healthcare organisation to adjust the empowerment program to fit the local setting, for example by discussing how meetings for module 3 could best be organised so that they fit the agenda of most of the healthcare professionals. For step 6, we generated an evaluation plan. This included a description of the used methods to evaluate feasibility, and their time planning.

Phase 2: feasibility

We present data collected between September and December 2020. An overview of the collected data at the initial start in March 2020 can be found in Additional Files 4 and 5. Results on the specific modules can be found in Additional File 5.

Participant characteristics

In total, 14 residents, 13 family caregivers and 18 healthcare professionals of two psychogeriatric nursing home units participated in the feasibility study. Quantitative data were collected from all residents, family caregivers and healthcare professionals, while for the qualitative data, seven healthcare professionals participated in the focus group interview and five healthcare professionals in the individual interviews.

The fourteen participating residents had a median age of 85 years (range: 67-95 years) and the majority were female (n=10). The median amount of time residents lived in the nursing home was 2.4 years (range: 0.2-5.3 years). The majority of residents were diagnosed with Alzheimer's disease (n=12), others had vascular dementia (n=1), or a combination of those (n=1). Residents were married (n=6), divorced (n=2) or widowed (n=5). Data was missing on age (n=1) and years spent living in the nursing home (n=2), respectively. The thirteen participating family caregivers had a median age of 67 years (range: 51-87 years) and approximately half were female (n=6). They were either partners (n=6), siblings (n=2) or children (n=5) of the residents, and spent time with the resident once every two weeks (n=2), once a week (n=1), multiple times a week (n=8) or every day (n=2).

The eighteen participating healthcare professionals had a median age of 55 years (range: 29-63 years) and the majority were female (n=17). Their median work experience in healthcare was 25 years (range: 2-46 years), with 15 years specifically on people living with dementia (range: 0.5-41 years), and 13 years within this organisation (range: 1-33 years). They worked as nursing assistants (n=13), or as a nurse, specialist nurse, well-being coach, psychologist and quality assurance officer (n=1 for all occupations). Age and years of work experience was missing for two participating healthcare professionals. In both participating psychogeriatric nursing home units, eight people reside. At both units have been working the same psychologist, specialist nurse, well-being coach and quality assurance officer. Six and eight nurses and nursing assistants have been working in the two teams respectively. No information was collected about the working hours of these nurses and nursing assistants.

Demand

Expectations before the start

In questionnaires prior to the start, almost all healthcare professionals who filled in the questionnaire indicated that they would like to work with WINC, and had the impression this was the same for their colleagues (7/8).

Acceptability

Expectations before the start

Similarly, in questionnaires prior to the start, all eight healthcare professionals who filled in the questionnaire indicated that their first impression of WINC was good, and they were motivated by WINC. Almost all of the healthcare professionals expected to enjoy working with WINC together with their colleagues, and expected WINC to be of value to their work, and for the care and support of the residents living with dementia (7/8).

Half of the family caregivers who filled in the questionnaire indicated that their first impression of WINC was good (5/10), while the majority thought that it was a good idea that the nursing home would work with WINC (8/10), and that WINC would be of value for the care and support of their family member (7/10).

Experiences

In the questionnaires at the end of the WINC empowerment program, half of all healthcare professionals indicated that they enjoyed working with WINC, that it was of value to their work, and that they would advise other teams of the care organisation to work with WINC (4/8). Further, just under half thought it was of value for the care and support of residents living with dementia, or indicated that they would like to keep using WINC in the future (3/8). The experiences of healthcare professionals varied, as illustrated by these two quotes from healthcare professionals:

> *This is how you want to look at the resident: replenish what needs and wishes are. I see the added value and I hope we can make the WINC feeling our own. (20)*
>
> *The project wasn't of added value for me. I think we as colleagues reflect a lot, and pay attention to our attitude towards residents. I don't think WINC will add to that. (07)*

In the follow-up questionnaires at the end, almost half of the family caregivers indicated that they were well informed about WINC (3/7), that they felt involved enough (4/7), while only a minority indicated that WINC had been of value for the care and support of their loved one (2/7).

Implementation

Experiences

From the qualitative analyses, the following themes emerged regarding implementation: barriers to promoting empowerment, and challenges involving family caregivers.

Theme: 'barriers to promoting empowerment'

One of the key themes that emerged was 'barriers to promoting empowerment'. This included (1) COVID-19 measures, and (2) a lack of time. Healthcare professionals mentioned in the interviews that these were barriers to implementing WINC in their daily work, as it hindered undertaking activities or giving attention to individual residents.

> *I think it is a nice program, but really putting it into practice... I don't think we now have the time to really put it into practice. (20)*

For example, to promote empowerment, healthcare professionals stated the importance of one-to-one activities. They indicated this was sometimes not possible due to other tasks, or they felt they were not giving enough attention to other residents.

> *That can be difficult. We have four ladies sitting at a table, with whom you can do an activity together. But when doing that, you have in the back of your mind that you are failing the others. I sometimes find that very difficult. (9)*

Healthcare professionals reported that this lack of time also caused them to take over tasks residents were performing, while to promote empowerment, they said it would be best if the residents completed the task themselves and therefore attained a sense of usefulness:

> *Peeling potatoes or something, I sometimes do it myself quickly. Otherwise [with residents] you could be busy with it for almost 45 minutes. So if it's busy, I just do it myself. (14)*

One healthcare professional mentioned during the interview that she thinks it is very important for the team to direct each other's attention to the themes of empowerment, as otherwise new activities and attitudes regarding empowerment are easily forgotten.

Theme: 'challenges involving family caregivers'

Another key theme that emerged was challenges in involving the family caregivers in WINC. Healthcare professionals reported having spoken to family caregivers about the specific goals which were formulated during the multidisciplinary meeting, but family caregivers often responded that the goals were suitable, and did not have any additional feedback.

> *In theory it seems very nice [involvement of family], but in practice it is just very difficult. (14)*

Nevertheless, healthcare professionals reported seeing value in involving family caregivers in WINC, although this differed between family caregivers.

> *But yeah, if people don't want to, it just stops. But I do think that if the family takes the time, they will have more ideas. (21)*

> *It also depends on the type of family. If there are four sons who all live far away or find the behaviour of their mother difficult, that will be very different. It depends on how people are in it. (05)*

Healthcare professionals reported COVID-19 measures to be a barrier for family involvement, as visits mostly took place in resident's apartments, and there were fewer informal meetings between family caregivers and healthcare professionals. To improve the involvement of family caregivers, healthcare professionals suggested changing their attitudes to family caregivers from the nursing home placement onwards:

> *But yeah, we also need to have a different attitude. When family visits say 'your father is coming to live here, but we also expect something of you'. I think we need to move in that direction in the future. (05)*

Practicality

Expectations before the start

From the questionnaires prior to the start of the program, less than half of all healthcare professionals indicated feeling that they would have enough time to work with WINC (3/8), and all eight indicated that it was clear to them what would be expected.

Experiences

During the follow-up questionnaires, less than half indicated that they felt they had enough time to work with WINC (3/9). Furthermore, the majority indicated it was clear what was expected of them (7/9).

In the interviews, participants reported that they perceived the four themes of empowerment to be overlapping, for example when making goals for residents or answering the questions in their personal booklet.

> *What I noticed when forming the specific goals for residents, it was sometimes difficult to tell what was exactly meant by a theme. [...] a lot of things overlapped. (03)*

Integration

Experiences

During the interviews, healthcare professionals mentioned that WINC suited their way of working. Many interviewees mentioned that the themes of empowerment were not new to them, but WINC helped direct attention to this way of working.

> *I saw it more as an addition, to refresh again. It provided a moment to stop and think about what we are doing. (25)*

They mentioned disliking that meetings for WINC were in addition to their normal working hours, which meant they had to come to work in their free time. Nevertheless, this is also the case for other projects.

Limited efficacy

From the qualitative analyses, the following theme emerged regarding limited efficacy: added value of WINC.

Theme: 'added value of WINC'

One of the key themes that emerged from the focus group discussions and interviews was the added value of WINC. During the interviews, healthcare professionals indicated that

Table 2. *Changes after implementing WINC intervention on the primary and secondary outcome measures for the person living with dementia (n=13), their family caregiver (n=14) and healthcare professionals (n=18).*

	Start median (range)	**End** median (range)
Resident living with dementia *		
Quality of life (TOPICS-MDS)		
Proxy perspective of residents by HCP	4.5 (3-7)	6.0 (3-8)[a]
Proxy perspective of residents by FC	6.0 (3-8)[e]	7.0 (5-8)[g]
Perspective of HCP	5.5 (3-6)[d]	5.0 (3-7)[a]
Perspective of FC	5.0 (3-8)[e]	6.0 (3-7)[g]
Health-related quality of life (TOPICS-MDS)		
Proxy perspective of residents by HCP	5.0 (3-7)[d]	5.0 (4-9)[a]
Proxy perspective of residents by FC	7.0 (3-7)[f]	7.0 (4-8)[g]
Perspective of HCP	6.0 (3-8)[d]	6.0 (5-8)[a]
Perspective of FC	6.0 (3-8)[e]	6.0 (3-7)[g]
Behaviour		
Apathy (AES-10)	28.0 (15-36)[d]	32.0 (17-39)[a]
Challenging behaviour (NPI-Q)	15.5 (0-47)[d]	11.0 (0-75)[a]
Mood (NORD)	3.0 (0-4)[d]	2.0 (1-4)[c]
Social engagement (RISE)	2.0 (0-6)[d]	4.0 (0-6)[b]
Family caregiver ^		
Quality of life (TOPICS-MDS)	7.5 (6-9)[e]	7.0 (6-9)[g]
Health-related quality of life (TOPICS-MDS)	3.0 (1-4)[e]	3.0 (1-4)[g]
Caregiver quality of life (carer-QoL)	88.3 (59.3-100)[f]	84.7 (73.8-95.4)[g]
Sense of competence (SSCQ)	31.5 (24-35)[e]	34.0 (20-35)[h]
Caregiver burden (TOPICS-MDS)	4.5 (0-7.5)[e]	2.0 (0-6)[g]
Healthcare professional +		
Job satisfaction (LQWQ)	20.0 (17-21)[j]	18.5 (17-22)[j]
Job demands (LQWQ)	14.5 (13-16)[j]	15.0 (12-17)[i]
Team climate (TCI)	76.5 (66-82)[j]	77.0 (68-87)[i]

HCP = healthcare professionals, FC = family caregiver

* For people living with dementia, higher scores indicate better (health-related) quality of life, more apathy, more challenging behaviour, more depressive symptoms, and more social engagement.

^ For family caregivers, higher scores indicate better (health-related) quality of life, a better care situation, and a higher sense of competence.

+ For healthcare professionals, higher scores indicate nurses perceive their job satisfaction and job demands more positive, and indicate a more positive team climate.

[a] 3, [b] 4, [c] 5, [d] 8 of 14 missing, respectively.

[e] 3, [f] 4, [g] 6, [h] 7 of 13 missing, respectively.

[I] 9, [j] 10 of 18 missing, respectively.

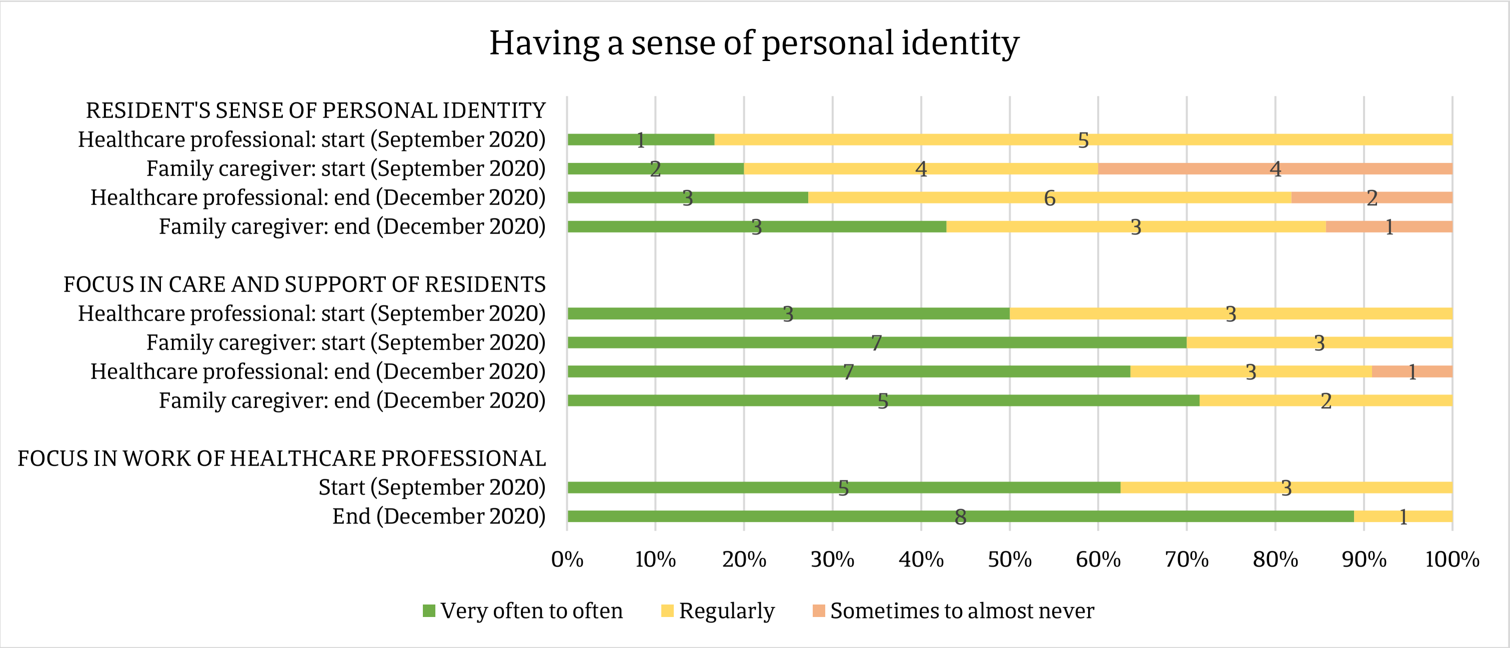

Figure 2. *Resident's sense of personal identity (from family caregivers and healthcare professionals perspectives), its focus in residents' care and support, and its focus in the work of healthcare professionals. For healthcare professionals, data from 10 and 8 of 18 were missing at the start and end, respectively. For family caregivers, data from 3 and 6 of 13 was missing at the start and end, respectively. And for proxy questionnaires filled in by healthcare professionals about the person living with dementia, data was missing from 8 and 3 of 14 at the start and end, respectively.*

