

Review Article

The Experience of Relations in Persons with Dementia: A Systematic Meta-Synthesis

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Keywords

Dementia · Meta-synthesis · Interviews · Lived relations · Life-world perspective · Person's experiences

Abstract

Background: Dementia influences a person's experience of social relationships, as described in several studies. In this systematic meta-synthesis of qualitative studies, we aim to interpret and synthesize the experiences of persons with dementias and their relations with others. **Summary:** Living with dementia changes life, leading to new social roles and different social statuses. Persons with dementia experience being disconnected and dependent on others, feeling like being a burden, and being a person who is treated in paternalistic ways. Family, friends and others with dementia might play significant roles in their ability to maintain a meaningful life. **Key Messages:** Three categories emerged from the data, change in life, change in relations, and maintenance of meaningful aspects in life; these categories are intertwined and essential in sustaining a lifeline for persons with dementia. The comprehensive meaning of the material is understood as the expression: *Living a meaningful life in relational changes*.

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Introduction

Strauss [1] has stated that to each and every single person there is nothing general about life – life is in the details. From this perspective, lived experience and lived understanding of illness and context are important aspects of healthcare.

The psychosocial dimension often influences a person's health from an overall perspective. House et al. [2] showed that good, robust social relationships have as much of an impact on

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physical health and length of life as other lifestyle-related components. Crooks et al. [3] found that larger social networks have a protective influence on cognitive function among elderly women. Relationships will influence biological, psychological, and social mechanisms [4, 5]. It is not only being involved in social relationships or the size of our network that counts but also how a person experiences the social relations that are of great importance. Individuals who experience positive support from their family and friends describe their life as more meaningful and valuable than others [6].

Several studies have described how dementia influences a person's experience of psychosocial aspects. In one meta-synthesis of dignity in dementia care, Tranvåg et al. [7] stated that worthiness and sense of self are particularly important for persons with dementia (PWD). Steeman et al. [8] reviewed qualitative studies of early-stage dementia and found that individuals living with dementia experience threatened feelings of security, autonomy and being a meaningful member of society. In the systematic review of qualitative studies by Strech et al. [9], social and content-dependent aspects were emphasized as important ethical issues in dementia care. In a qualitative study of the perspective of anxiety in dementia, Qazi et al. [10] stated that surroundings and relations to others are important aspects of the development of anxiety in this group. Furthermore, 2 qualitative studies on ethics by Heggstad et al. [11] and Tranvåg et al. [12] highlighted that a lack of freedom and the feeling of not being confirmed and respected as an autonomous person might threaten personal dignity in PWD; moreover, relational interactions will preserve dignity for the same group of persons.

Several single studies have explored perspectives of how lived relations are experienced by PWD, for example how PWD hold on to their roles in social relationships in which they experience being valuable to others [13], the importance of deep, long-term friendships that still remain [14], and how PWD adjust to their relational situation of feeling incompetent, but still loved [15]. Additionally, one study focused on how PWD feel useless and a burden to their family and therefore avoid sharing their thoughts and worries in order to protect the family and themselves [16]. Considering how important relationships with others are for health and well-being, the challenges faced by PWD, and the help and support PWD require, there is a need for a systematic review that synthesizes the knowledge on this particular perspective.

Theoretical Frame

Lived relations with others are social and cultural phenomena that cannot be separated from the life-world perspective [17]. This meta-synthesis is guided by the theoretical frame of the Dutch philosopher Max van Manen [18], who stated that the grounding level of human existence has fundamental and thematic structures. The structures of the human life-world, as experienced in everyday situations and relations differ from human to human and during a day or a period. van Manen identified four fundamental existential themes of the life-world to describe and constitute the complexity of the life-world: (1) lived body, (2) lived space, (3) lived time, and (4) lived others.

According to the *lived experience of the body*, van Manen postulated the position of the body by describing human beings as living in the world with the body, and living and being in relation with others through the body [18]. *The experience of lived space* is described as the "felt space." The experience of space is often pre-verbal, in contrast to mathematical space or the length, depth, or height dimensions of space. *The experience of lived time* covers the experience of perceived time as opposed to clock time or objective time. Lived time describes our temporal way of being in the world. The three dimensions of past, present, and future constitute the horizons of a temporal landscape.

According to the fourth existential describing lived relation to other persons, *lived other*, we share an "interpersonal space" with the people around us. When we meet other persons, we have the opportunity to develop a conversational relationship, which allows us to tran-

scend ourselves. van Manen highlights that within the experience of others, human beings search for a sense of purpose in life, meaningfulness and grounds for living.

The existentials may be reflected upon separately, but they are interwoven and only as a whole will they constitute the life-world. van Manen claimed that a changed experience in one of the four life-world existentials would influence the others and therefore the experience of the life-world as a whole [18]. However, in this systematic meta-synthesis, we will emphasize the perspective of lived others.

The Review

Aim

The aim of this systematic meta-synthesis was to interpret and synthesize PWD's experiences of lived relations with others.

Design

An interpretative qualitative meta-synthesis was conducted, inspired by the approaches and methods described by Paterson et al. [19] and Zimmer [20].

Search Method

Literature Search and Selection

We conducted a systematic, computerized search of MEDLINE, Embase, CINAHL Complete, PsycINFO and AgeLine. The search strategy combined MeSH terms and text words for different types of *dementia* with different descriptions of *experience*. The combinations of search terms are shown in Table 1. Studies were restricted to peer-reviewed research articles, qualitative studies with best specificity, written in the English language and published between January 2004 and May 2016. The searches resulted in 1,309 articles, of which 131 were identified as eligible. A flow chart for the selection of articles is presented in Figure 1.

Two pairs of authors (E.K.G. and S.E./L.K.J. and S.E.) independently reviewed the titles, abstracts, and, in some cases, the full articles of all the identified studies to ensure that there were always 2 authors selecting the articles in terms of screening, eligibility and inclusion, according to the PRISMA standard of systematic reviews [21]. Disagreement was resolved by discussion, and, if necessary, by consulting one of the other authors. Studies were included if they met the following criteria: (1) sample of PWD only; (2) qualitative interview as a research method; (3) persons' with dementia voices should be explicit; and (4) describing experiences of lived relations with other persons. Studies were excluded according to the following criteria: (1) mixed sample or uncertainty due to dementia (i.e., probable or possible dementia), and (2) studies of a certain intervention.

