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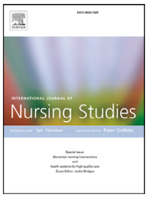

Defining empowerment for older people living with dementia from multiple perspectives: A qualitative study

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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 informal caregivers, and healthcare professionals.
Research design and methods: Qualitative research using focus group discussions and individual interviews with people living with dementia ($n = 15$), informal 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.

What is already known about the topic?

- Empowerment seems a promising concept for providing care and support for people living with dementia.
- It is still unclear what empowerment means and includes for people living with dementia.

What this paper adds

- 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 are the four themes of empowerment for people living with dementia.
- Empowerment takes place within the person living with dementia, but is achieved through interaction between the individual and their environment.

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- The conceptual framework developed in this study can be used in the development of new interventions for people living with dementia with a focus on empowerment, and therefore aid health care professionals and informal caregivers in providing care and support for people living with dementia.

1. 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 et al., 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 living without dementia.

Even though the word ‘empowerment’ is often used in dementia research in describing the aim of an intervention, as a theme in the result section, or as a word used to interpret results in the discussion (Giguere et al., 2018; Hobden et al., 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 informal 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.

2. Design and methods

2.1. Design and procedure

We performed a qualitative study with fourteen focus group discussions with people living with dementia (2 focus group discussions, $n = 11$), informal 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, informal caregivers, and healthcare professionals. One focus group discussion was organized for people living with dementia residing at home and their informal 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 Elderly 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.

2.2. Participants

In each organization, a contact person approached people living with dementia, informal caregivers and/or healthcare professionals to participate in a focus group discussion. This was done either by

Table 1
Overview of focus group discussions and individual interviews.

	People living with dementia	Informal 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 living with dementia ($n = 3$) and their informal caregiver ($n = 2$)			

[a] Context for person living with dementia.

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 informal 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. Informal 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.

2.3. 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 group discussions. 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 informal 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 min with people living with dementia, and 90 min with informal 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. 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.

2.4. Participant characteristics

In total, 15 people living with dementia, 16 informal caregivers and 46 healthcare professionals participated. Demographic characteristics of the participants are shown in Tables 2 and 3. Since informal 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 informal 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.

2.5. 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), see Additional file 2.

2.6. 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 living with dementia, written consent was also obtained from the informal caregiver.

3. Results

Based on the perspectives of people living with dementia, informal caregivers, and healthcare professionals, we were able

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

	Participating people living with dementia ($n = 15$)	Participating informal caregivers	
		Informal caregiver ($n = 16$)	Family member living with dementia ($n = 16$)
	Mean (SD) or n (%)	*Mean (SD) or n (%)*	*Mean (SD) or n (%)*
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 person living with dementia	–	9 (56.3)	–
Married/Partner	–	5 (31.3)	–
Child	–	2 (12.5)	–
Child-in-law			
Living with person living with dementia (% 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 Alzheimer's disease and vascular dementia	2 (13.3)	–	3 (18.8)
Combination vascular dementia and frontotemporal dementia	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)	–

[a] One missing in group of people living with dementia, one missing in informal caregiver group.
[b] Indication of healthcare professional (participating people living with dementia) or informal caregiver (family member living with dementia).
[c] Rating on a scale from 0 (low caregiver burden) to 10 (high caregiver burden).

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 Fig. 1.

4. 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 informal 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.

4.1. Being the person you have always been

Healthcare professionals and informal 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.

4.2. Being the person you are now

Healthcare professionals and informal 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

Table 3
Demographic characteristics of participating healthcare professionals.

	Healthcare professional working with people living with dementia residing at home (*n* = 19)	Healthcare professional working with people living with dementia residing in a nursing home (*n* = 27)
	Mean (SD) or n (%)	*Mean (SD) or% (n)*
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 people living with dementia	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 depart. 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)

[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, 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).

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*

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.

4.2.1. 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 informal 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 informal 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 informal caregivers mentioned they tried to overcome this by obtaining information about a person's life story (including their former