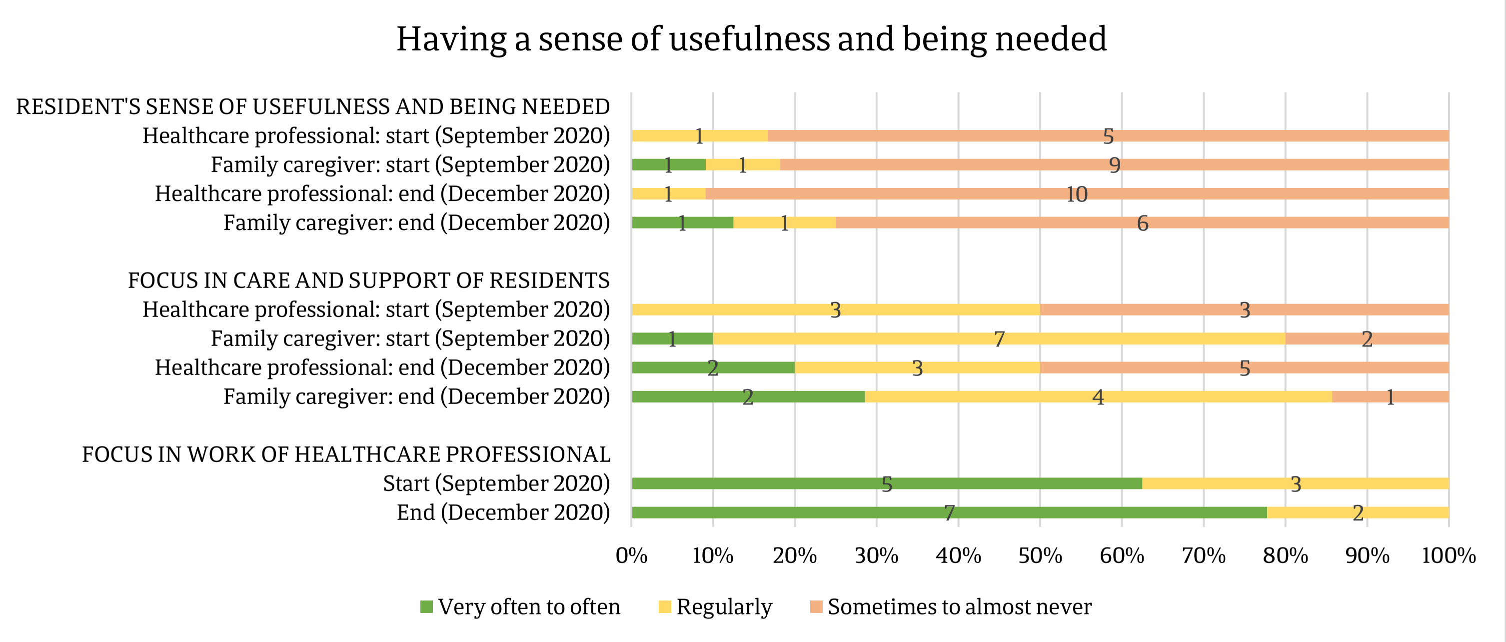

Figure 3. *Resident's sense of usefulness and being needed (from family caregivers and healthcare professionals perspectives), its focus in residents' care and support, and its focus in the work of healthcare professionals. For healthcare professionals, data from 10 and 8 of 18 were missing at the start and end, respectively. For family caregivers, data from 3 and 6 of 13 was missing at the start and end, respectively. And for proxy questionnaires filled in by healthcare professionals about the person living with dementia, data was missing from 8 and 3 of 14 at the start and end, respectively.*

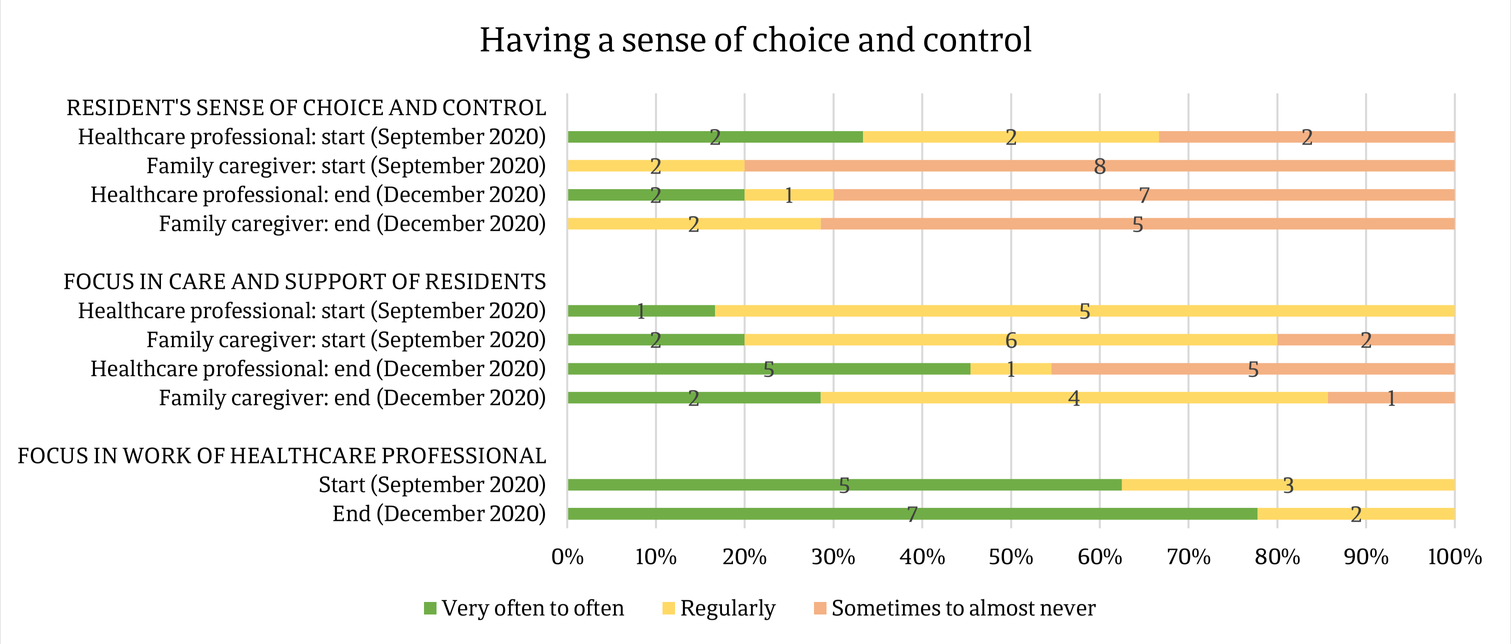

Figure 4. *Resident's sense of choice and control (from family caregivers and healthcare professionals perspectives), its focus in residents' care and support, and its focus in the work of healthcare professionals. For healthcare professionals, data from 10 and 8 of 18 were missing at the start and end, respectively. For family caregivers, data from 3 and 6 of 13 was missing at the start and end, respectively. And for proxy questionnaires filled in by healthcare professionals about the person living with dementia, data was missing from 8 and 3 of 14 at the start and end, respectively.*

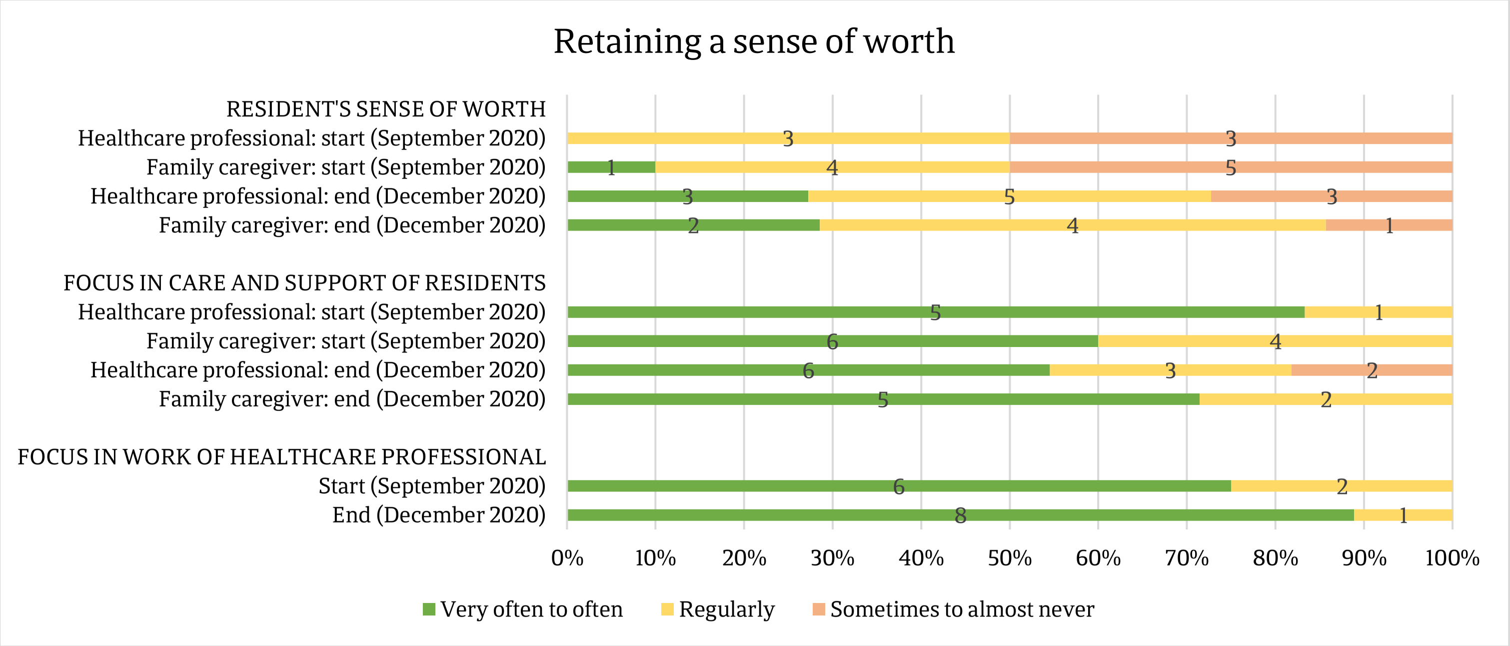

Figure 5. *Resident's sense of worth (from family caregivers and healthcare professionals perspectives), its focus in residents' care and support, and its focus in the work of healthcare professionals. For healthcare professionals, data from 10 and 8 of 18 were missing at the start and end, respectively. For family caregivers, data from 3 and 6 of 13 was missing at the start and end, respectively. And for proxy questionnaires filled in by healthcare professionals about the person living with dementia, data was missing from 8 and 3 of 14 at the start and end, respectively.*

the greatest benefit of WINC was raising awareness regarding the four themes of empowerment. They reported that reflecting on their way of working broke through their regular and established routines:

> *We already do a lot, so the program only helped to make me more aware. For example, one of our residents can make a lot of choices himself, you become aware of that again. I have to be honest that the program didn't have any added value, except this increased awareness, because we already do a lot of things. (14)*

Furthermore, healthcare professionals indicated having focused more on small things that matter to the residents due to WINC. A healthcare professional added that she appreciated that more focus was given to well-being, instead of just physical matters. A member of the local multidisciplinary working group indicated that contact between the care team and the well-being coach increased, which was reported as positive:

> *I feel a lot of nice little things were done as a result of WINC. And that you are also aware of doing it together. What would the resident like and how does someone retain their self-worth? A lot of colleagues are very creative in that. (03)*

Outcome measures

Table 2 shows all of the outcome measures for the starting and follow-up measurements. Healthcare professionals and family caregivers also reported on residents' feelings of empowerment, how much focus was on empowerment in the care and support of residents, and how much focus there was on empowerment in the daily work of healthcare professionals (see Figure 2, Figure 3, Figure 4 and Figure 5, respectively).