Assessment of the Quality of the Studies

One hundred and thirty-one full-text articles were read and reviewed according to the CASP criteria for qualitative studies (<http://www.casp-uk.net/#|casp-tools-checklists/c18f8>). The quality of all studies was assessed by pairs of authors (L.K.J. and E.K.G./L.H.F. and K.S./A.-S.H. and S.E.). Disagreement was resolved by discussion, and, if necessary, by consulting one of the other authors. The CASP appraisal tool includes the following 9 criteria: (1) clear statement of aims; (2) appropriate choice of method; (3) appropriate research design; (4) congruence between recruitment strategy, aims and research; (5) data collection method addresses the research issue; (6) relationship between researcher and participant was considered; (7) ethical issues were considered; (8) process of data analysis was sufficiently rigorous; and (9) clear statement of the findings. Each criterion was given an equal weight

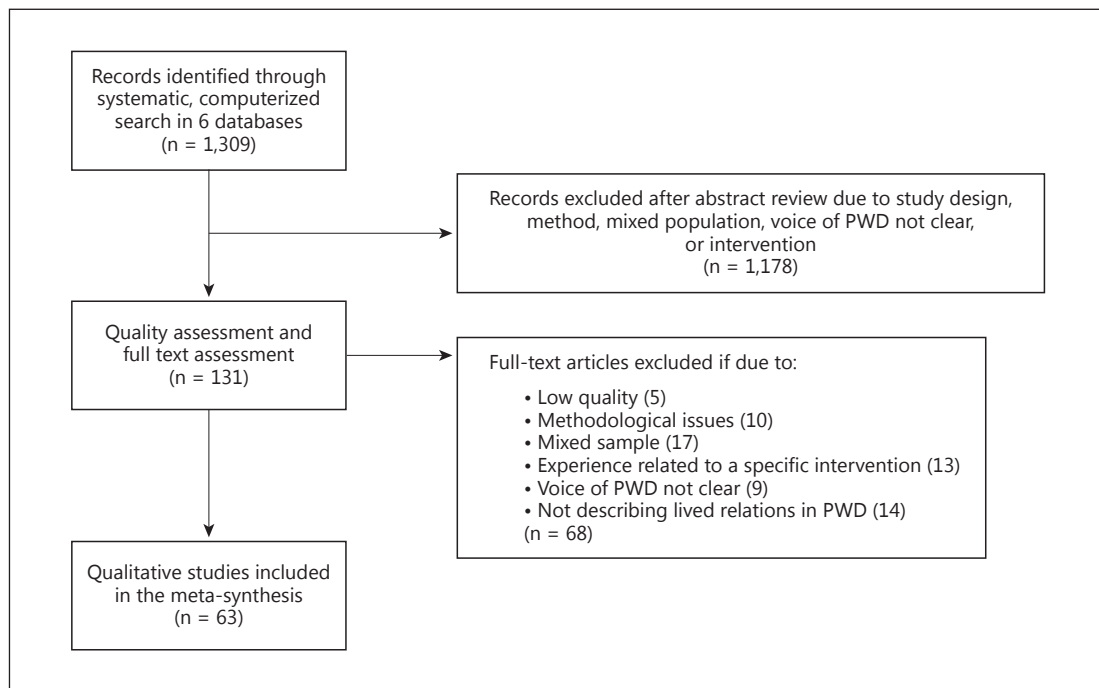


Fig. 1. Flow chart of the literature search.

Table 1. Search terms

Population	Experience
<p>MeSH terms: Dementia (CINAHL, Embase, MEDLINE, PsycINFO) Dementia, presenile (CINAHL, Embase, MEDLINE, PsycINFO) Dementia, senile (CINAHL, Embase, MEDLINE, PsycINFO) Alzheimer’s disease (CINAHL, Embase, MEDLINE, PsycINFO) Dementia, multi-infarct (CINAHL, Embase, MEDLINE, PsycINFO) Lewy body disease (CINAHL, Embase, MEDLINE, PsycINFO) Dementia, vascular (CINAHL, MEDLINE, PsycINFO) Dementia, frontotemporal (Embase)</p> <p>Text words: Dement* Presenile dement* Senile dement* Alzheimer* Multi-infarct dement* Lewy body dement* Vascular dement* Frontotemporal dement*</p> <p>All words combined with OR</p>	<p>MeSH terms: Life experience (CINAHL, PsycINFO) Experience (Embase) Personal experience (Embase)</p> <p>Text words: Personal experience* Experience* Lived experience* Life experience* Patient experience* Subjective experience* First-person **</p> <p>All words combined with OR</p>

** AgeLine had no exclusion parameters for clinical queries, and we had to search for study design: nursing methodologies OR case study OR constant comparison OR content analysis OR descriptive study OR discourse analysis OR ethnography OR exploratory OR feminist OR grounded theory OR hermeneutic OR interview OR narrative OR naturalistic OR participant observation OR phenomenology OR qualitative research OR qualitative methods OR qualitative study.

