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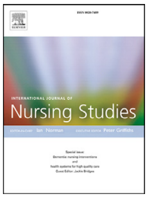

Empowerment for people living with dementia: An integrative literature review

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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. 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.

What is already known

- For people living with dementia to feel empowered, a sense of identity, usefulness, control, and self-worth is important.
- Empowerment takes place within the person living with dementia, but is achieved through interaction with their environment.

What this paper adds

- The concept of empowerment for people living with dementia is widely used in scientific literature. Nevertheless, empirical studies on what empowerment means and includes for people living with dementia are scarce.
- Empowerment of people living with dementia can be considered a dynamic process, with empowerment taking place

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within the interaction of, and relationship between, the person living with dementia and their environment.
- This literature review specifies the empowerment process and the environment's role therein.

1. 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-centered 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 et al., 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. (2019) 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.

2. 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).

2.1. 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 exluded.

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.

2.2. 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.

2.3. 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.

3. Results

The systematic searches identified 990 potentially eligible articles. The flow diagram in Fig. 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 sixteen countries. Most articles came from the United Kingdom ($n = 26$), followed by the United States ($n = 12$), Australia ($n = 5$), Canada ($n = 5$), the Nederlands ($n = 5$), 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.

3.1. 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 et al., 2018; Hung and Chaudhury, 2011; Kannaley et al., 2018; Manthorpe and Samsi, 2013; Mmako et al., 2020; Parveen et al., 2017; Prato et al., 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 et al., 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.

3.2. 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 et al., 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