Discussion

This study described the development and feasibility evaluation of the WINC empowerment program. It showed that, according to healthcare professionals, the newly developed empowerment program was feasible for promoting empowerment in people living with dementia in a nursing home. The program was considered practical and suitable to their way of working. Nevertheless, the enthusiasm that healthcare professionals had about the program, and their feelings of its added value, varied. Regarding the implementation, healthcare professionals experienced difficulties in involving family caregivers in the program, and felt that a lack of time hindered their focus on the themes of empowerment. Yet, some healthcare professionals also mentioned after using the empowerment program, having an increased awareness regarding the four themes of empowerment, and gave greater focus on the small things that mattered to residents. Responses to the questionnaires showed no improvement on the self-reported focus on empowerment for healthcare professionals and the feelings of empowerment of residents from the perspectives of the healthcare professionals and family caregivers. However, this might not be a valid reason for the research team to discontinue the further development and evaluation, as due to the hindrance of the COVID-19 outbreak, results should be interpreted with caution. During the COVID-19 pandemic, healthcare professionals had to work under complex and stressful circumstances (Snyder et al., 2021, White et al., 2021). Considering the high workload due to COVID-19 related priorities, the lower number of healthcare professionals who were able to participate, and COVID-19 restrictions, such as a maximum number of healthcare professionals that could attend a meeting, results could have been negatively affected.

The local multidisciplinary working group was of added value for the implementation of the program, as it helped to adjust the WINC empowerment program to fit the local setting and working routines. However, the role of family caregivers requires extra attention in the future, as involving family caregivers was challenging, and healthcare professionals highlighted the added value of family caregivers taking a more active role in formulating specific goals for the resident. Previous studies have reported on the challenges of family involvement (Puurveen et al., 2018, Reid and Chappell, 2017, Tasseron-Dries et al., 2021). Involvement may differ between family caregivers, as it depends on the degree to which family caregivers consider their own involvement to be important (Reid and Chappell, 2017). Healthcare professionals may have a crucial leadership role in demonstrating mutual recognition and respect through the creation of welcoming environments that enable the family to participate, the provision of adequate information, and enacting collaborative relationships (Puurveen et al., 2018). Meaningful family involvement may be established by clear communication about mutual expectations, with an emphasis on the benefits for both the resident and family caregiver (Tasseron-Dries et al., 2021). Future research should, together with all stakeholders, investigate how family caregivers can be included and feel motivated to be involved in the WINC project.

Furthermore, it is interesting to note that the modules that are not incorporated in normal working routines (such as the Empowerment Café and observation of a colleague) were perceived more positively than modules that fall within normal working routines (such as the exercise to focus on the themes of empowerment). This is possibly not surprising, as changing daily routines can be more disruptive or difficult. Another explanation for this could be that the modules outside of the daily routines were performed together with colleagues, in contrast to individual exercises. This could have increased enthusiasm and motivation (Willemse et al., 2012), which would advocate for emphasising collaboration and shared experiences between healthcare professionals during the WINC empowerment program. During this feasibility evaluation, the sharing of experiences was hindered due to COVID-19 restrictions.

Strengths and limitations

To our knowledge, this is the first study to develop and evaluate an intervention specifically aimed at promoting empowerment in people living with dementia in nursing homes. A strength of the study is the evidence-based methods used in the development and feasibility evaluation of the intervention. The combination of quantitative and qualitative data collection provided valuable insights into the feasibility. A limitation of this study is the potential selection bias towards motivated care teams, as participation was done by invitation. Yet, motivation was seriously hindered by the consequences of the COVID-19 pandemic. The study had to stop, and restart six months later, which took increased effort to regain the motivation and focus of healthcare professionals during the restart. Also, the results on the limited efficacy of the program could be biased, as changes in the COVID-19 situation may have influenced outcome measures. Lastly, not all questionnaires were completed by all participants, and not all pre-planned focus groups discussions could take place due to COVID-19 restrictions, which caused a more limited sample size. Since firm conclusions cannot be drawn due to these limitations, more research is needed to substantiate our results.

Further research

Based on the experiences of healthcare professionals, we will optimise the empowerment program in a refined intervention by addressing the issues from this evaluation, such as promoting collaboration between healthcare professionals and the involvement of family caregivers. It is useful to include multiple stakeholders in this refinement process. Also, the program may benefit from addressing ways promoting empowerment for multiple residents at the same time, as healthcare professionals perceived this as advisable yet difficult. Our study showed that healthcare professionals experienced a lack of time as a barrier, and this suggests that having more staff available might encourage healthcare professionals to support residents to complete tasks themselves instead of taking over these tasks. This might contribute to promoting empowerment. However, it seems important that the WINC empowerment program is feasible within available resources. Therefore, it is important to further investigate the feasibility. More information is needed about the refined intervention, and its feasibility in a non-pandemic situation. Thereafter, following the MRC framework, future research may be undertaken to investigate the effects of the program by means of a randomised controlled trial.

Conclusion

This study shows that the WINC empowerment program is a feasible intervention for healthcare professionals to promote empowerment in residents living with dementia. An important step is to take into account implementation prerequisites that follow from the findings of this study, and accordingly, further investigate the effects of the WINC empowerment program on feelings of empowerment within residents, and the changes in awareness, attitudes and behaviour of healthcare workers towards an empowerment-promoting approach.

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Additional File 1. Feasibility results at initial start, restart and end

Table 1. *Demand.*

Healthcare professionals	Start	Restart
I would like to work with WINC	16 of 16[a]	7 of 8[b]
I think my colleagues would like to work with WINC	12 of 16[a]	7 of 8[b]

[a] 2, [b] 10 of 18 missing

Table 2. *Acceptability.*

Healthcare professionals – expectations	Start	Restart
My first impression of WINC is good	14 of 16[a]	8 of 8[b]
I am motivated to work with WINC	15 of 16[a]	8 of 8[b]
I expect to enjoy working with WINC together with my colleagues	16 of 16[a]	7 of 8[b]
I expect that WINC is of value to my job as a healthcare professional	14 of 16[a]	7 of 8[b]
I expect that WINC is of value to the care and support of residents	15 of 16[a]	7 of 8[b]

Family caregivers – expectations	Start	Restart
My first impression of WINC is good	7 of 8[c]	5 of 10[e]
I think it is a good idea that the nursing homes will work with WINC	7 of 7[d]	8 of 10[e]
I think WINC will be of value to the care and support of residents	6 of 8[c]	7 of 10[e]

Healthcare professionals – experiences	End
I enjoyed working with WINC	4 of 8[b]
WINC was of value to my job as a healthcare professional	4 of 8[b]
WINC was of value to the care and support of residents	3 o f8[b]
I would like to keep using WINC in the future	3 of 8[b]
I would advise other teams in my organisation to work with WINC	4 of 8[b]

Family caregivers - experiences	End
I was well-informed about WINC	3 of 7[f]
WINC was of value to the care and support of residents	2 of 7[f]
I was involved enough in WINC	4 of 7[f]

[a] 2, [b] 10 of 18 missing
[c] 5, [d] 6, [e] 3, [f] 6 of 13 missing

Table 3. Implementation.

Healthcare professionals	End
I’ve shared my experiences with WINC with colleagues	7 of 9[a]

[a] 9 of 18 missing

Table 4. Practicality.

Healthcare professionals – expectations	**Start**	**Restart**
I have enough time to work with WINC	8 of 16[a]	3 of 8[b]
It is clear what is expected of me during WINC		8 of 8[b]

Healthcare professionals – experiences	**End**
I had enough time to work with WINC	3 of 9[c]
It was clear what was expected of me during WINC	7 of 9[c]

[a] 2, [b] 10, [c] 9 of 18 missing

Additional File 2. Outcome measures

Person living with dementia

Themes of empowerment

The four themes of empowerment were assessed by the family caregiver and healthcare professional, whereby they questioned the feelings of empowerment for each theme and how much attention was given to empowerment in the care and support of the resident. Questions were answered on a five-point Likert scale from 'almost never' to 'always'.

(Health-related) Quality of life

Quality of life and health-related quality of life was assessed through proxy and proxy-proxy with the TOPICS-MDS by the family caregiver and healthcare professional (Lutomski et al., 2013). Participants rated the residents (health-related) quality of life from 0 to 10. Higher scores indicate a higher (health-related) quality of life.

Neuropsychiatric symptoms

Neuropsychiatric symptoms were assessed using the Neuropsychiatric Inventory nursing home version (NPI-NH) (Cummings et al., 1994). In the NPI-NH, twelve neuropsychiatric symptom domains are assessed by healthcare professionals: delusions, hallucinations, agitation or aggression, dysphoria or depression, anxiety, euphoria or elation, apathy or indifference, disinhibition, irritability or lability, aberrant motor behaviours, night-time behavioural disturbances, and appetite or eating disturbances. A screening question determines if the behaviour is present (yes or no). If the symptom is present, both frequency (F) and severity (S) are scored on a four-point and three-point Likert scale, respectively. By multiplying the F and S score (F × S), a separate score can be calculated, resulting in values ranging from 0 to 12 points per symptom. The sum of the F × S score for each symptom provides a total score that ranges from 0 to 144. A higher score indicates a higher frequency and/or severity of neuropsychiatric symptoms.

Initiative

Apathy was examined using the abbreviated Apathy Evaluation Scale (AES-10) (Lueken et al., 2007). Scores could range from 10 to 40, and higher scores indicate more apathy. This 10-item observational scale was completed by the healthcare professional. The healthcare professional evaluates to what degree a specific apathetic behaviour is characteristic of the resident. The four response categories range from 'not at all characteristic' to 'very characteristic'. Total scores can range from 10 to 40. Higher scores indicate more apathetic behaviour. Scores were invalid if more than one answer was missing (Leontjevas et al., 2012, Lueken et al., 2007).

Mood

Mood was assessed by the healthcare professional using the Nijmegen Observer-Rated Depression scale (NORD). The NORD consists of five questions regarding depressive behaviours, rated as either absent or present. The sum of present symptoms provides a total score that ranges from 0 to 5, with higher scores indicating more depressive symptoms. Total scores were invalid if one or more answers were missing (Leontjevas et al., 2012)

Social engagement

Social engagement was assessed by the healthcare professional using the Revised Index for Social Engagement for Long-Term Care (RISE). The RISE consists of six questions regarding social engagement, rated as either absent or present. The sum of present symptoms provides a total score that ranges from 0 to 6, with higher scores indicating more social engagement. Total scores were invalid if one or more answers were missing (Gerritsen et al., 2008).

Family caregivers

The perceived quality of life and health-related quality of life of family caregivers was measured using the TOPICS-MDS question on a scale from 1 to 5. Subjective caregiving burden was assessed by the carer-QoL. The carer-QoL comprises of seven items with three response categories that range from 'none' to 'much'. The visual analogue scale ranged from 0 to 10, labelled from 'not heavy at all' to 'way too heavy', to rate a caregiver's level of burden in providing care and support. Total scores could range from 0-100, and scores were invalid if more than one answer was missing. Higher scores indicated a better care situation (Brouwer et al., 2006, Melis et al., 2019).

To examine the caregivers' sense of competence, the Short Sense of Competence Questionnaire (SSCQ) was used (Vernooij-Dassen et al., 1999). This scale assesses the family caregivers' feelings of capability in caring for a person with dementia. The SSCQ totals seven items with five response categories that range from 'agree very strongly' to 'disagree very strongly'. The SSCQ has satisfactory validity and reliability (Vernooij-Dassen et al., 1999). Total scores could range from 0 to 7, and scores were invalid if more than one answer was missing. A higher score indicated a greater sense of competence.

Healthcare professionals

Job satisfaction and job demands

Job satisfaction and job demands were assessed with two subscales of the Leiden Quality of Work Questionnaire (van der Doef and Maes, 1999). This questionnaire is a validated and reliable instrument assessing thirteen job characteristics of nursing staff (van der Doef and Maes, 1999). Job satisfaction consists of seven items (range 7–28) and job demands has six items (range 6–24). Questions are answered on a four-point Likert scale ranging from 'totally disagree' (1) to 'totally agree' (4). A higher score indicates that nurses perceive their job satisfaction and job demands as more positive. Scores were invalid if more than one answer was missing.

Team climate

Team climate was assessed with two subscales of the Team Climate Inventory: participative safety and support for innovation (Anderson and West, 1998). This Dutch version of the questionnaire is a validated and reliable instrument (Ouwens et al., 2009), and has been used for healthcare professionals in nursing homes previously (Heponiemi et al., 2012). Questions are answered on a five-point Likert from 'totally disagree' (1) to 'totally agree' (5). A higher score indicates a more positive team climate. Total scores could range from 20 to 100, and scores were invalid if more than one answer was missing.