Table 2. Quality assessment of studies included

First author [Ref.], year	Criteria ^a									Total/9	Quality
	1	2	3	4	5	6	7	8	9		
Aminzadeh [36], 2009	+	+	+	+	+	+	+	+	+	9	high
Aminzadeh [37], 2010	+	+	+	+	+	-	-	+	+	7	moderate
Atta-Konadu [38], 2011	+	+	+	+	+	-	-	+	+	7	moderate
Barrett [39], 2015	+	+	+	-	+	-	+	+	+	7	moderate
Bronner [40], 2016	+	+	+	+	+	-	-	+	+	7	moderate
Chaplin [41], 2016	+	+	+	+	+	-	+	+	+	8	moderate
Clare [42], 2008	+	+	+	+	+	+	+	+	+	9	high
Clemerson [43], 2014	+	+	+	+	+	+	+	+	+	9	high
Dalby [44], 2012	+	+	+	+	+	+	+	+	+	9	high
Derksen [13], 2006	+	+	+	+	+	-	+	+	+	8	moderate
Fleming [45], 2015	+	+	+	+	+	+	+	+	+	9	high
Frazer [16], 2012	+	+	+	+	+	+	+	+	+	9	high
Genoe [47], 2010	+	+	+	+	+	+	+	+	+	9	high
Genoe [48], 2012	+	+	+	+	+	+	+	+	+	9	high
Genoe [49], 2014	+	+	+	+	+	+	+	+	+	9	high
Gill [50], 2011	+	+	+	+	+	+	+	+	+	9	high
Gilmour [51], 2005	+	+	+	+	+	+	+	+	+	9	high
Goodman [52], 2013	+	+	+	+	+	-	+	+	+	8	moderate
Hain [53], 2014	+	+	+	-	+	-	+	+	+	7	moderate
Harman [54], 2006	+	+	+	+	+	+	+	+	+	9	high
Harmer [55], 2008	+	+	+	+	+	+	+	+	+	9	high
Harris [56], 2012	+	+	+	+	+	+	+	+	+	9	high
Harris [14], 2013	+	+	+	+	+	+	+	+	+	9	high
Hedman [57], 2013	+	+	+	+	+	+	+	+	+	9	high
Hedman [58], 2016	+	+	+	+	+	+	+	+	+	9	high
Heggstad [11], 2013	+	+	+	+	+	+	+	+	+	9	high
Hellström [59], 2015	+	+	+	-	+	-	+	+	+	7	moderate
Hulko [60], 2009	+	+	+	+	+	+	+	+	+	9	high
Hyden [61], 2015	+	+	+	+	+	-	+	+	-	8	moderate
Johannessen [62], 2011	+	+	+	+	+	-	+	+	+	8	moderate
Johannessen [63], 2014	+	+	+	+	+	-	+	+	+	8	moderate
Karlsson [64], 2014	+	+	+	+	+	+	+	+	+	9	high
Keller [65], 2010	+	+	+	+	+	+	-	+	+	8	moderate
Langdon [66], 2007	+	+	+	+	+	+	+	+	+	9	high
Lawrence [67], 2009	+	+	+	+	+	+	+	+	+	9	high
Lee [68], 2014	+	+	+	+	+	+	+	-	+	8	moderate
MacKinlay [69], 2009	+	+	+	+	+	+	+	+	+	9	high
MacRae [70], 2011	+	+	+	+	+	+	+	+	+	9	high
Mazaheri [71], 2013	+	+	+	+	+	+	+	+	+	9	high
Mazaheri [15], 2014	+	+	+	+	+	+	+	+	+	9	high
Merrick [72], 2016	+	+	+	+	+	-	-	+	+	7	moderate
Mok [16], 2007	+	+	-	+	+	+	-	+	+	7	moderate
Molyneaux [73], 2012	+	+	+	+	+	+	+	+	+	9	high
Moyle [74], 2011	+	+	+	+	-	-	+	+	+	7	moderate
Mushi [75], 2014	+	+	-	+	+	+	+	+	+	8	moderate
Nowell [76], 2013	+	+	+	+	+	+	+	+	+	9	high
Nygård [77], 2008	+	+	+	+	+	-	-	+	+	7	moderate
Öman [78], 2005	+	+	+	+	+	-	-	+	+	7	moderate
Pesonen [79], 2013	+	+	+	+	+	+	+	+	+	9	high
Phinney [80], 2006	+	+	+	+	+	-	+	+	+	8	moderate
Pipon-Young [81], 2012	+	+	+	+	+	+	+	+	+	9	high
Roach [82], 2016	+	+	+	+	+	-	+	+	+	8	moderate
Rostad [83], 2013	+	+	+	+	+	-	+	+	+	8	moderate
Samsi [84], 2013	+	+	+	+	+	-	+	+	+	8	moderate
Sixsmith [85], 2007	+	+	+	+	+	-	+	+	+	8	moderate

Table 2 (continued)

First author [Ref.], year	Criteria ^a									Total/9	Quality
	1	2	3	4	5	6	7	8	9		
Svanström [86], 2015	+	+	+	+	+	-	+	+	+	8	moderate
Tak [87], 2015	+	+	+	+	+	-	+	+	+	8	moderate
Toms [88], 2015	+	+	+	+	+	-	+	+	+	8	moderate
Van Zadelhoff [89], 2011	+	+	+	+	+	-	+	+	+	8	moderate
Vernooij-Dassen [90], 2006	+	+	+	+	+	-	-	+	+	7	moderate
Vikström [91], 2008	+	+	+	+	+	-	-	+	+	7	moderate
Weaks [32], 2015	+	+	+	+	+	+	+	+	+	9	high
Wolverson [92], 2010	+	+	+	+	+	+	-	+	+	8	moderate

9, high quality, 7–8, moderate quality, 6 or less, low quality. ^a CASP criteria: 1, Clear research statement; 2, Qualitative methodology; 3, Research question appropriate; 4, Recruitment strategy; 5, Data collection; 6, Relationship researcher-participants described adequately; 7, Ethical considerations; 8, Data analysis; 9, Clear statements of findings.

(i.e., 1 point) for a maximum score of 9 for each quality assessment per article. A score of 9 was considered high methodological quality, whereas 7–8 points was considered moderate quality; see Table 2. Only studies with moderate (13) and high quality (50) were included in this review. Five studies were excluded due to low quality (scores <7). This meta-synthesis is based on 63 articles.

The meta-synthesis includes interviews with 874 PWD. In 13 of the studies, the participants were living in nursing homes or other care facilities. In 55 of the studies, individual interviews with PWD were the main data collected. Eight studies performed interviews with dyads or pairs, and 4 studies performed focus group interviews. The included studies are presented in Table 3, along with the information described in the different papers (see Table 3).

Data Abstraction and Synthesis

The abstraction process was conducted according to the principles of interpretative synthesis [22] by focusing on the development of concepts based on the data from primary studies and further developing and specifying theories that integrated those concepts [23]. The analysis was inspired by the analytic approach of Graneheim and Lundman [24]. The analytic process comprised 5 steps:

In the *first step*, pairs of authors (L.K.J. and E.K.G./L.H.F. and K.S./A.-S.H. and S.E.) read and reread one-third of the papers each. The results from each paper describing lived relations for PWD were extracted as direct citations into a form created for further analysis: “meaning units,” according to Graneheim and Lundman [24].

Three of the authors (A.-S.H., E.K.G., and S.E.) conducted the further analysis of the descriptions of lived relations for PWD.

In the *second step*, meaning units were further condensed and labelled with codes to organize the material. The *third step* involved comparing codes, identifying similarities and differences, and structuring the codes into subcategories. The 8 subcategories identified through this process were ultimately gathered into 3 categories in the *fourth step* to describe the manifest meaning of the material (Table 4). In the *fifth step*, the *comprehensive understanding phase*, the categories were summarized and reflected upon to reach a presentation of the text as one overall, latent theme.