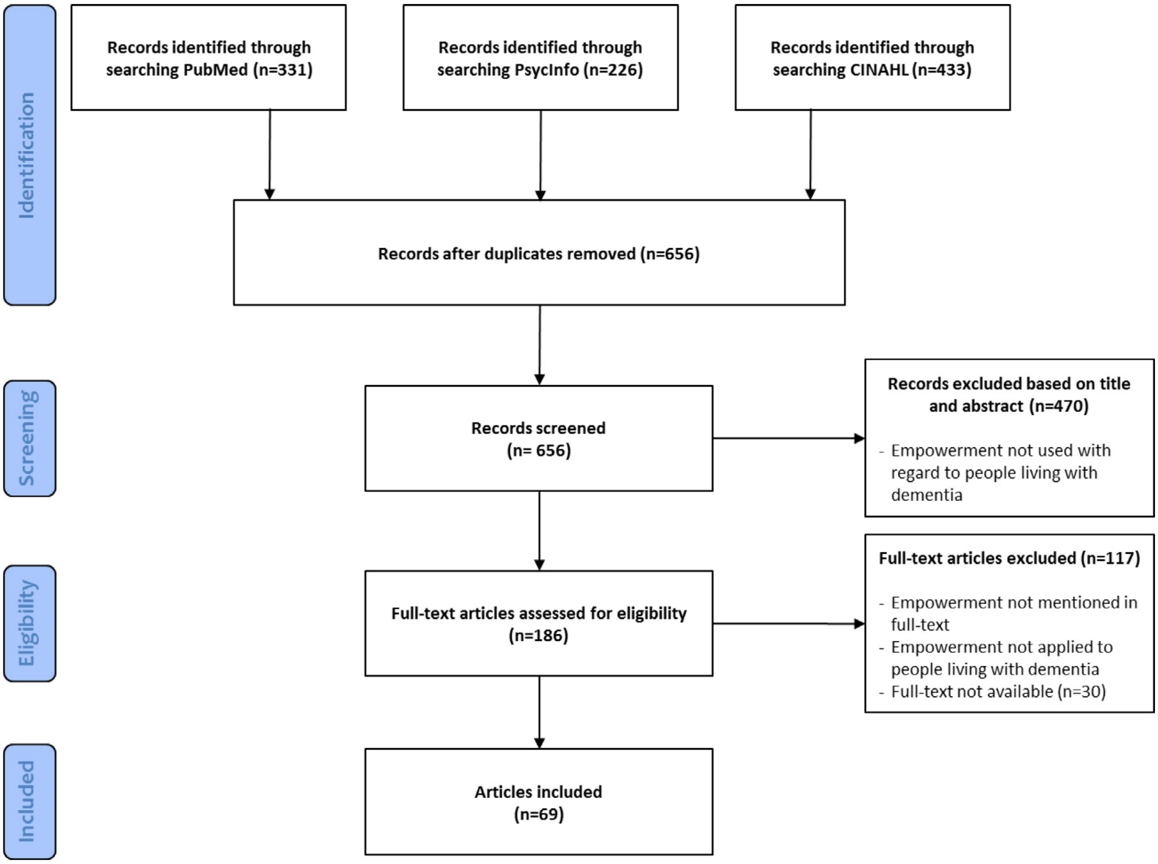

Fig. 1. PRISMA flow diagram.

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 et al., 2018).

3.3. 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.

3.4. 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).

3.4.1. 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 et al., 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 et al., 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).

3.4.2. 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 et al., 2017; McConnell et al., 2018). To illustrate, Nomura and colleagues

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	–
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	–
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	–
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	–
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

(*Continued on next page*)

Table 1 (*Continued*).

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
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
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
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	–	–
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	–
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

(*Continued on next page*)

Table 1 (*Continued*).

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
Mahieu et al. (2017)	Discussion paper	Nursing home, Belgium	Empowerment used to interpret results	–	–	(1) Care approaches	–
Parveen et al. (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
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	–
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	–	–	–
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
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 professionals, (2) Professional care, (3) Dementia friendliness, inclusion and low stigma	–

(*Continued on next page*)

Table 1 (*Continued*).

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	–	–
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	–
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.

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*

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 et al., 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 et al., 2018).

3.4.3. *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).

3.5. *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).

3.5.1. *Relationships and social interaction*

Authors suggested that empowerment is promoted through meaningful communication (Alsawy et al., 2019; Martin and Younger, 2000; Prato et al., 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 et al., 2018; Ryan et al., 2009). Furthermore, authors implied that the relationships between the person living with dementia and their family caregivers (Parke et al., 2016; Prato et al., 2018) and healthcare professionals (Hallberg et al., 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 et al. (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 et al., 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 et al., 2017; Passmore et al., 2007), but also through peer support and a shared social identity with other people living with dementia (Kannaley et al., 2018; McConnell et al., 2018; Mmako et al., 2020; Nomura et al., 2009; Passmore et al., 2007).

3.6. 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).

3.6.1. 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 et al., 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 et al., 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 et al., 2017; Martin and Younger, 2000), control (Hallberg et al., 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).

3.6.2. Care approaches

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

3.6.3. 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 et al., 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 et al., 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 et al., 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).

3.6.4. 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).

3.7. *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).

3.7.1. *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 et al., 2017; McConnell et al., 2018; Parveen et al., 2017) and well-being (Hebert and Scales, 2017; Kenigsberg et al., 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)

3.7.2. *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 et al., 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).

3.7.3. *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).

3.7.4. *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).

3.7.5. *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).

3.7.6. *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 Alzheimerś patients, enabling them to exercise their citizenship, participate and share with their community their life experiences and aspirations.”* (Ramos et al., 2005)

Furthermore, McConnell et al. (2018) 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.

3.8. *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 Fig. 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 gray circle. The dark gray boxes show how the environment can promote empowerment, specified 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.