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Additional File 3. Intervention mapping step 2

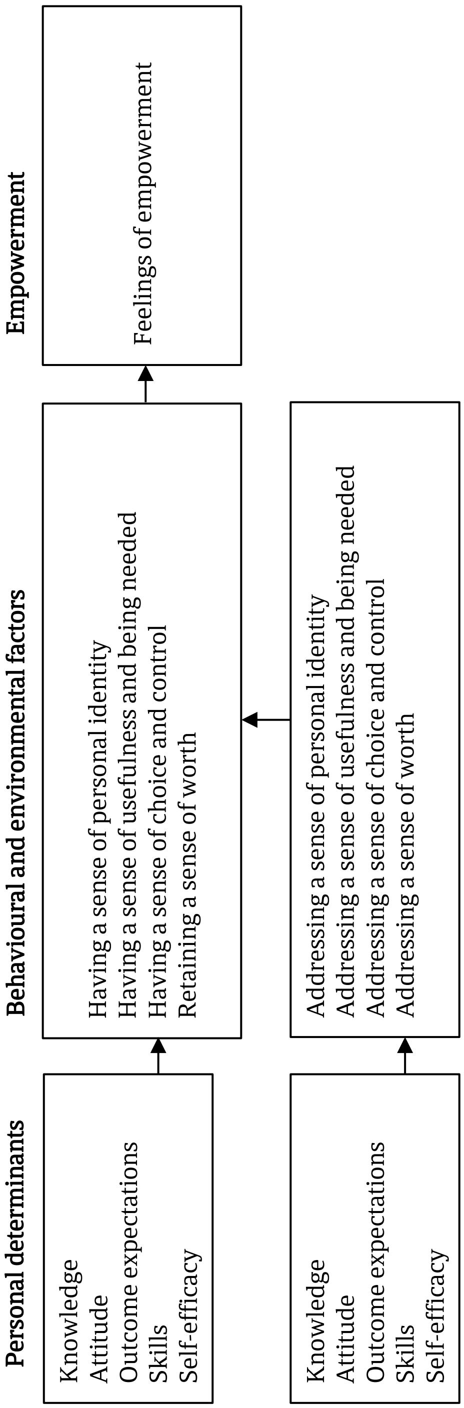

Figure 1. *Logic model of change.*

Table 1. *Individual matrix of change objectives.*

	Knowledge	Attitude	Outcome expectations	Skills	Self-efficacy
Having a sense of personal identity	Describe components to be the person you are	Recognise the advantages of being the person you are	Expect that being the person you are will increase well-being	Demonstrate the ability to be the person you are	Express confidence in the ability to be the person you are
Having a sense of usefulness and being needed	Identify methods to have a sense of usefulness and being needed	Recognise the advantages of having a sense of usefulness and being needed	Expect that having a sense of usefulness and being needed will increase well-being	Demonstrate the ability to have a sense of usefulness and being needed	Express confidence in the ability to have a sense of usefulness and being needed
Having a sense of choice and control	Identify methods of making choices and having control	Recognise the advantages of making choices and having control	Expect that making choices and having control will increase well-being	Demonstrate ability to make choices and have control	Express confidence in the ability to make choices and have control
Retaining my sense of worth	List the steps to successfully retain my sense of worth	Recognise the advantages of retaining my sense of worth	Expect that retaining my sense of worth will increase well-being	Demonstrate the ability to retain my sense of worth	Express confidence in the ability to retain my sense of worth

Table 2. *Environmental matrix of change objectives.*

	Knowledge	Attitude	Outcome expectations	Skills	Self-efficacy
Having a sense of personal identity	Know methods of promoting a sense of personal identity	Recognise the advantages of promoting a sense of personal identity	Expect that promoting a sense of personal identity will increase well-being	Demonstrate ability to promote a sense of personal identity	Express confidence in the ability to promote a sense of personal identity
Having a sense of usefulness and being needed	Know methods of promoting a sense of usefulness or being needed	Recognise the advantages of promoting a sense of usefulness or being needed	Expect that promoting a sense of usefulness or being needed will increase well-being	Demonstrate ability to promote a sense of usefulness or being needed	Express confidence in the ability to promote a sense of usefulness or being needed
Having a sense of choice and control	Know methods of promoting a sense of choice and control	Recognise the advantages of promoting a sense of choice and control	Expect that promoting a sense of choice and control will increase well-being	Demonstrate ability to promote a sense of choice and control	Express confidence in the ability to promote a sense of choice and control
Retaining a sense of worth	Know methods of promoting a sense of self-worth	Recognise the advantages of promoting a sense of self-worth	Expect that promoting a sense of self-worth will increase well-being	Demonstrate ability to promote a sense of self-worth	Express confidence in the ability to promote a sense of self-worth

Additional File 4. Intervention mapping step 3

Behavioural change techniques:

- **Promoting focus on past successes** = involves instructing the person to think about or list previous successes in performing the behaviour (or parts of it) (Michie et al., 2011 – 18)
- **Facilitate social comparison** = involves explicitly drawing attention to others' performance to elicit comparisons (Michie et al., 2011 – 28)
- **Motivational interviewing** = this is a clinical method including a specific set of techniques involving prompting the person to engage in change talk in order to minimise resistance and resolve ambivalence to change (includes motivational counselling) (Michie et al., 2011 – 37)
- **Action planning** = involves detailed planning of what the person will do including, as a minimum, when, in which situation and/or where to act (Michie et al., 2011 – 7)
- **Plan social support / social change** = involves prompting the person to plan how to elicit social support from other people who help them achieve their target behaviour or outcome (Michie et al., 2011 – 29)
- **Barrier identification / problem solving** = this presumes having formed an initial plan to change behaviour. The person is prompted to think about potential barriers and identify ways of overcoming them (Michie et al., 2011 – 8)
- **Repeated exposure** = making a stimulus repeatedly accessible to the individual's sensory receptors.
- **Provide instruction on how to perform the behaviour** = involves telling the person how to perform the behaviour or preparatory behaviours, either verbally or in written form (Michie et al., 2011 – 21)
- **Provide information on consequences of the behaviour** = information about the relationship between the behaviour and its possible or likely consequences (Michie et al., 2011 – 1,2)

Table 3 illustrates how and which behaviour change techniques were chosen to address the determinants.

Table 3. *Behaviour change techniques of determinants of behaviour.*

Determinants of behaviour	Behaviour change techniques	Application
Knowledge: know methods of empowering a person with dementia	Provide instruction on how to perform the behaviour Provide information on consequences of the behaviour	M1: Empowerment Café
Attitude: recognise the advantages of empowering a person with dementia	Provide information on consequences Active learning Direct experience Facilitate social comparison Goal setting	M1: Empowerment Café M2: Observe a colleague M2: Focus on themes M3: Empowerment for residents
Outcome expectations: expects that empowering a person with dementia will increase well-being	Provide information on consequences Motivational interviewing Active learning Direct experience Goal setting Prompt review of behavioural and outcome goals Prompting self-monitoring	M1: Empowerment Café M2: Observe a colleague M2: Focus on themes M3: Empowerment for residents
Skills: demonstrate the ability to empower a person with dementia	Provide instruction on how to perform the behaviour Active learning Direct experience Prompt practice Prompting generalisation of behaviour	M2: Observe a colleague M2: Focus on themes M3: Empowerment for residents
Self-efficacy: express confidence in the ability to empower a person with dementia	Motivational interviewing Prompting focus on past successes Provide feedback on performance Direct experience Self-affirmation Prompt review of behavioural and outcome goals Prompting self-monitoring Prompting generalisation of behaviour	M1: Empowerment Café M2: Observe a colleague M2: Focus on themes

Other behavioural change methods used throughout the whole program are: (1) repeated exposure, (2) barrier identification / problem, (3) action planning, (4) plan social support / social change, and (5) relapse prevention / coping planning.

Additional File 5. Evaluation phase results per module

Acceptability

Expectations before the start of WINC

In questionnaires at the initial start in March 2020 for the first module specifically, 15/16 healthcare professionals expected it to be useful to discuss with colleagues the themes of empowerment, and expected the Empowerment Café to be of value to their job as a healthcare professional.

For the second module, 8/8 healthcare professionals indicated that they expected to enjoy observing a colleague, and expected that this would be valuable for their job as a healthcare professional (same in March 2020). Furthermore, 7/8 healthcare professionals reported that it seemed useful to them to reflect on this observation using their personal booklet (8/8 in March 2020), and 8/8 indicated this appraisal for sharing experiences with colleagues (same in March 2020). Furthermore, 7/8 healthcare professionals indicated that they expected to enjoy the exercise of focusing on the four themes of empowerment, and expected that this would be of value for their job as a healthcare professional (8/8 in March 2020). Furthermore, 7/8 healthcare professionals reported that it seemed useful to them to reflect on this exercise using their personal booklet, and by sharing experiences with colleagues (8/8 in March 2020).

Experiences using WINC

In follow-up questionnaires for the first module, 6/7 healthcare professionals indicated that they found it beneficial to discuss the themes of empowerment with colleagues, 8/8 noted that there was a good atmosphere, and 5/7 reported that the Empowerment Café was of value for their work as a healthcare professional (7/8 in March 2020). 6/7 healthcare professionals reported that the Empowerment Café made them motivated to work with WINC (8/8 in March 2020).

For the second module, 6/6 healthcare professionals reported enjoying observing a colleague, and 5/6 indicated that this was valuable to their work as a healthcare professional. 3/5 healthcare professionals indicated that reflecting on this by means of questions in their personal booklet was useful. Furthermore, 3/7 healthcare professionals stated that they enjoyed the exercise in which they focused on the themes of empowerment in their daily work, and found this beneficial for their work as a healthcare professional. 3/6 healthcare professionals stated that reflecting on this by means of questions in a personal booklet was useful. During the interviews, healthcare professionals highlighted the usefulness of observing a colleague. Nevertheless, some mentioned that they felt nervous or insecure when a colleague observed them.

With regards to the third module, 7/7 healthcare professionals reported enjoying reflecting on the themes of empowerment for each resident in a small multidisciplinary group, and 3/6 indicated this was of value for the care and support of residents. Furthermore, 4/6 healthcare professionals reported enjoying working on the specific goals that arose from the meetings.

Implementation

From the field notes, for the first module specifically, 25 people participated in one of the two Empowerment Cafés, which means that all care professionals in the participating teams were present during an Empowerment Café (except one due to illness).

In the questionnaires, for the second module, 6/9 healthcare professionals indicated having observed a colleague, nurse, nursing assistant or well-being coach. From the interviews and field notes, it appeared to differ between the healthcare professionals if, during the observation, the focus was on the four themes of empowerment, or more general, such as the work of other disciplines or the organisation. The three healthcare professionals who reported that they did not observe a colleague stated COVID-19 as the reason. Only one of them specified this in the questionnaire, as she indicated, due to the COVID-19 restrictions, she could not observe a colleague from another location, which she would have liked to have done so. Observation ranged from 1-4 hours. 5/6 healthcare professionals reported filling in the reflection questions in their personal booklet afterwards. Furthermore, 7/9 healthcare professionals indicated that they performed the exercise in which they focused on each theme of empowerment during their daily work. The two healthcare professionals who indicated that they did not noted COVID-19 as the reason, but did not provide specification on this. 6/6 healthcare professionals filled in the reflection questions in their personal booklet afterwards.

Regarding the third module, 7/9 healthcare professionals reported attending a multidisciplinary meeting in which reflection on each theme of empowerment per resident was considered. From the field notes and interviews, it emerged that some healthcare professionals did not attend due to the COVID-19 restrictions as the group would have been too big with their presence. In the questionnaires, 4/6 healthcare professionals indicated having actively worked on the specific goals that arose from the meetings, and 5/6 shared their experiences of working on these goals with colleagues. During the interviews, possible strategies mentioned by healthcare professionals for implementing the specific goals included linking activities to certain shifts, or to specifically plan them for yourself. Healthcare professionals indicated reporting these goals in the resident's care plans. These goals were reported for all participating residents. From the care plans, it emerged that most goals pertained to pleasurable or meaningful activities, or actions to promote comfort. From the field notes and interviews, it was apparent that other healthcare professionals read the specific goals. Nevertheless, disciplines who work with many residents mentioned in interviews that they do not read all of the care plans. They only worked with the goals when others specifically asked them. The well-being coach reported to be actively involved in putting specific goals for residents into practice.

For the fourth module, only one Empowerment Café was held, with seven participants, as the other Empowerment Café's were cancelled due to new COVID-19 measures.

Practicality

Expectations before the start of WINC

In questionnaires prior to the start, 13/16 healthcare professionals felt they had enough time to attend the Empowerment Café, 7/8 to observe a colleague (same in March 2020), while only 3/8 felt they had enough time to work with the exercises focusing on the themes of empowerment in their daily work (4/8 in March 2020).

Experiences using WINC

In the follow-up questionnaires for the first module, 6/7 healthcare professionals indicated that the provided information was not difficult, and 8/8 noted that the duration and location of the Empowerment Café was good.

For the second module, 2/7 felt they had enough time to perform the exercises to focus on the themes of empowerment, 4/6 said they felt they had enough time to observe a colleague. During the focus group interview, a healthcare professional noted that observing colleagues can also cause distress for residents as they see multiple new faces.