Table 3. Presentation of studies included

First author [Ref.], year	Aim	Participants	Method
Aminzadeh [36], 2009	To explore the subjective meaning of relocation for persons with dementia moving into residential care	n = 16 persons diagnosed with dementia living at home and planning to move to residential care within 2 months Mean MMSE: 23.8 (13 mild, 3 moderate) Mean age: 85.3 (range 76–93) years Women: 68.8% Living with someone: 31.3% Canada	Individual in-depth interviews Field notes as supplementary data Analyses were guided by the work of Corbin and Strauss
Aminzadeh [37], 2010	To examine the significance of home at the time of relocation to residential care from the perspective of persons with dementia	n = 16 persons diagnosed with dementia living at home and planning to move to residential care within 2 months Mean MMSE: 23.8 (13 mild, 3 moderate) Mean age: 85.3 (range 76–93) years Women: 68.8% Living with someone: 31.3% Canada	Individual in-depth interviews Field notes as supplementary data Analyses were guided by the work of Corbin and Strauss
Atta-Konadu [38], 2011	To provide a broader perspective and insight into the food-related role shift experiences of husbands and their wives with dementia by presenting the accounts of both spouses in the couple	n = 9 persons diagnosed with dementia living in their home and their spousal care partners Stage of dementia? Age range: 58–86 years Women: 100% Living with partner: 100% Canada	Participants were interviewed yearly over a 3-year period (the last year only 5 husbands and wives were still involved); first couples interviewed in dyads, and then individual interviews were accomplished 1 week to 1 month later Data were analyzed using the constant comparative method described by Corbin and Strauss
Barrett [39], 2015	To outline the experiences and needs of lesbian, gay, bisexual, and trans Australians living with dementia, and their partners	n = 9 persons living with dementia, partners (21) and service providers Age range: 47–79 years Australia	In-depth interviews, mostly face to face (20) Data were analyzed using qualitative data analysis for applied policy research in line with Ritchie and Spencer
Bronner [40], 2016	To identify medical and social topics which become relevant in the period following diagnosis of Alzheimer disease (AD), for which a decision may eventually need to be made and which has implications for the life and well-being of the persons with AD	n = 5 persons with AD, relatives (6) and professionals (13) Mild AD according NINCDS-ADRDA MMSE >24 (mean 25.5) Mean age: 65 years Women: 80% Germany	Semi-structured face-to-face interviews Data were analyzed using content analysis in accord with Mayring
Chaplin [41], 2016	To focus specially on the experiences of people developing a dementia while still in employment in the UK	n = 5 persons with AD still being employed Diagnosis of AD according to ICD-10 MMSE: score range 25–28 Age range: 58–74 years Women: 20% UK	Individual semi-structured interviews on a single occasion Data were analyzed using interpretative phenomenological analysis

Table 3 (continued)

First author [Ref.], year	Aim	Participants	Method
Clare [42], 2008	To explore the subjective experience of living with dementia in residential care and to understand the psychological impact of being in this situation	n = 81 persons diagnosed with dementia living in residential care homes MMSE score: range 0–20 Mean age: 83.4 (range 59–96) years Women: 85% UK	An existing dataset consisting of individual unstructured conversations with people with dementia from a study of well-being in residential care were used The number of conversations recorded with each participant ranged from 1 to 8 The total dataset consisted of 304 transcripts Interpretative phenomenological analysis as guiding design
Clemerson [43], 2014	To explore the individuals' subjective experiences of young-onset dementia	n = 8 persons diagnosed with AD living at home MMSE: score range 17–21 Age range: 35–60 years Women: 12.5% Living with someone (partner or others): 75.0% UK	Individual semi-structured interviews were performed Data were analyzed using interpretative phenomenological analysis
Dalby [44], 2012	To understand the experience of spirituality in the context of living with dementia In addition, a second aim was to understand the experience of dementia in the context of spiritual belief	n = 6 persons diagnosed with dementia living at home (75%), in assisted living (12.5%) or in nursing home (12.5%) MMSE/stage of dementia: not described Age range: from 70s to 90s Women: 83.3% Living with partner: 16.7% UK	Individual semi-structured interviews with participants were performed Data were analyzed using interpretative phenomenological analysis
Derksen [13], 2006	To describe and appraise the experiences, beliefs, and fears regarding the diagnosis of dementia in both patients and carers	n = 18 persons diagnosed with dementia and their family carers Mean MMSE score: 22 (range 15–30) Mean age: 71 years Women: 20% Living with partner: 85% The Netherlands	Individual semi-structured interview with patient and the carer were performed separately Two interviews with participants; the first 2 weeks after the diagnostic disclosure and 10 weeks later Data were analyzed using the constant comparative method in line with Corbin and Strauss
Fleming [45], 2015	To identify the environmental features that are desirable in buildings used to provide care for people with dementia nearing the end of their lives	n = 2 persons with young onset dementia, family carers (10) and health care personnel (5) More information about the persons with dementia not described Australia	Mixed method; 3 focus group interviews In addition, a survey with experts in environmental design of care facilities for older people (21) Interview data were analyzed using management software NVivo 8
Frazer [46], 2011	To explore how women who live alone with dementia see themselves and how they cope in their everyday lives	n = 8 persons diagnosed with dementia (AD = 5) living in their own home MMSE score range: 14–26 Age range: 75–89 years Women: 100% Living with someone: 0% UK	Individual, semi-structured interviews were performed Data were analyzed using interpretative phenomenological approach

Table 3 (continued)

First author [Ref.], year	Aim	Participants	Method
Genoe [47], 2010	To explore the experience and meaning of food and mealtimes for persons with dementia living in the community and their primary partners in care	n = 27 persons diagnosed with dementia (AD = 25) living in their own home together with their primary family caregivers (19 spousal relationships, 8 adult-child relationships) Majority were in early stage of dementia Age range: 56–88 years Women: 59.3% Living with someone: 100% Canada	Dyad interviews were followed by individual interviews within 2 weeks were conducted Data were analyzed using grounded theory approach as described by Charmaz – the constant comparative method
Genoe [48], 2012	To explore the meaning and experience of change surrounding mealtimes for persons with dementia living in the community and their primary partners in care	n = 27 persons diagnosed with dementia (AD = 25) living in their own home together with their primary family caregivers (19 spousal relationships, 8 adult-child relationships) Majority were in early stage of dementia Age range: 56–88 years Women: 59.3% Living with someone: 100% Canada	Dyad interviews were followed by individual interviews within 2 weeks were conducted Data were analyzed using grounded theory approach as described by Charmaz – the constant comparative method
Genoe [49] 2014	To explore how persons with dementia think about and describe leisure in the context of their lives	n = 4 persons with diagnosed dementia living in their own home Early stage of dementia Age range: 70–82 years Women: 50% Living with partner: 50% (both men) Canada	Individual interviews with each participant were accomplished Data were also collected through participant observation and photo voice Data were analyzed using van Manen's phenomenological reflection
Gill [50], 2011	To understand how people with dementia receiving community care services in their own homes perceive interaction in the context of their service experience	n = 22 persons diagnosed with dementia receiving community care services in their own home Stage of dementia: not described Age range: 80–92 years Women: 63.6% Living with someone: 77.3% Australia	Individual semi-structured interviews were performed Data were analyzed using thematic and constant comparison analyses
Gilmour [51], 2005	To explore the experiences of living with memory loss	n = 9 persons diagnosed with dementia living at home Stage of dementia: not described Age range: 56–79 years Women: 44.4% Living with partner: 88.9% New Zealand	Individual, semi-structured interviews using open questions were used To assist participants, questions were provided on beforehand, and many participants wrote reminder notes prior to the interview Thematic analyses were undertaken

Table 3 (continued)