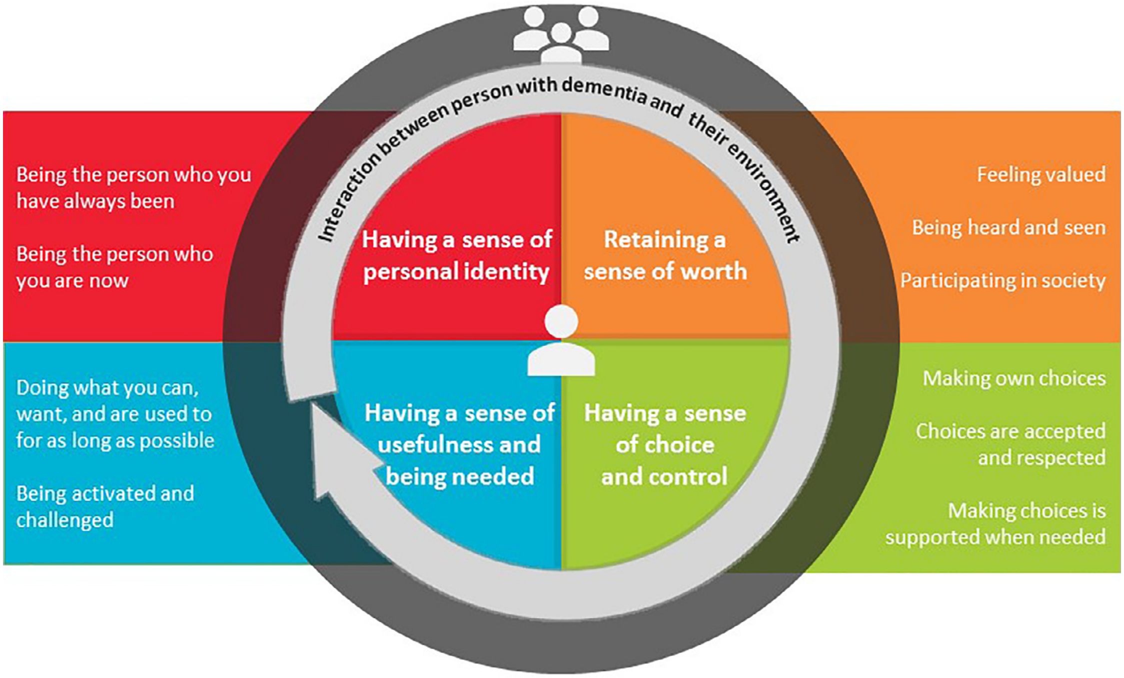

Fig. 1. Conceptual framework of empowerment in people living with dementia.

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.

4.3. 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, informal 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.

4.4. Making own choices

People living with dementia, informal 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, informal caregivers and healthcare professionals as an example of choice and control.

Furthermore, people living with dementia, informal 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 resident states 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)*

4.5. Choices are accepted and respected

Healthcare professionals and informal 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? (informal 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.

4.6. Making choices is supported when needed

Healthcare professionals and informal 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)*

4.6.1. Differences in living situation and/or severity

Healthcare professionals and informal 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.

5. 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, informal 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.

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

The majority of people living with dementia, informal 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 informal 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:

Informal 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"*
Informal 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 informal 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)*

5.2. Being activated and challenged

Healthcare professionals and informal 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 informal 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 informal 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. (informal caregiver of person living with dementia residing in nursing home, I06)*

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

5.2.1. Differences in living situation and/or severity

Healthcare professionals and informal 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.

5.3. 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, informal caregivers and healthcare professionals. This included feeling valued, being heard and seen, and participating in society.

5.3.1. Feeling valued

Both people living with dementia, informal caregivers and healthcare professionals stressed the importance of feeling valued. Some people living with dementia, informal 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, informal 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 informal 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. (informal caregiver of a person living with dementia residing at home, I16)*

It was suggested by healthcare professionals and informal 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.

5.4. Being heard and seen

People living with dementia, informal 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, informal 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)*

5.5. Participating in society

To retain a sense of worth, people living with dementia, informal 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)*

6. 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.

7. Conceptual framework of empowerment

Based on the four themes, we developed a conceptual framework (Fig. 1), incorporating all different perspectives on needs and wishes regarding empowerment, and perspectives on how to support this empowerment 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)*

8. 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 people 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 informal 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 informal caregivers to address and support strengths.

8.1. Strengths and limitations

A key strength of this study is the participation of all stakeholders involved: people living with dementia, their informal 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.

9. Conclusion

Based on the perspectives of people living with dementia, their informal 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.

Information about the authors

Charlotte van Corven, PhD student, collected the data (as an observer), analyzed and interpreted the data, and wrote the paper. Annemiek Bielderman, postdoc researcher, collected the data (as a moderator), interpreted the data and wrote the paper. Mandy Wijnen, research assistant, analyzed and interpreted the data. Ruslan Leontjevas, Peter Lucassen and Maud Graff interpreted the data and assisted in writing the paper. Debby Gerritsen, professor, collected the data (as a moderator), interpreted the data, supervised the data collection and assisted in writing the paper. We have no conflict of interest to declare.

Conflict of interest

None.

CRediT authorship contribution statement

Charlotte T.M. van Corven: Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing - original draft, Visualization, Project administration. **Annemiek Bielderman:** Conceptualization, Methodology, Investigation, Writing - original draft, Funding acquisition. **Mandy Wijnen:** Formal analysis, Investigation, Data curation, Project administration. **Ruslan Leontjevas:** Conceptualization, Methodology, Writing - review & editing, Funding acquisition. **Peter L.B.J. Lucassen:** Conceptualization, Methodology, Writing - review & editing. **Maud J.L. Graff:** Conceptualization, Methodology, Writing - review & editing, Supervision, Funding acquisition. **Debby L. Gerritsen:** Conceptualization, Methodology, Investigation, Writing - original draft, Supervision, Funding acquisition.

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