Regarding the third module, 3/6 healthcare professionals noted having enough time to attend the multidisciplinary meetings, and 3/7 reported having enough time to work with the goals formulated in these meetings. In the interviews, one point for improvement was assigning a moderator (for example a psychologist/team leader) for the meetings, as this may help to structure the meeting.

Limited efficacy

With regards to module 3, when observing colleagues specifically, it appeared from the interviews and field notes to differ for healthcare professionals if, during the observation of a colleague, the focus was on the four themes of empowerment, or more general, such as the work of other disciplines or the organisation as a whole. Moreover, healthcare professionals mentioned that observing a colleague increased the sense of togetherness. They reported that the multidisciplinary meeting helped to get to know residents better, and that reflecting on each resident together with colleagues was inspiring and led to new ideas about care and support. Nevertheless, some healthcare professionals also mentioned they experienced no benefits of the meetings, as they stated that nothing new was discussed.

Chapter 7

General discussion

This thesis investigated empowerment for people living with dementia. It focused on what the concept of empowerment means and includes for people living with dementia, and how their empowerment can be promoted. In this way, this thesis aimed to contribute to enabling people living with dementia to live according to their competencies, talents and wishes, and support family caregivers and healthcare professionals in this.

In this general discussion, an overview of the main findings is provided and these are elaborated on against the background of the recent literature. Next, several conceptual and methodological considerations are addressed. Finally, implications and recommendations for practice, education and future research are provided.

Summary of the main findings

What empowerment for people living with dementia means and includes

Based on focus group discussions and interviews with people living with dementia, their family caregivers and healthcare professionals, we identified four domains of empowerment: (1) having a sense of personal identity, (2) having a sense of choice and control, (3) having a sense of usefulness and being needed, and (4) retaining a sense of worth. The four domains seem to be important both at home and in nursing homes, and during the different stages of dementia.

Furthermore, a subsequent extensive review of the literature identified descriptions of (1) the state of being empowered, (2) the process of empowerment, and (3) contribution of the environment to the empowerment process. The state of being empowered regards the experience of the person with dementia and is a result of the empowerment process. The empowerment process relates to striving for the domains of empowerment in interactions between the person living with dementia and their environment. The contribution of the environment addresses the role of the environment during this empowerment process. We constructed a conceptual framework of empowerment for people living with dementia, combining the results of this integrative review with the results from the focus group discussions and interviews with people with dementia, their family caregivers and healthcare professionals. Our findings showed that empowerment of people living with dementia can be considered a dynamic process, with empowerment taking place within the interaction of, and relationship between, the person living with dementia and their environment. As such, the process of empowerment might be initiated by either the person living with dementia themselves, or by their environment.

How empowerment of people living with dementia can be promoted

Regarding ways in which family caregivers may need support in promoting empowerment, we identified three themes concerning the perspectives of family caregivers on their interaction and relationship with their loved one living with dementia in a nursing home: (1) changes in the interaction and relationship, (2) strategies to promote connection, and (3) appreciation of the interaction and relationship. The results showed that some family caregivers experience difficulties in making a meaningful connection with their loved one, while others succeed in constructing togetherness despite the decreased communicative abilities of the resident. This implies that, for family caregivers to contribute to the empowerment process, a prerequisite may be that family caregivers are supported to maintain or redesign a meaningful connection with the resident.

In our European survey identifying empowering interventions for people living with dementia, we found that many different types of interventions, with wide-ranging aims, are considered empowering by professionals involved in psychosocial support for people living with dementia. As no interventions could be identified that specifically aim to promote empowerment for people living with dementia, it followed that an important step needed to be taken was developing and testing such an intervention.

Lastly, we developed, and evaluated the feasibility, of a program that specifically aims to promote empowerment for people living with dementia – the WINC empowerment program. The study showed that, according to healthcare professionals, this empowerment program was feasible for promoting empowerment for people living with dementia in a nursing home. However, healthcare professionals experienced difficulties in involving family caregivers in the program, while a lack of time hindered their focus on the empowerment domains. Yet, healthcare professionals mentioned an increased awareness regarding the four domains of empowerment after using the empowerment program, and that they focused more on the small things that mattered to the residents. Nevertheless, enthusiasm about the program varied among healthcare professionals, and responses to questionnaires showed no improvement on self-reported focus on empowerment of healthcare professionals, nor on the sense of identity, usefulness, control and self-worth of residents, according to both healthcare professionals and family caregivers.

Discussion of key findings

The findings of this thesis highlight the (growing) interest in empowerment for people living with dementia. In focus group discussions, more than 75 people living with dementia, their family caregivers and healthcare professionals enthusiastically discussed the relevance of empowerment for care and support of people living with dementia. In our integrative literature review, many articles that used the word empowerment appeared to be published in the last 10 years. Also, for the European survey, more than 70 European professionals involved in psychosocial support for people living with dementia replied to our call to share information about empowering interventions. Moreover, the first nursing home we approached to participate in the feasibility study on the WINC empowerment program was willing. These aspects reflect the clinical relevance of this thesis.

Domains of empowerment

Next to the growing interest in empowerment, research has also addressed what we found to be domains of empowerment, as discussed in Chapter 2. More specifically, our first empowerment domain *having a sense of personal identity* is consistent with previous studies, of which many demonstrated the importance of acknowledging the person behind the dementia (Brown, 2017, Hicks et al., 2019). Secondly, many studies have highlighted the importance of independence and being involved in decision-making as much as possible (Bhatt et al., 2018, Lynn et al., 2022). This is in line with the empowerment domain of *having a sense of choice and control*. Moreover, regarding a *sense of usefulness and being needed*, previous research also showed that people living with dementia felt greater purpose in life when having the opportunity to support others and feel needed (Owen et al., 2021). Lastly, studies regarding the empowerment domain of *retaining a sense of worth* encouraged supporting a sense of worth through life storytelling, reminiscing, and by helping to find meaning in life through enriching activities (Heggestad et al., 2015, Tranvag et al., 2016).

The identified domains also raise the question as to whether our findings on empowerment for people living with dementia are more universal, and can go beyond the context of dementia. It can be argued that having a sense of identity, usefulness, control, and self-worth is valuable for everyone. This implies that our framework may also be applicable to other target groups. That may be a good thing, as a characterization of empowerment for people living with dementia that is too specific may reduce the person to their condition. This could result in the exclusion of aspects that might not be affected by dementia, but might be highly relevant for feeling empowered (see (Gerritsen, 2021)). However, it is important to note that definitions of empowerment and how empowerment can be promoted may change depending on the population to which it is applied (Tengland, 2008), and, therefore testing our framework for other groups is recommended. In these efforts, we should always account for the unique characteristics of specific groups, and the individuals within a group.

Process of empowerment

We found that empowerment is a dynamic process, taking place within the interactions with and relationship between the person living with dementia and their environment. This may not be surprising, as earlier research suggested that people living with dementia experience their identity, autonomy, and self-worth as more dynamic and interpersonal than is often thought. More specifically, regarding identity, Brown and colleagues argue that some parts of identity 'reside in the space between individuals'. They highlight the degree to which aspects of our selves and identities thrive in the minds of others (Brown, 2017). Furthermore, concerning autonomy, instead of seeing it as something individual, autonomy may result from contexts and relationships. Following this, as argued by Lyreskog and colleagues, autonomy is not something that is gradually lost in a person living with dementia, but is something that is increasingly supported (Lyreskog et al., 2020). Considering self-worth, Tranvag and colleagues found that experiences of dignity could be preserved by interactions with family, friends and healthcare professionals. People living with dementia may experience love, confirmation, social inclusion, and equality (Tranvag et al., 2015). This previous research confirms our findings regarding the dynamic nature of empowerment.

Importantly, the process of empowerment may be initiated by either the person living with dementia themselves, or by their environment – together striving for the four domains of empowerment in their interaction. Who initiates the empowerment process and to which degree may depend on individual and contextual differences, such as the stage of dementia and the possibilities enabled by the social environment. Nevertheless, the person living with dementia is an active agent in the empowerment process, not just being passively empowered by their environment, but has an active role in striving towards achieving the four domains. Yet, it is important to note that our findings mostly elucidate the contribution of the environment to the empowerment process. Indeed, the role of people living with dementia themselves has been given less attention in this thesis. An important issue for future research is to investigate ways and strategies as to how people living with dementia can contribute to the empowerment process themselves.

Contribution of the environment to the empowerment process

While acknowledging the role of family caregivers and healthcare professionals in the empowerment process, we should not forget that they too face challenges. This thesis highlighted some of the difficulties family caregivers encounter in their interactions and relationship with their loved one living with dementia in a nursing home, and how they experience these challenges. Previous research has shown that similar challenges are experienced by family caregivers of people living with dementia who reside at home, for example losing meaningful communication or shared everyday routines (Stefánsdóttir et al., 2021). These difficulties may hinder the empowerment process of people living with dementia. Our study does not provide answers as to what extent relationship quality is a prerequisite for the empowerment process, but it can be argued that having the knowledge and tools on how to maintain a meaningful connection between people living with dementia and their family caregivers is essential to promoting a sense of identity, usefulness, choice and self-worth for people living with dementia. Therefore, it seems of great value to support family caregivers with constructing togetherness, both in nursing homes as well as at home. Our findings showed that strategies for a meaningful connection may not differ between family caregivers who succeed and those who experience difficulties in connecting with the resident. For example, going for a walk may help in interacting and connecting for one family caregiver, but may be used as a way to avoid interaction for others. Establishing a meaningful connection, therefore, does not seem to lie in *what* family caregivers do, but in *how* they do it. As such, the strategies used to construct togetherness identified in Chapter 4 seem to be *what-to*-strategies, and do not guarantee a meaningful connection, but are a useful starting point to construct *how-to*-strategies. All strategies should be tailored to the needs and wishes of people living with dementia and their family caregivers, and to their personal context. Separate studies with the voice of family caregivers at the heart may provide more clarity on how to support positive caregiving experiences. This would create opportunities to support the well-being of family caregivers (Wu et al., 2022), and so create further opportunities that contribute to the empowerment process.

Taking into account the challenges family caregivers may face in interacting with their loved one, we conclude that our newly-developed empowerment intervention for nursing homes may benefit from adding support for family caregivers, in addition to their involvement in the program. Earlier studies that focused on supporting the connection between people living with dementia and their family caregivers underscored the value of individual support for family caregivers (Eggenberger et al., 2013, Perkins et al., 2021). However, it is not yet clear who should provide this support. Previous research found that interventions that used psychological models such as cognitive behavioral therapy or social cognitive theory appeared most optimal in supporting family caregivers. This support should minimally consist of psychoeducation about dementia, communication-related difficulties and specific communication strategies based on these theories (Perkins et al., 2021). Moreover, follow-up support also seems beneficial (Eggenberger et al., 2013). Nevertheless, more research should be undertaken to build on these findings: a more rigorous investigation of the effects and experiences with such support is needed, so that it can be integrated into our empowerment program.

Conceptual considerations

Person-centered care

The five psychological needs as proposed by Kitwood are often considered the basis of person-centered dementia care (Huijsman et al., 2020, Kitwood, 1997). These five needs regard comfort, occupation, attachment, inclusion, and identity (Kitwood, 1997). However, it has been argued that these needs do not provide the full picture, and might require an extension within the domain of agency, which represents the need for self-determination, freedom of action and independence (Kaufmann and Engel, 2016). The results of this thesis underpin the relevance of agency, as the empowerment process addresses a person's talents, capabilities, and personal strengths, with the person living with dementia having an active role in this process.

The concept of empowerment contributes to shaping person-centered care for people living with dementia. The focus on interaction in the empowerment process fits within the approach of person-centered care, as person-centered care highlights the importance of interpersonal relationships (American Geriatrics Society Expert Panel on Person-Centered Care, 2016, Kitwood, 1997). However, reciprocity in relationships may be underemphasized in this approach, as the person living with dementia is largely described as the receiver of personalized support. For this reason, previous research has put forward the term *relationship-centered care* to highlight the importance of reciprocity in the interactions and relationships with others. Relationship-centered care highlights that not only the person living with dementia should receive support, but also that focus should be placed on creating a social environment emphasizing reciprocity. This affects the health, emotions and personhood of the person living with dementia, but also their family caregivers and healthcare professionals (Nolan et al., 2006, Nolan et al., 2004). The empowerment process may contribute to this reciprocity, and therefore may enrich person-centered care.

During the course of the studies presented in this thesis, the question rose as to whether empowerment can be seen as a care approach, similar to person- and relationship-centered care – that there is something like empowerment-centered care. Empowerment indeed gives direction in how to provide care and support for people living with dementia. However, whereas care approaches have as outcome how care and support is provided, empowerment is a process taking place between the person living with dementia and their environment, most likely having its outcomes within these persons. We may therefore argue that empowerment can be categorized not as a care approach, but as a concept shaping interaction, and that it may contribute to shaping person-centered care.

Related concepts

It is important to note that the concept of empowerment is also related to, or shows overlap with, other concepts. For instance, the concepts of autonomy and self-management also have consideration for people living life as they choose with a degree of independence and control over their own situation, similar to empowerment (Boumans et al., 2021, Mangiaracina et al., 2019). However, in contrast to current approaches to autonomy and self-management, it seems key to the concept of empowerment that (1) it is a dynamic process, and (2) it takes place in interaction between the person living with dementia and their environment.