First author [Ref.], year	Aim	Participants	Method
Goodman [52], 2013	To explore how people with dementia discuss their priorities and preferences for end-of-life care, and how this might inform subsequent discussions with family and practitioners	<i>n</i> = 18 persons diagnosed with dementia living in residential care homes Stage of dementia: not described Age range: 68–92 years Women: 72.2% Length of stay in care home: 3–61 months UK	Individual, semi-structured interviews in the form of a “guided-conversation” were conducted as a part of a longitudinal mixed method study Thematic analyses were undertaken
Hain [53], 2014	To explore the experience of living with dementia from multiple perspectives, namely, the individual, spouse, and dyad of the person and spouse	<i>n</i> = 6 persons diagnosed with AD and their spousal caregiver (6) Mean MMSE: 23.3 (20–25) Mean age: 79.3 (71–85) years Women: 16.7% Living with partner: 100% USA	Individual, semi-structured interviews conducted from multiple perspectives; the individual, spouse, and dyad of the person and spouse Analyses were performed using the Giorgi’s descriptive phenomenological approach
Harman [54], 2006	To explore representations of illness and how these relayed to daily lived self-reported experience	<i>n</i> = 9 persons with dementia (AD = 5) living in their home Early-stage dementia (CDR 0.5 or 1) Mean age: 65 (range 58–67) years Women: 55.6% Living with partner: 88.9% UK	Individual semi-structured, individual interviews were performed Interpretative phenomenological analyses in accord with Smith and Jarman were used
Harmer [55], 2008	To explore the experience of living with dementia with focus on what makes activities meaningful for people with dementia	<i>n</i> = 17 persons diagnosed with dementia living in residential care homes, in addition their family caregivers (8), and staff (15) Mean MMSE: 12 (5–25) Mean age: 85.6 (72–99) years Women: 70.5% Living with partner: 17.6% UK	Focus group design with a constructed question guide with residents, staff and relatives of the residents were performed Mind map notes Data were analyzed using grounded theory approach with contents analysis
Harris [56], 2011	To study factors of importance for maintaining and retention of friendship in early stage dementia	<i>n</i> = 8 persons diagnosed with dementia (AD = 7) living in their home Early stage of dementia Mean age: 75 (59–85) years Women: 100% USA	Individual in-depth interviews were performed Data were analyzed using grounded theory approach in accord with Glaser and Strauss
Harris [14], 2013	To explore the quality and nature of friendship relationship of people with dementia	<i>n</i> = 10 persons diagnosed with dementia (AD = 9), in addition their carers (9: 7 spouses/2 sons) and friends (4) Early stage of dementia Mean age: 72 (57–85) years Women: 60% Living with spouse: 70% USA	Individual, semi-structured interviews were performed Focus group interview with care person at association’s main office

Table 3 (continued)

First author [Ref.], year	Aim	Participants	Method
Hedman [57], 2013	To explore the use of Harré's social constructionist theory of selfhood to describe how people with mild and moderate AD express their sense of self	<i>n</i> = 12 persons diagnosed with AD living in their home Mild to moderate dementia Age range: 60–80 years Women: 41.7% Living with partners: 83.3% Sweden	Individual, semi-structured interviews were performed Data were analyzed using phenomenological approach in accord with Harré's theory of social constructionist
Hedman [58], 2016	To describe how 5 people with mild and moderate AD express their personal attributes and life histories	<i>n</i> = 5 persons with AD Mild to moderate AD Age range: 59–78 years Women: 60% Living with partners: 80% Sweden	10 support group sessions during an 8-month period Data were analyzed using an abductive approach in accord with McAdams and Graneheim and Lundman
Heggestad [11], 2013	To investigate how life in Norwegian nursing homes may affect experiences of dignity among persons with dementia	<i>n</i> = 5 persons diagnosed with dementia living in nursing home Mild to severe dementia Age range: 84–94 years Women: 80% Norway	Individual interviews and observations field notes were used Data were analyzed using qualitative phenomenological and interpretative hermeneutical approach in accord with Kvale and Brinkman
Hellström [59], 2015	To describe how older women with dementia express the importance of their homes and chores in everyday life	<i>n</i> = 7 women with dementia Diagnosed with dementia Age: 65–84 years Living with spouse: 100% Sweden	Supplementary secondary analysis of a longitudinal study exploring ways in which people with dementia and their spouses (20 couples) experienced dementia over time Several individual interviews (3–5) were performed Data were analyzed in accord with the method of qualitative description according to Sandelowski
Hulko [60], 2009	To explore the experience of older people with dementia and in which way socio-culture plays a role in diverse dementia patients' daily living	<i>n</i> = 8 persons diagnosed with dementia (AD = 7) living in their home and their relatives (50) Stage of dementia: mild (4), moderate (3), severe (1) Average age: 77 (74–87) years Women: 50% Canada	Series of individual in-home interviews over 1–2 month and observation sessions were used Data were analyzed in accord with grounded theory
Hydén [61], 2015	To investigate how spouses in couples with dementia position themselves in relation to each other by analysing their use of pronouns	<i>n</i> = 11 persons with dementia and their spouse (11) AD (9), Lewy body (1), vascular dementia (1) MMSE: 22–29 Age: 57–86 years Women: 45% Sweden	Individual interviews with a task-oriented character with a main focus on interactive and communicative aspects rather than on content-related aspects Data were analyzed in accord with positioning theory by Harré and van Langenhove

Table 3 (continued)

First author [Ref.], year	Aim	Participants	Method
Johannessen [62], 2011	To find out how people experience living with early-onset dementia, and to assess the implications for practice and the development of further services	n = 20 young persons with a diagnosis of dementia Age: 54–67 years Women: 40% Living with spouse: 75% Norway	Individual, thematic interviews were conducted Data were analyzed in line with grounded theory according to Glaser and Strauss
Johannessen [63], 2014	To investigate and interpret metaphorical expressions of the lived experiences of everyday life in people with young-onset dementia	n = 20 young persons with a diagnosis of dementia Age: 54–67 years Women: 40% Living with spouse: 75% Norway	Individual, thematic interviews were conducted Secondary analysis of the data in line with cognitive-semantic theory according to Lakoff and Johnson
Karlsson [64], 2014	To explore how people with AD present their life story	n = 9 participants with dementia living in their homes All had AD MMSE: 19–25 Age: 60–81 years Women: 55.5% Living with spouse: 88.9% (8) Sweden	Individual, narrative interviews were conducted Data were analyzed with the method for analysis of narrative in accord with Polkinghorne
Keller [65], 2010	To explore the mealtimes to provide opportunity for social activity and emotional connection	n = 27 participants with early to mild stage of dementia living in their home and their next of kin (28) Early stage of dementia Age: 56–88 years Women: 59.3% Living together with someone: 88.9% Canada	Active interviews with both individual and dyads were performed Data were analyzed using grounded theory methodology in accord with Charmaz and team analysis
Langdon [66], 2007	To explore the social effects of diagnosis of dementia	n = 12 persons diagnosed with dementia living in their own home MMSE range: 19–30 Mean age: 79 (range 66–87) years Women: 50% UK	Individual semi-structured in-depth interviews were performed Data were analyzed in accord with interpretative phenomenological approach
Lawrence [67], 2009	The subjective reality of living with dementia from the perspective of three minority ethnic groups Thoughts and other reactions to the diagnosis dementia	n = 30 persons diagnosed with dementia living at home or in sheltered accommodations (4) Mean MMSE: 17 (range 1–29) Age range: 65–96 years Women: 56.7% Living with someone: 73.3% UK	Individual in-depth interviews were performed Data were analyzed using grounded theory approach in accord with Glaser