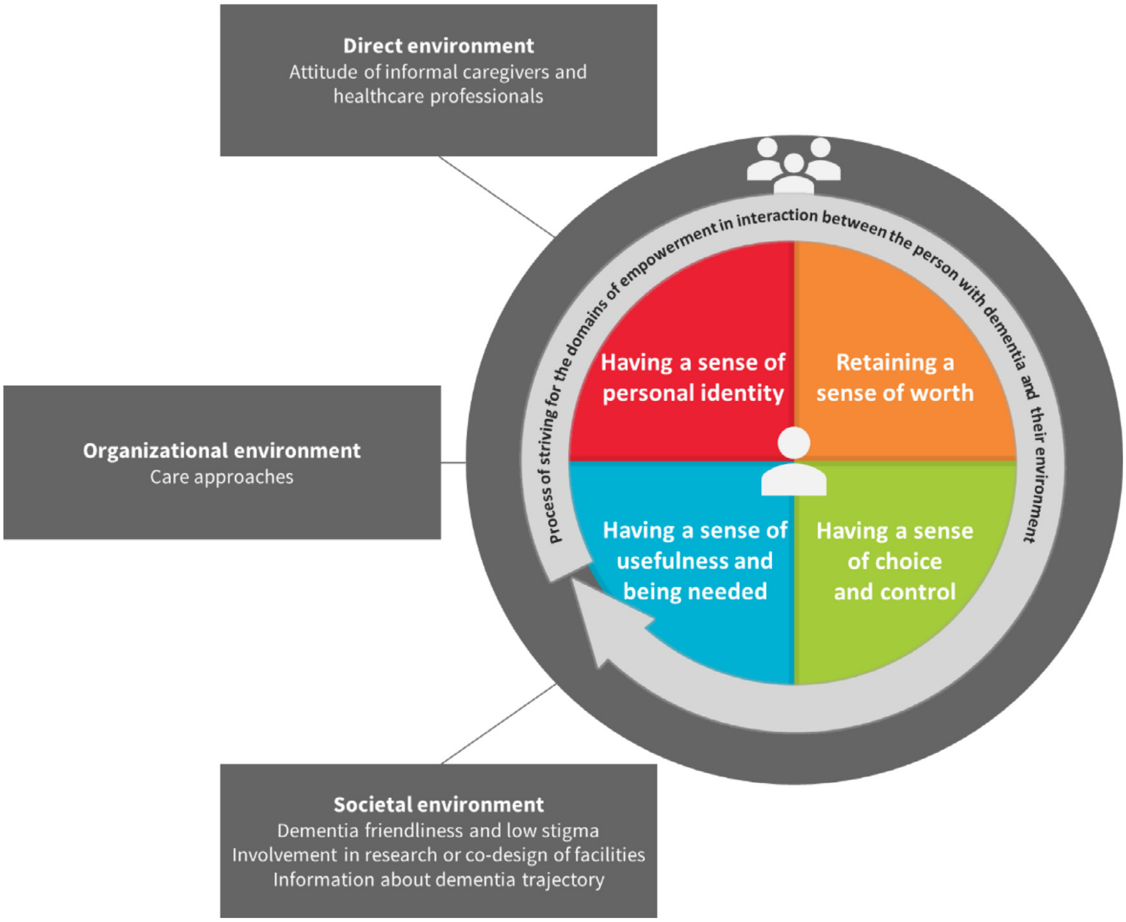

Fig. 2. Revised conceptual framework of the process of empowerment for people living with dementia.

4. 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 (Fig. 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 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-centered 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 substansive 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.

4.1. 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.

5. 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.

Declaration of Competing 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, Formal analysis, Investigation, Writing – original draft, Funding acquisition. **Mandy Wijnen:** 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, Formal analysis, Investigation, Writing – original draft, Supervision, Funding acquisition.

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Information about the authors

Charlotte van Corven, PhD student, performed the literature search, screened the titles, abstracts and full-text, analyzed and interpreted the data, and wrote the paper. Annemiek Bielderman, postdoc researcher, screened full-texts, interpreted the data, and wrote the paper. Mandy Wijnen, research assistant, screened titles and abstracts, and interpreted the data. Ruslan Leontjevas, Peter Lucassen and Maud Graffinterpreted the data and assisted in writing the paper. Debby Gerritsen, professor, interpreted the data, supervised the data collection and assisted in writing the paper. We have no conflict of interest to declare.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.ijnurstu.2021.104098.

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