Another concept that is considered as a process with context playing an essential role is resilience. However, there is controversy in the literature as to how resilience should be defined, it can be seen as a contextual and dynamic process whereby people respond more positively to stressors or challenging situations than can be expected through the use of personal, social, environmental and societal resources (Aburn et al., 2016, Angevaare et al., 2020). Empowerment and resilience are both considered as ongoing processes rather than concrete outcomes (Buggins et al., 2021), involving both the person living with dementia and their environment (Angevaare et al., 2020). Although, in contrast to resilience, stressors or challenging situations (such as a dementia diagnosis) do not have a central place within the concept of empowerment. Resilience and empowerment seem to be closely linked, and the challenge remains as to how to relate these concepts.

Additionally, empowerment fits within the paradigm of social health (Droes et al., 2017, Stiekema et al., 2018, Vernooij-Dassen and Jeon, 2016). Social health concerns the ability to fulfil one’s potential, the ability to manage one’s own life with some degree of independence, and participate in social activities. Empowerment fits within this way of thinking, as both emphasizes that people living with dementia should live according to their competencies, talents and wishes, with the support of family, friends and healthcare professionals. Nonetheless, as social health seems to describe an outcome, one might argue that social health considers the ‘what’ and the empowerment process describes the ‘how’. Empowerment might be a prerequisite for people living with dementia to achieve the dimensions of social health.

Methodological considerations

This thesis is the first to investigate the concept of empowerment for people living with dementia. A key strength is the involvement of all stakeholders: people living with dementia, their family caregivers, and healthcare professionals with a broad range of occupations. Also, both the home and nursing-home settings were involved. This guarantees that multiple perspectives are taken into account throughout this thesis. Furthermore, an advisory expert team was involved during the entire project. This assured that the design of the research project and data collection was suitable for all stakeholders, and the advisory expert team helped interpret the findings. Also, the European Working Group of People living with Dementia was consulted several times during the course of our studies, providing valuable information on the relevance of the study, interpretation of the findings, and international applicability (Roberts et al., 2020).

A second strength is that we applied a mixed methods design to answer what empowerment means and includes, using a wide range of methodologies: focus group discussions and interviews to identify lived experiences, an integrative review to account for existing scientific literature, and a European survey identifying empowerment interventions, going beyond what can be found in the literature. This methodological triangulation gives a more complete picture of the concept of empowerment, and suggests directions on how empowerment can be promoted (Begley, 1996). The results of this thesis have high clinical relevance, as we developed concrete opportunities and tools to promote empowerment both at home and in nursing homes.

Specifically for the development and feasibility evaluation of the WINC empowerment intervention, a major strength is the evidence-based methods used, following the MRC framework (Skivington et al., 2021). Intervention Mapping was helpful in systematically identifying the needs of all stakeholders and designing the program, and Bowen's aspects for evaluation of feasibility was helpful in systematically assessing the different aspects of feasibility (Bartholomew et al., 1998, Bowen et al., 2009). The combination of quantitative and qualitative data collection provided valuable insights into the feasibility of the WINC empowerment intervention.

A limitation of this thesis may be the potential selection bias towards motivated and enthusiastic participants, as the recruitment of all studies was done by invitation. However, we included a very heterogenous group of participants, which suggests that our study population reflects the wide range of people living with dementia and their caregivers in different settings. Yet, it seems important to involve people from various minority and marginalized groups in future discussions about what constitutes empowerment from their perspectives and what improvements are needed in care and support (Duran-Kiraç et al., 2021, Gove et al., 2021). Also, as the studies mostly reflected Western ideas and experiences, we must be aware that other interpretations of empowerment for people living with dementia may exist in other cultures.

Due to the COVID-19 pandemic, we were not able to investigate the second research question as thoroughly as we would have liked. For the feasibility evaluation of the WINC empowerment intervention, this study was seriously hindered by consequences of the pandemic. The study had to stop, and restart six months later, which took substantial effort to regain the motivation and focus of healthcare professionals during the restart. Considering the high workload due to COVID-19 related priorities, the lower number of healthcare professionals who were able to participate, and COVID-19 restrictions, such as a maximum number of healthcare professionals that could attend meetings, the results could have been negatively affected. For instance, we noticed a decrease in motivation when restarting six months later, as for some healthcare professionals they felt it was not the right time to work with WINC, for example due to shifts in team composition. Also, the fact that fewer healthcare professionals attended meetings (for example, the multidisciplinary meeting to reflect about residents) could have caused a decrease in dialogue and reflection between colleagues. Moreover, the development and evaluation of an empowerment intervention for people living with dementia at home ended up being beyond the scope of this thesis; the start of the randomized controlled trial regarding our newly-developed empowerment intervention for people living with dementia at home had to be postponed.

Implications and recommendations for practice, education, and future research

Practice

This thesis provides important clinical implications for care and support of people living with dementia. Our results underscore the need for structural attention for the sense of identity, usefulness, control, and self-worth of people living with dementia residing at home and in nursing homes. We showed that support must be adjusted to the personal situation and individual capabilities.

Our newly-developed WINC empowerment intervention may help healthcare professionals in nursing homes to promote a sense of identity, usefulness, choice and self-worth of residents, together with family caregivers and other healthcare professionals. Healthcare professionals taking on the unique responsibility to provide care and support for people living with dementia deserve to be facilitated in an environment that encourages them to take time to connect with people living with dementia, their family caregivers, and for dialogue and reflection with colleagues. The WINC empowerment program may contribute to this, as it promotes reflection with colleagues, family caregivers, and residents. Yet, it is apparent that pressures on communication, teamwork, staffing and time present enduring barriers to implementation (Lawrence et al., 2012). Policy makers and managers of long-term care organizations could benefit from embracing the promising effects of empowerment as a means of shaping person-centered care through the facilitation of necessary prerequisites.

This thesis does not provide the answers as to how empowerment of people living with dementia can specifically be promoted at home, but has provided useful starting points for the development of an empowerment intervention for home-dwelling people living with dementia.

Education

Healthcare professionals may benefit from education on setting realistic goals regarding the four domains of empowerment together with all of the stakeholders. This can be promoted in vocational training, as well as continuous educational opportunities. In this way, healthcare professionals might become accustomed to focusing on the strengths and abilities of people living with dementia, while respecting their limitations. Furthermore, the education of healthcare professionals could profit from focusing on the determinants of behavior that could promote empowerment, as found in Chapter 6: knowledge (identify methods of promoting empowerment), their attitude (recognize the advantages of promoting empowerment), outcome expectations (expect that promoting empowerment will increase well-being), skills (demonstrate the ability to promote empowerment), and self-efficacy (express confidence in the ability to promote empowerment). Training healthcare professionals to think creatively, to reflect on their own behavior, and to brainstorm solutions tailored to the person living with dementia will be beneficial. Vocational training and continuous education could provide concrete suggestions and examples for healthcare professionals to provide person-centered care, for instance by emphasizing that meaningful activities are not limited to large social activities and hobbies, but may also be small activities such as daily habits and self-care (Giebel and Sutcliffe, 2018).

As the care and support for people living with dementia involves various professionals from different sectors of healthcare, interprofessional collaboration and the sharing of knowledge is needed. One of the preconditions for this is interprofessional education. In interprofessional education, different professions learn about, from and with each other, thus enabling effective collaboration and improving well-being outcomes. There is a benefit to familiarization with other disciplines, and learning to collaborate and complement each other. The involvement of supportive supervisors and leaders is of value to stimulate personal development (Cummings et al., 2018).

Future research

The first insights into what empowerment for people living with dementia means and includes presented in this thesis call for more empirical studies regarding empowerment for people living with dementia, as these appeared to be scarce. Also, this thesis mainly focused on promoting empowerment on an (inter)personal level. Therefore, additional research regarding empowerment on an organizational, communal and societal level would be of value (Zimmerman, 2000). These future studies may consolidate and expand the presented conceptual framework of empowerment.

Moreover, an important question to answer is whether empowerment may lead to, or be a prerequisite for, quality of life and well-being. Quality of life and wellbeing may be direct outcomes of the empowerment process, but the empowerment process may also act as a moderator for the relationship between determinants of quality of life and well-being. Future studies which provide more clarity on the relationship between empowerment and quality of life and well-being should be undertaken. Moreover, as discussed above, further work is required to investigate the position of empowerment in relation to other concepts such as resilience and social health.

Secondly, future studies should focus on how empowerment can be measured. To our knowledge, for people living with dementia, no instruments exist to assess empowerment. For people living with dementia at home, the Engagement and Independence in Dementia questionnaire (EID-Q) seems promising (Stoner et al., 2018). The EID-Q questions are in line with the four domains of empowerment, and it asks about interaction and relationships. Further work is required to investigate if empowerment can be measured through this questionnaire, and to determine the psychometric properties of the Dutch translation. For people living with dementia in a nursing home, to our knowledge, no existing instruments are available to assess empowerment. Future research may develop such an instrument, for example through observations and assessment of family caregivers and healthcare professionals regarding the different domains of empowerment. Such an observer-rated instrument seems necessary, as self-reported instruments may not be feasible in the more severe dementia stages. Nevertheless, we should be aware that in outcome measures proxy perspectives can vary greatly from the perception of residents (Griffiths et al., 2020). Therefore, when possible, we should try our best to also capture self-reported empowerment by residents themselves. Moreover, it is crucial to reach a consensus between researchers about these outcomes measures, and therefore facilitate meaningful comparison between different studies (Moniz-Cook et al., 2008).

The last recommendation for future research would be to further investigate the feasibility of the WINC empowerment intervention for people living with dementia in nursing homes, as intervention use and data collection in our study was seriously hindered due to the COVID-19 outbreak. Such an extra feasibility study could investigate experiences in a non-pandemic situation, and also assess adjustments based on first experiences. Thereafter, following the MRC-framework, future research may be undertaken to investigate the effects of WINC on empowerment and well-being.

Concluding remarks

In conclusion, this thesis adds important knowledge to what empowerment for people living with dementia means and includes, and how empowerment can be promoted.

- For people living with dementia to feel empowered, a sense of identity, usefulness, control, and self-worth is important. The four domains seem to be important both at home and in nursing homes, and during different stages of dementia.
- Empowerment can be considered a dynamic process, with empowerment taking place within the interaction of, and relationship between, the person living with dementia and their social environment.
- It is of value for family caregivers and healthcare professionals to be aware of their role in the empowerment process, and to be supported by knowledge and tools on contributing to the empowerment process.
- Our newly-developed empowerment intervention can be used as a starting point for promoting empowerment for people living with dementia in nursing homes.

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Chapter 8

Samenvatting (summary in Dutch)
Datamanagement
Dankwoord (acknowledgments in Dutch)
About the author
Publications, presentations and training activities

Samenvatting (summary in Dutch)

Empowerment lijkt veelbelovend als één van de uitgangspunten van persoonsgerichte zorg en ondersteuning voor mensen met dementie. Het focust op talenten en competenties met ondersteuning van familie, vrienden en zorgprofessionals. Er is aandacht voor persoonlijke wensen en behoeften. Om meer te weten te komen over mogelijke toepassingen van empowerment in zorg en ondersteuning van mensen met dementie hebben we onderzocht (1) wat empowerment bij dementie inhoudt, en (2) hoe empowerment bevorderd kan worden.

Om inzicht te krijgen in wat empowerment bij dementie inhoudt, beschrijft **hoofdstuk 2** groepsbijeenkomsten en interviews met mensen met dementie, hun naasten en zorgprofessionals, zowel thuiswonend als in het verpleeghuis. Uit de analyse van deze gesprekken kwamen vier domeinen naar voren die belangrijk zijn voor empowerment bij dementie: (1) jezelf zijn, (2) je nodig en nuttig voelen, (3) een gevoel hebben van keuze en controle, en (4) behoud van eigenwaarde. Deze domeinen bleken zowel belangrijk voor mensen met dementie thuis als in het verpleeghuis, en in de verschillende stadia van dementie.

In **hoofdstuk 3** beschrijven we hoe empowerment bij dementie wordt gebruikt in de wetenschappelijke literatuur. We hebben de literatuur systematisch onderzocht en bekeken alle artikelen van studies die empowerment bij dementie noemden in de titel of samenvatting. We hebben 69 relevante artikelen gevonden. In de artikelen vonden we beschrijvingen van (1) wat het betekent om 'empowered' te zijn, (2) het proces van empowerment, en (3) wat de omgeving kan bijdragen aan empowerment. De resultaten van het literatuuronderzoek en de resultaten van de groepsbijeenkomsten en interviews uit hoofdstuk 2 hebben we gecombineerd in een conceptueel raamwerk over empowerment bij dementie. De bevindingen laten zien dat empowerment een dynamisch proces is: het vindt plaats in de interactie en relatie tussen de persoon met dementie en de omgeving.