Table 3 (continued)

First author [Ref.], year	Aim	Participants	Method
Lee [68], 2014	To explore personal experiences of receiving a diagnosis and to investigate aspects of the experience of adjusting and adapting to dementia	n = 10 persons diagnosed with mild AD living at home Mean MMSE: 25 (22–30) Mean age: 69 (57–84) years Women: 70% Living with partner: 50% UK	Individual, semi-structured interviews were performed Data were analyzed using interpretative phenomenological approach
Mac Kinlay [69], 2009	To examine spirituality and meaning in the experience of dementia of older Latvians who had immigrated to Australia during World War II	n = 3 persons diagnosed with dementia living in an aged-care facility MMSE: 18–20 Age: 87–94 years Gender: Not described Australia	Individual in-depth interviews were performed Data were analyzed using grounded theory in accord with Strauss and Corbin
MacRae [70], 2011	To examine how others' reactions to and treatment of persons living with early-stage AD influence their experience of dementia	n = 9 persons diagnosed with AD living at home (7), in senior's residence (1) or in a convent (1) Early stage of dementia Mean age: 74 years Women: 22.2% Living with partner: 44.4% Canada	Individual in-depth interviews using a symbolic interactionist perspective were performed Data were analyzed using inductive emergent process in accord with Coffey and Atkinson, Lofland and Lofland, and Taylor and Bogdan
Mazaheri [71], 2013	To describe experience of living with dementia in Iran	n = 15 persons diagnosed with moderate AD or vascular dementia living at home Mean MMSE: 16.5 (range 14–19) Mean age: 72 (range 60–87) years Women: 40% Living with someone: 80% Iran	Individual semi-structured interviews were performed Data were analyzed using content analysis in accord with Graneheim and Lundman
Mazaheri [15], 2014	To explore the subjective experience of living with dementia among Iranian immigrants in Sweden	n = 15 persons diagnosed with dementia living at home (10) or in group dwellings for people with dementia Stage of dementia: not described Age range: 66–88 years Women: 53.3% Living with someone (partner or child): 53.3% Sweden	Individual semi-structured interviews were performed Data were analyzed using content analysis in accord with Graneheim and Lundman
Merrick [72], 2016	To enrich understanding of the experience of dementia from a relational perspective	n = 7 persons with dementia and their care partners (7) AD (4), frontotemporal dementia (1), vascular dementia (1) mixed (1) Age range: 65–87 years Women: 29% UK	Semi-structured dyad interviews Data were analyzed using an interpretative phenomenological approach

Table 3 (continued)

First author [Ref.], year	Aim	Participants	Method
Mok [16], 2007	To describe the lived experience of people with early stage dementia and their ways of coping with the illness	n = 15 persons with dementia living at home in Hong Kong Early stage of dementia Age range: 56–80 years Women: 73.3% Living with someone: 100% China	Individual interviews were performed Data were analyzed using phenomenological approach in accord with Colaizzi
Molyneux [73], 2012	To understand “couplehood” as it is co-constructed by the couple when one partner has dementia	n = 5 persons diagnosed with AD and their partner living at home Stage of dementia varied Age range: 72–83 years Women: 60% Living with partner: 100% UK	The couples were interviewed simultaneously Data were analyzed using constructivist grounded theory approach in accord with Charmaz
Moyle [74], 2011	To understand the factors that influence quality of life for people living with dementia in long term care, including understanding of how they perceived they were valued	n = 32 persons diagnosed with dementia living in long term care Stage of dementia: not described Age range: 70–74 to >90 years Women: 68.8% Australia	Individual, semi-structured interviews were performed Data were analyzed in accordance with Laximancer using computer-assisted concept mapping program
Mushi [75], 2014	To explore the socio-cultural beliefs surrounding dementia and the life experience of people with dementia and their caregivers in the Tanzania	n = 41 persons diagnosed with dementia living at home and their caregivers, but only 25 persons with dementia were interviewed Stage of dementia: not described Mean age: 84 (range 70–100) years Women: 63.4% Living with someone: 100% Tanzania	Semi-structured paired interviews (25) and individual interviews (16) with the caregiver alone were performed Data were analyzed using content analysis
Nowell [76], 2013	To understand personhood by exploring the subjective experiences of those with dementia in UK	n = 7 people diagnosed with dementia living in dementia care units Stage of dementia: not early-onset, otherwise not described Mean age: 74 (range 62–87) years Women: 42.9% UK	Individual semi-structured individual interviews were performed Data were analyzed using an interpretative phenomenological approach
Nygård [77], 2008	To explore how people with dementia who live alone experienced the meaning of their everyday technology, such as telephone and electronic equipment, and the use of it	n = 8 persons diagnosed with dementia living at home MMSE: 19–28 Age: 57–82 years Women: 62.5% Living with someone: 0% Sweden	Repeated individual interviews and observations (during 3 weeks) were performed Two to 4 sessions of interviews and observations per person, each session lasting between 1 and 2 h Data were analyzed using a phenomenological, hermeneutical approach

Table 3 (continued)

First author [Ref.], year	Aim	Participants	Method
Öhman [78], 2005	To uncover and describe the meaning and motives for engagement in self-chosen daily life occupation for elderly individuals with AD dwelling in community	n = 6 community-dwelling persons diagnosed with AD MMSE: 15–28 Age range: 65–80 years Women: 50% Living with spouse: 50% Sweden	Repeated individual interviews and observations; totally 2 or 3 times per person A qualitative comparative analysis method was used in accord with Bogdan and Biklen
Pesonen [79], 2013	To explore the shared experience of dementia from the viewpoint of people with newly diagnosed dementia and their family members, and to understand how they manage their lives after the diagnosis	n = 8 persons diagnosed with dementia (AD = 6) living in their home or nursing home/assisted living facility (4) and their family members (8) Newly diagnosed Age: 55–68 years Women: 62.5% Finland	Conversational, low-structured face-to-face interviews Unstructured observations were conducted during the interviews, field notes were written after each interview Descriptive analysis using grounded-theory framework and constant comparative analysis in accord with Corbin and Strauss
Phinney [80], 2006	To learn more about the experiences the person with dementia and their families have in regard to meaningful activity	n = 8 persons diagnosed with AD living in their home with one family member Mean MMSE: 19.3 (range 16–23) Age: 64–88 years Women: 50% Family members: 7 spouses and 1 daughter Canada	Repeated individual in-depth, conversational interviews with persons with dementia and one family member in line with van Manen were conducted Data were analyzed using interpretative phenomenological approach in accord with Brenner
Pipon-Young [81], 2012	To explore the experiences of younger persons with dementia and develop an understanding of helpful support To identify areas of the service in need for change	n = 8 persons diagnosed with dementia living in their home Stage of dementia: not described Age: 60–67 years Women: 87.5% Living with partners: 87.5% UK	Action research across three phases; semi-structured individual interviews and field notes were used Data were analyzed using action research; interpretative approach including thematic analysis techniques in line with Charmaz and concept mapping in accord with McNiff and Whitehead
Roach [82], 2016	To develop deeper understanding of the family experience of transition in early-onset dementia and to develop a representative model of this experience	n = 9 persons with early onset dementia and their family members (11) AD (7), mixed (1), posterior cortical atrophy (1) Age range: 58–68 years Women: 0 Canada	Individual, initial and follow-up semi-structured interviews Data were analyzed in accord with a framework approach to qualitative data analysis by Ritchie and Spencer
Rostad [83], 2013	To gain understanding of the lived experience of younger persons with dementia (<65 years) who lived at home and suffered with early onset, and the meaning that could be found in their experiences	n = 4 persons diagnosed with dementia living in their home Early onset of dementia Age: 55–62 years Women: 50% Living with partner: 75% Norway	Individual, narrative individual interviews in a conversational style with broad open-ended questions were used Phenomenological hermeneutic approach to the analysis in line with Lindseth and Nordberg