Om inzicht te krijgen in mogelijke ondersteuning die naasten nodig hebben bij het bevorderen van empowerment, beschrijft **hoofdstuk 4** de perspectieven van naasten op hun interactie en relatie met de bewoner met dementie. Door middel van telefonische interviews vroegen we naasten naar hun interactie met de bewoner en hoe zij deze interactie ervaarden. Uit deze interviews kwamen drie thema's naar voren: (1) veranderingen in de interactie en relatie, (2) gebruikte strategieën voor betekenisvol contact, en (3) waardering van het contact. De resultaten toonden dat sommige naasten het lastig vinden om een betekenisvolle connectie te maken met de bewoner, terwijl het anderen goed lukt om een gevoel van verbondenheid te creëren, ondanks afgenomen communicatieve vaardigheden van de bewoner.

Hoofdstuk 5 beschrijft de resultaten van een Europese inventarisatie naar empowerment interventies. We verstuurden een online vragenlijst naar Europese onderzoekers, beleidsmakers en professionals geïnteresseerd in psychosociale ondersteuning voor mensen met dementie. We onderzochten welke interventies worden gezien als empowerment bevorderend en waarom. Drieënzeventig respondenten uit 23 landen beschreven samen 98 interventies, waarvan 90 interventies uniek waren. De resultaten gaven een interessant overzicht dat toonde dat veel verschillende interventies, met uiteenlopende doelen, werden beschouwd als empowerment bevorderend. Denk hierbij aan een programma dat helpt medicijnen op tijd in te nemen, tot een project dat beoogt een dementievriendelijke samenleving te bevorderen. Desalniettemin vonden we geen interventies die specifiek als doel hebben om empowerment te bevorderen bij mensen met dementie. Daarom bleek een belangrijke vervolgstap om interventies te ontwikkelen, en evalueren, die *specifiek* als doel hebben om empowerment te bevorderen bij mensen met dementie.

Hoofdstuk 6 omschrijft de ontwikkeling en haalbaarheidsevaluatie van het WINC empowerment programma. Dit programma heeft als doel om empowerment van mensen met dementie in het verpleeghuis te bevorderen. De interventie ontwikkelde we samen met een werkgroep. Deze bestond uit een specialist ouderengeneeskunde, een verzorgende, een casemanager dementie en een kwaliteitsmedewerker. Twee zorgteams zijn daarna voor het eerst aan de slag gegaan met het WINC empowerment programma. We evalueerden de haalbaarheid van het programma op verschillende aspecten zoals de integratie in hun manier van werken, de meerwaarde die ze in het programma zagen en de eerste effecten. We vonden dat voor zorgprofessionals het WINC programma haalbaar was om empowerment te bevorderen van bewoners. Het bleek voor zorgprofessionals echter lastig om naasten te betrekken. Sommige zorgmedewerkers gaven aan dat ze te weinig tijd hadden om voldoende te kunnen focussen op de domeinen van empowerment in hun dagelijkse werk. Desalniettemin ervaarden zorgprofessionals na het gebruik van het WINC programma meer bewustwording rondom de domeinen van empowerment, en meer focus voor de kleine dingen die er toe doen voor bewoners. Het enthousiasme van zorgprofessionals over het WINC programma wisselde. Ook werd in vragenlijsten door zorgprofessionals en naasten geen verbetering gerapporteerd in de domeinen van empowerment bij bewoners.

Hoofdstuk 7 bespreekt tenslotte de belangrijkste bevinden uit dit proefschrift tegen de achtergrond van recente literatuur. Hoewel er tegenwoordig steeds meer aandacht is voor de kracht van mensen met dementie, bijvoorbeeld met concepten als autonomie en eigen regie, is het concept empowerment zoals dat hier is uitgewerkt uniek om twee redenen: (1) empowerment is een dynamisch proces, en (2) empowerment vindt plaats in de interactie tussen de persoon met dementie en zijn omgeving. De resultaten van dit proefschrift hebben ook belangrijke implicaties. Ze laten zien dat het belangrijk is om in de dagelijkse zorg en ondersteuning van mensen met demente aandacht te hebben voor de vier domeinen van empowerment. Daarnaast is het van belang om in het onderwijs van toekomstige zorgprofessionals aandacht te besteden aan het opstellen van realistische doelen rondom de domeinen van empowerment en samenwerking met naasten. Verder is het belangrijk meer empirisch onderzoek te doen naar empowerment met dementie. Dit kan ons conceptuele raamwerk over empowerment bij dementie versterken.

Conclusie

Ons onderzoek laat zien dat voor empowerment bij dementie een gevoel van jezelf zijn, je nodig en nuttig voelen, het gevoel van keuze en controle en behoud van eigenwaarde belangrijk is. Empowerment is een dynamisch proces dat plaatsvindt in de interactie tussen de persoon met dementie en zijn omgeving. Het is van belang om naasten en zorgprofessionals bewust te maken van hun rol in het empowerment proces, en om kennis en handvaten aan te reiken om empowerment te bevorderen. Het nieuw ontwikkelde WINC empowerment programma lijkt haalbaar om empowerment te bevorderen bij bewoners met dementie in het verpleeghuis.

Data management

Informed consent

All participants provided consent to participate in this research. Informed consents on paper are stored for 15 years at the locked archive of the department of Primary and Community care of the Radboud University Medical Center (room number m245.-2.0053), only accessible to employees responsible for archiving, and to the project manager of the SPAN+ project upon request.

Ethical considerations

The study was conducted in accordance with Dutch Law and the Declaration of Helsinki (World Medical Association). Data storage was guided by the Findable, Accessible, Interoperable and Reusable (FAIR) principles (Wilkinson et al., 2016). The medical and ethical review board Committee on Research Involving Human Subjects Region Arnhem Nijmegen, Nijmegen, the Netherlands has given approval to conduct this study.

Research data

This thesis is based on scientific literature, and qualitative and quantitative of people living with dementia, their family caregivers and healthcare professionals. The privacy of all participants is warranted by use of encrypted and unique individual subject codes. The codes were stored separately from the study data.

Scientific literature

De results of the literature search were saved in Endnote (.enl files) and included all full-texts. Data extraction and methodological appraisal were saved in Microsoft Excel. Tables containing all information from the included articles were saved in Microsoft Word.

Qualitative data of participants

Focus group discussions and interviews were tape-recorded and transcribed verbatim in Microsoft Word. Transcripts were entered into Atlas.ti for data analysis.

Quantitative data of participants

All digital data was collected using the online survey tool LimeSurvey. All digital and paper data were entered into Castor EDC. Data management and monitoring were also performed within Castor EDC. An audit trail was incorporated to provide evidence of the activities that has altered the original data. Data were converged from Castor EDC to SPSS.

Data storage

All digital data is stored at the H-station of the department of Primary and Community care in the folder H:\OZ-Ouderen-Langdurige-Zorg\OLZ-SPANplus. The data is only accessible to employees responsible for archiving, and to the project manager of the SPAN+ project upon request.

Data is anonymized and stored for 15 years. After expiry of this period, dr. Debby Gerritsen will decide if the data can be destroyed or has to be stored for a longer period of time. In the latter case, the period and conditions of data storage will be again determined.

Availability data

The datasets generated and analyzed during the current study are not publicly available to ensure participants' privacy, but are available from the researchers on reasonable request

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World Medical Association, Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects.

Dankwoord (acknowledgements in Dutch)

Mijn naam staat op de voorkant van dit proefschrift, maar veel mensen hebben bijgedragen aan de totstandkoming ervan. Een aantal van hen wil ik in het bijzonder bedanken.

Deelnemers met dementie, naasten, zorgprofessionals en alle anderen die een rol hebben gehad in het SPAN+ project: dank voor alle inzet en medewerking.

Begeleidingsteam en collega's

Debby, Annemiek, Maud, Roeslan en Peter, ik had me geen fijnere projectgroep kunnen wensen. Samen waren we meer dan de som der delen - onze expertises versterkten elkaar. Ik wil jullie bedanken voor de inspirerende discussies, het delen van jullie kennis en betrokkenheid. Jullie hebben me altijd het gevoel gegeven dat ik op de goede weg was. Dat waardeerde ik ontzettend.

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Annemiek, op een hete zomerse dag in 2015 stapte ik als jonge student Bewegingswetenschappen je werkkamer binnen. Een stage bij SPANkracht, dat leek me wel wat. Gelukkig zag jij het ook zitten met mij. Dat het zou uitgroeien tot een bijna zes jaar durende samenwerking hadden we toen niet kunnen vermoeden. Sindsdien stond je week in week uit voor me klaar, en onze promovenda-copromotor relatie bleek even succesvol als die van stagiaire-stagebegeleider. Bedankt voor je goede raad, relativeringsvermogen en optimisme.

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Papa, mama en Tim, vanuit een liefdevolle thuisbasis hebben jullie altijd gestimuleerd om me te ontwikkelen. Ik waardeer dat echt enorm, bedankt!

Publications and presentations

Publications other than outlined in this thesis

Denkbeeld – Eigen kracht bij dementie, hoe draag je bij aan eigen kracht in de zorg en ondersteuning? (2022)

Interviews

Magazine Alzheimer Europe *Dementia in Europe* – SPAN+: Empowerment among people living with dementia (2020)

Magazine Dutch Alzheimer Association *Alz* – Het welbevinden van mensen met dementie staat bovenaan (2021)

Website Dutch Alzheimer Association – Vier thema's belangrijk voor behoud 'eigen kracht' bij dementie (2021)

Presentations

Presentation during Alzheimer Europe conference in Barcelona (Spain) – Empowering people living with dementia, results from a European survey (2018)

Presentation during annual meeting Radboud Alzheimer Centre in Nijmegen (the Netherlands) – Empowerment bij dementie (2018)

Presentation during Alzheimer Europe conference in the Hague (the Netherlands) – Defining empowerment for elderly people with dementia from multiple perspectives (2019)

Workshop during Nijmegen University Network for long-term care symposium in Den Bosch (the Netherlands) – Empowerment bij dementie: aansluiten bij wensen en mogelijkheden (2019)

Presentation during PhD days of Netherlands School of Public Health and Care Research in Den Bosch (the Netherlands) – Empowerment for people living with dementia (2019)

Presentation during online Alzheimer Europe conference – Development and pilot study of the SPAN+ empowerment intervention for people living with dementia in the community (2020)

Presentation during online SANO science day – Empowerment bij dementie het verpleeghuis (2021)

Workshop during Nijmegen University Network for long-term care symposium in Den Bosch (the Netherlands) – Empowerment bij dementie in het verpleeghuis (2021)

Presentation during online conference International Psychogeriatrics Association – Empowerment for people living with dementia: an integrative literature review (2021)

Presentation during online conference International Psychogeriatrics Association – Promoting empowerment for nursing homes residents with dementia: a feasibility study of the SPAN+ empowerment program (2021)

Presentation during online Alzheimer Europe conference – Family caregivers' perspectives on their interaction and relationship with people living with dementia in a nursing home (2021)

PhD portfolio of Charlotte van Corven

Department: Primary and Community care
Graduate school: Radboud Institute for Health Sciences
PhD period 01-01-2018 to 31-12-2021
Promotors: prof. dr. D.L Gerritsen and prof. dr. M.J.L. Graff
Copromotors: dr. A. Bielderman and dr. R. Leontjevas

Training activities

Courses

Radboudumc - eBROK course (2018)	26 hours
Maastricht Univ. – Summer course Intervention Mapping (2018)	56 hours
RU – Projectmanagement voor Promovendi (2018)	56 hours
RU – The Art of Presenting Science (2019)	42 hours
RU – Qualitative Research Methods and Analysis (2019)	84 hours
DGS – Graduate School Day (2019)	7 hours
RU – Effective Writing Strategies (2019)	84 hours
Radboudumc – Scientific integrity (2019)	20 hours
DGS – Scientific Integrity Course (2019)	7 hours
RU – Education in a Nutshell (2020)	28 hours
RU – The Art of Finishing Up (2021)	28 hours

Seminars

Lunch meetings Primary and Community care (2018 – 2021)	28 hours
Radboud Research rounds (2018 – 2021)	14 hours
-Meetings Radboud Alzheimer Center (2018 – 2021)	14 hours

Conferences

UKON symposium (2018)	8 hours
CaRe PhD day, oral presentation (2018)	14 hours
Mix&Match Alzheimer Nederland ZonMw (2018)	8 hours
Radboud Alzheimer Centrum nazomersessie (2018)	4 hours
Alzheimer Europe conference, oral presentation (2018)	16 hours
SANO wetenschapsdag (2018)	8 hours
Onderzoekssymposium Eerstelijnsgeneeskunde (2018)	4 hours
UKON symposium, oral presentation (2019)	8 hours
CaRe PhD day, oral presentation (2019)	14 hours
Mix&Match Alzheimer Nederland ZonMw (2019)	8 hours
SANO wetenschapsdag (2019)	8 hours
Radboud Alzheimer Centrum nazomersessie (2019)	4 hours
INTERDEM day (2019)	8 hours
Alzheimer Europe conference, oral presentation (2019)	16 hours
UKON symposium, oral presentation (2020)	7 hours
INTERDEM day (2020)	4 hours

Alzheimer Europe conference, oral presentation (2020)	14 hours
SANO wetenschapsdag (2021)	4 hours
UKON symposium, oral presentation (2021)	7 hours
INTERDEM day (2021)	4 hours
Alzheimer Europe conference, oral presentation (2021)	16 hours

Other

Donders introduction day (2018)	7 hours
Start PhD network Primary and community care (2018 – 2019)	28 hours
Organisatie Mix&Match (2021), 28 hours	
Peer coaching meetings Donders (2019 – 2021)	28 hours

Teaching activities

Lecturing

Lecturing “critically reading a scientific article” (2021)	4 hours

Supervision of internships / other

Supervision of internships biology bachelor students, and health and society master students (2019 – 2021)	350 hours
Supervision of biomedical students writing a research proposal 2019	40 hours

Total number of hours = 1163

Over de auteur (about the author in Dutch)

Charlotte van Corven werd op 11 juni 1993 geboren in Oss. In 2011 behaalde zij haar tweetalig-VWO diploma aan het Maasland College in Oss.

Vervolgens studeerde zij Bewegingswetenschappen aan de Rijksuniversiteit van Groningen. In 2015 begon zij aan de onderzoeksmaster Human Movement Science met als afstudeerrichting 'Motor function and cognition in healthy ageing'. Haar afstudeeronderzoek vond plaats bij het SPANkracht project van de afdeling Eerstelijnsgeneeskunde van het Radboudumc in Nijmegen, waar zij beweeggedrag van jonge mensen met dementie onderzocht.

In 2018 startte zij als promovenda op de SPAN+ studie bij het Universitair Kennisnetwerk Ouderenzorg Nijmegen en de afdeling Eerstelijnsgeneeskunde van het Radboudumc in Nijmegen. Deze studie heeft geresulteerd in dit proefschrift.

Radboudumc Alzheimer Center series

Van Corven, C (2022). Empowerment in people living with dementia.

Linden, R (2022). "Synaptic loss in Alzheimer's disease: From genes to mechanisms"

Maasakkers, C.M. (2021). Sitting brains won't stand – Sedentary behaviour, brain health, and cognitive function in older adults.

Tengeler, A (2020) "Mind the Microbes. The impact of the gut microbiota on brain structure and function in mice"

Thomas, J (2020). Slow waves - Assessing sleep and detrimental effects of sleep disruption on brain amyloid-β and cognitive function in shift workers

Boumans, R (2020). Feasibility and effectiveness of social robots in acquiring patient reported outcomes from older adults.

Sanders, M (2020). NeuroExercise: The effects of exercise on cognition, central and cerebral hemodynamics in mild cognitive impairment.

Heus, de R (2020). The ups and downs of blood pressure variation in cognitive impairment and dementia.

Van Waalwijk van Doorn, L.J.C. (2020). Cerebrospinal fluid biomarker assays for Alzheimer's disease: standardization, validation and analysis of confounders

Gerritsen, A (2020). The course and clinical aspects in young-onset dementia. Results of the Needs in Young-onset Dementia study

Tilburgs, B (2020). Advance care planning in dementia; Development and evaluation of an educational intervention in primary care.

Nieuwboer, M. (2019). Interprofessional communication and clinical leadership in the development of network-based primary care.

Smeets, C. (2019). Psychopharmacological treatment of neuropsychiatric symptoms: proper prescription in perspective.

Mariani, E. (2019). Let Me Participate: Using shared decision-making to involve persons with dementia in care planning in long-term care

Haaksma, M. (2019). Different but the same, unravelling the progression of dementia

Karssemeijer, E (2019). Brain in Motion: Combined cognitive and physical exercise training in people with dementia.

Borsje, P. (2019). Dementia related problems in primary care of greatest concern. The occurrence and course of neuropsychiatric symptoms in people with dementia and psychological distress in their informal caregivers.

Appelhof, B (2019). The management of neuropsychiatric symptoms in people with young-onset dementia. Improving specialized long-term care.

Ooms, S.J. (2018). Sleep well, age well? Assessing sleep disruption as a player in Alzheimer’s disease pathogenesis.

Arnoldussen, I. A.C. (2018). Adiposity and the Brain. The adiposity-brain-axis in mice and men

Jong, D.L.K. de (2018). Regulation of cerebral perfusion in Alzheimer’s disease: from seconds to months.

Donkers, H.W. (2018). Social Participation Dilemma’s in dementia.

Richters, A. (2018). Network-based care for people with dementia: a complex transition.

Spek, K. van der (2018). Appropriate psychotropic drug use in institutionalized people with dementia. The PROPER-study

Wiesmann, M. (2017). Vascular risk factors and Alzheimer’s disease.

Rijpma, A. (2017). Multi-nutrient interventions and brain metabolism in Alzheimer’s disease: a spectrum of effects.

Elsen, G. van den (2016). Tetrahydrocannabinol in the treatment of neuropsychiatric symptoms in dementia.

Vermeij, A. (2016). Cognitive plasticity in normal aging and mild cognitive impairment: Shedding light on prefrontal activation.

Müller, M. (2016). Footprints of Alzheimer's disease. Exploring proteins and microRNAs as biomarkers for differential diagnosis.

Bruggink, K.A. (2016). Amyloid-β and amyloid associated proteins in the pathology and diagnosis of Alzheimer’s disease.

Aalbers, T. (2016). eHealth in the primary prevention of cognitive decline; The Brain Aging Monitor study.

Maaden, T. van der (2016). Improving discomfort in nursing home residents with dementia and pneumonia. Development, implementation and evaluation of a practice guideline for optimal symptom relief.

Millenaar, J. (2016). Young onset dementia, towards a better understanding of care needs and experiences.

Döpp, C.M.E. (2015). Making the jump-The translation of research evidence into clinical occupational therapy practice.

Herbert, M. (2014). Facing uncertain diagnosis: the use of CSF biomarkers for the differential diagnosis of neurodegenerative diseases.

Ven, G. van de (2014). Effectiveness and costs of Dementia Care Mapping intervention in Dutch nursing homes

Aisha Sadie Sade Meel-vanden Abeelen (2014). methodological and clinical aspects of cerebral autoregulation and haemodynamics

Bakker, C. (2013). Young onset dementia: care needs & service provision.

Meeuwsen, E.J. (2013). Towards efficient dementia care : a comparison of memory clinics and general practitioners.

Spijker, G.J.A.A (2013). Systematic care for caregivers of people with dementia in community mental health services.

Janssen, D. (2013). The role of nutrition in Alzheimer’s disease : a study in transgenic mouse models for Alzheimer’s disease and vascular disorders.

Zerbi, V. (2013). Impact of nutrition on brain structure and function : a magnetic resonance imaging approach in Alzheimer mouse models.

Voight-Radloff, S. (2012). Cross-national transfer of community occupational therapy in dementia.

Spies, P.E. (2012). The reflection of Alzheimer disease in CSF.

Joosten-Weyn Banning, E.W.A. (2012). Learning to live with Mild Cognitive Impairment: development and evaluation of a psychological intervention for patients with Mild Cognitive Impairment and their significant others.

Vasse, E. (2012). A stepwise process for developing and implementing quality indicators to improve psychosocial dementia care in European countries.

Slats, D. (2012). CSF biomarkers of Alzheimer's disease; serial sampling analysis and the study of circadian rhythmicity.

Leontjevas, R. (2012). Act in case of Depression! Validation and effectiveness of a multidisciplinary depression care program in nursing homes.

Timmer, N.M. (2011). The interaction of heparan sulfate proteoglycans with the amyloid β protein

Schölzel-Dorenbos, C.J.M. (2011). Quality of life in dementia: From concept to practice

Bruinsma, I.B. (2011). Amyloidogenic proteins in Alzheimer’s disease and Parkinson’s disease: interaction with chaperones and inflammation

Perry, M. (2011). Development and evaluation of a Dementia Training Programme for Primary care

Derksen, E.W.C. (2011). Diagnostic disclosure: a basic intervention in dementia care

Wetzels, R.B. (2011). Neuropsychiatric symptoms in institutionalized residents with dementia: Course and interplay with cognition,quality of life and psychotropic drug use.

Dado- Van Beek, H.E.A. (2010). The regulation of cerebral perfusion in patients with Alzheimer’s disease

Jong, D. de (2010). Anti-inflammatory therapy and cerebrospinal fluid diagnosis in Alzheimer’s disease

Persoon, J.W.B. (2010). Development and validation of the Nurses’ Observation Scale for Cognitive Abilities – NOSCA

Meulenbroek, O.V. (2010). Neural correlates of episodic memory in healthy aging and Alzheimer’s disease

Zuidema, S.U. (2008). Neuropsychiatric symptoms in Dutch nursing home patients with dementia

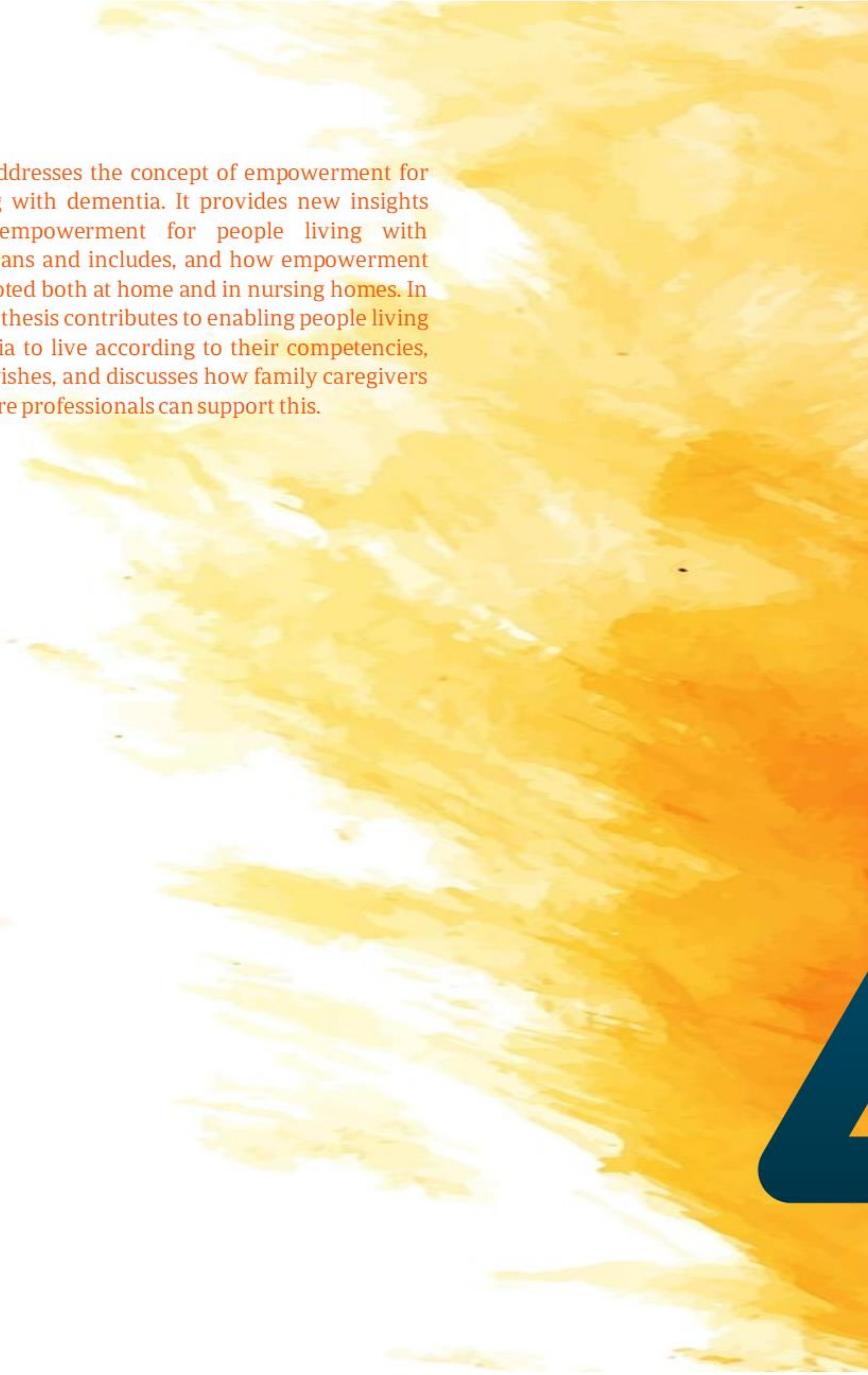
Graff, M.J.L. (2008). Effectiveness and efficiency of community occupational therapy for older people with dementia and the caregivers

Claassen, J.A.H.R. (2008). Cerebral hemodynamics in aging: the interplay between blood pressure, cerebral perfusion, and dementia

Wilhelmus, M.M.M. (2006). Small heat shock proteins and apolipoprotein E in Alzheimer's disease

Van Horssen, J. (2005). Heparan sulfate proteoglycans and vascular pathology in Alzheimer's disease

This thesis addresses the concept of empowerment for people living with dementia. It provides new insights into what empowerment for people living with dementia means and includes, and how empowerment can be promoted both at home and in nursing homes. In this way, this thesis contributes to enabling people living with dementia to live according to their competencies, talents and wishes, and discusses how family caregivers and healthcare professionals can support this.



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