Table 3 (continued)

First author [Ref.], year	Aim	Participants	Method
Samsi [84], 2013	To gain understanding of how everyday decision-making occur and change among people with dementia and carers from their perspective	n = 12 persons diagnosed with dementia living in their home and their family caregivers (12) Mild to moderate dementia Age: 72–89 years Women: 50% Living with someone: 66.7% UK	Face to face interviews 3–4 times during 1 year (approximately every 3–4 months) using a person-centred interviewing style were performed Both joint and separate interviews were performed, according to the preferences of those interviewed (it may vary over time) Phenomenological study in accord with Smith using thematic analysis in line with Braun and Clarke
Sixsmith [85], 2007	To study the role and importance of music in the lives and activities of the participants, the benefits they derived from music and music-related activities	n = 26 persons diagnosed with dementia living in their home (16) or staying in care homes (10) and their family caregivers Stage of dementia: not described Age: 62–96 years Women: 69.2% Living with someone: 70% UK	Individual interviews in their natural setting, at home (16–18) and in the care homes (8–10) were performed Open-ended interviews, which were loosely structured Observational data from private home settings were gathered
Svanström [86], 2015	To elucidate the phenomenon of living alone with dementia and having a manifest care need	n = 6 persons with dementia living in own homes Age range: 80–90 years Women: 83% Sweden	Several conversational interviews and field notes; 32 visits with six participants Data were analyzed in accord with an in-depth phenomenological analysis
Tak [87], 2015	To describe types of current activity involvement and barriers to activities reported by nursing home residents with dementia	n = 37 nursing home residents with dementia MMSE: 10–26 Average age: 84.5 (72–92 years) Women: 67% USA	Individual, short, open-ended interviews (31) and individual in-depth interviews (6) were performed Data were analyzed in accord with descriptive, content analysis within ethnographic framework
Toms [88], 2015	To explore the view of people with dementia and family caregivers on the use of self-management in dementia	n = 13 persons with dementia and their caregivers (11) MMSE >20 Early-stage dementia Age: 62–89 years Women: 69.2% Living with partner: 84.6% Family members: 11 spouses UK	Individual semi-structured interviews with open-ended questions were performed Thematic analysis in accord with Braun and Clarke
Van Zadelhoff [89], 2011	To investigate experiences of residents with dementia, their families and nursing staff in group living homes for older people with dementia and their perception of the care process	n = 5 persons diagnosed with dementia living in a non-profit nursing home, in addition residents' family members (4) and staff (5) Persons with moderate to severe dementia Age: 68–93 years The Netherlands	Individual in-depth interviews with open-ended questions were performed separately with each of the participants Observations and field notes were taken Inductive and theoretical analysis was used

Table 3 (continued)

First author [Ref.], year	Aim	Participants	Method
Vermooij-Dassen [90], 2006	To prospectively describe and understand the impact of receiving a diagnosis for individuals and their family carers over time, in order to suggest best practice for services and practitioners	n = 18 persons with dementia living in their home and their family carers Mean MMSE: 22 (range 15–30) Mean age: 71 years Women: 22.2% Living with someone: 83.3% The Netherlands	Individual semi-structured interviews about 2 weeks and 12 weeks after diagnosis were performed of PWD and family caregivers Constant comparative analysis using grounded theory in accord with Corbin and Strauss
Vikström [91], 2008	To identify and describe how persons with dementia and their caregiving spouses perceive their own, their spouses' and their mutual engagements in everyday activities	n = 26 persons with dementia living in their home and their caregiving spouses (26) Mean MMSE: 22 (range 16–24) Mean age: 78 (range 62–85) years Women: 46.2% Living with partner: 100% Sweden	Individual semi-structured individual interviews with open-ended questions were performed for PWD and caring spouse Analyzed using constant comparative method in line with grounded theory by Corbin and Strauss
Weeks [32], 2015	To explore the ways in which people with dementia, and those close to them, negotiated the task of disclosure of the diagnosis	n = 5 persons with early AD living in their home, and persons close to them (18) Age: 68–79 years Women: 60% Living with partner: 80%	Sequential interviews combined with participant observation over a 6-month period Data were analyzed with Grounded Theory approach in accord with Corbin and Strauss; NVivo Qualitative Data Analysis program was used
Wolverson [92], 2010	To investigate the subjective experience of hope of people with dementia	n = 10 persons diagnosed with AD living in their home Mean MMSE: 23 (range 19–28) Mean age: 81 (range 72–87) years Women: 70% Living with someone: 20% UK	Individual semi-structured interviews with open-ended questions were performed Data were analyzed using interpretative phenomenological approach in line with Smith

Table 4. Results

Category	Change in life	Change in relations	Maintenance of meaningful aspects in life
Sub-categories	<ul style="list-style-type: none"> – new roles and different social status – protecting roles and stabilizing life 	<ul style="list-style-type: none"> – being disconnected – being dependent – being a burden – being treated paternalistically 	<ul style="list-style-type: none"> – supportive interactions – being with peers
Condensed meaning units	<p>New roles and different social status</p> <p>Past and current family and social relationships differ [37]</p> <p>Changes in roles between couples [38]</p> <p>Changes in roles and responsibilities in couples [73]</p> <p>Decreasing capacity to fulfil roles [44]</p> <p>Contribute with their remaining abilities in family made them feel valuable [47]</p> <p>An invisible line crossed, making interaction with others different [54]</p> <p>Change in relations within the family, loss of intimacy in family, increase protective behaviour to protect them [16]</p> <p>Decreased trust from family due to communication difficulties [16]</p> <p>Previous roles and identity need to be reconstructed [79]</p> <p>Losing the job meant an end to working life and loss of colleagues and part of their social network [62]</p> <p>Feeling stigmatized and being embarrassed to have dementia [62]</p> <p>Loss of initiative, everything moving slowly [62]</p> <p>Dementia leading to invisible sexual orientation [39]</p> <p>Losing a sense of agency and position of status and authority once held [72]</p> <p>Distribution of power changed within the family [40]</p> <p>Leaving work had affected their family and their relationships in relation to finances [41]</p> <p>Feared becoming even more helpless [58]</p> <p>Talking about communion in past and present, but not future [58]</p>	<p>Being disconnected</p> <p>Hindrance to all kind of social activities outside the house – social isolation [42]</p> <p>Residential care promoted isolation from family [42]</p> <p>Discontinuity to others [44]</p> <p>Felt excluded by other people and society due to their difficulties [46]</p> <p>Freedom restricted, experience of homesickness, not being confirmed and respected as individuals: living among strangers in their (nursing) home [11]</p> <p>Lack of ability to follow topic, word-finding issues caused frustration and misunderstandings [65]</p> <p>Being a conversational disaster, comparing themselves to the rest of the population [68]</p> <p>Family restrict their activities and social participation [75]</p> <p>Difficulties speaking lead to social isolation [69]</p> <p>Loss of social relations are related to loss of identity, self-esteem, and self-respect [83]</p> <p>Wants social interactions and communication with others, but sees difficulties [83]</p> <p>Friendships were difficult to sustain [91]</p> <p>Social engagement in family and society diminished [91]</p> <p>Being all alone, having no one to talk with [63]</p> <p>Embarrassing cannot remember people's names [88]</p> <p>Suddenly wake up and then slide out of it again [63]</p> <p>Others discovered that something was wrong before receiving the diagnosis of dementia, but themselves had not noticed anything [62]</p> <p>Being left out of regular social life [62]</p> <p>Losing opportunities for participation in previous activities [62]</p> <p>Feeling isolated and having difficulties accessing appropriate informal support networks when there is a not-telling rule [32]</p> <p>Telling others mean admitting that I am no longer normal [32]</p> <p>Change in relationship was one of the most difficult transitions during the dementia journey [82]</p> <p>Being watched covertly at their work place and would have preferred to have been consulted about it [41]</p> <p>Losing contact with people who are not close [86]</p>	<p>Supportive interactions</p> <p>Contact with family is central to acceptance of their situation, being in residential care [42]</p> <p>Change in identity/self, due to response from others [43]</p> <p>Family helps them to hold themselves together [44]</p> <p>Engagement in spiritual communities and being spiritually connected – keeping the person intact [44]</p> <p>Neighbours important both emotionally and practically [46]</p> <p>Having a meaningful role important for maintaining identity [47]</p> <p>Supportive relations vital to cope with life with disease [49]</p> <p>Family members are important contributors to well-being [52]</p> <p>Facing interpersonal dilemmas [54]</p> <p>Talking to family members made links with important current and past relationship [55]</p> <p>Friendship is important for life existence, psychological well-being, understanding the situation [56]</p> <p>The importance of friendship [14]</p> <p>Construction of self in social situations [57]</p> <p>“If a man doesn't have a wife, he is in trouble” [60]</p> <p>Interaction and strengthened bonds, being able to respond and comprehend, gaining knowledge and gaining other perspectives (mealtime) [66]</p> <p>Adjusting their expectations [15]</p> <p>Using past roles to manage present life [76]</p> <p>Keeping family ties to be socially coherent [78]</p> <p>Awoke mixed feelings seen in those healthier than themselves [90]</p>

Table 4 (continued)

Category	Change in life	Change in relations	Maintenance of meaningful aspects in life
Condensed meaning units	<p>Protecting roles and stabilizing life</p> <p>Try to communicate effectively [53]</p> <p>Wanting to understand or avoiding thinking about it, actively fighting it or passively accepting it [54]</p> <p>The importance of basic human courtesies in interaction [55]</p> <p>Do not tell others about their disease [16]</p> <p>Recognized that others with dementia do not want to talk about it [88]</p> <p>Use common technology to be regarded as normal (as everybody else) [77]</p> <p>Wish to spare close relatives from grief, a reason for not telling about diagnosis [79]</p> <p>Cover-up their dementia [81]</p> <p>Resist change in life since change would indicate acceptance of progression of disease [48]</p> <p>The sense of being a part of a larger community counteract feelings of estrangement [64]</p> <p>A great consolidation in having family and friends around [64]</p> <p>Holding on to daily routines, fighting the disease [64]</p> <p>Want to be connected to family and friends through technology: "Like my husband to be able to check on the web cam" [45]</p> <p>Coping with stigma, struggling to find a way back to activities and social life [63]</p> <p>Coming to terms with the situation before being open with others [62]</p> <p>Trying to protect others from bad news [32]</p> <p>Not telling others helps to preserve an intact self [32]</p> <p>To offer an explanation to people who might have observed changes in behaviour or way of being [32]</p> <p>Fear of discrimination resulted in delayed services [39]</p>	<p>The feeling of loneliness was the characteristic of the domain of daily life [86]</p> <p>Feeling entirely alone without any awareness of others in the world [86]</p> <p>Separated and rejected from parts of society [58] Because of AD, difficult to keep informed and partake in discussions as before [58]</p> <p>Not keep in touch themselves because of embarrassment over symptoms [58]</p> <p>Being dependent</p> <p>Conflicting needs, tension between needs [36]</p> <p>Loss of adult competence [43]</p> <p>Loss of independence due to reduced mobility and cognitive function [46]</p> <p>Losing valued skills and abilities increase their reliance on others (family and friends) [49]</p> <p>Increasing need of support from others [70]</p> <p>Relies increasingly on family members [79]</p> <p>Change in decision process as dementia increases (less participation) [84]</p> <p>Difficult to recall the loved ones [86]</p> <p>Carers from home services not able to satisfy the longing for other people [86]</p> <p>Frustrating to need help with previously simple tasks such as dressing [58]</p> <p>Being a burden</p> <p>Concerning about their partner [43]</p> <p>Put burden on the partner [13]</p> <p>Fear of being a burden to the family [49]</p> <p>Fear of being a burden for care service [50]</p> <p>Being more concerned about their family than themselves [57]</p> <p>See the family struggle with them [80]</p> <p>Sensitive about the burden they cause the partner [89]</p> <p>The experience of burdening relatives and being concerned about behaviour irritating or upsetting others is a cultural phenomenon [67]</p> <p>Being a burden to society [62]</p> <p>Advised to take sickness leave when their employers became aware of the extent of their difficulties at work [41]</p> <p>Some had no recurrent contact with other people than home care services [86]</p> <p>People lacked patience and understanding and did not listen to them [58]</p> <p>The worst thing is being a burden to family [58]</p>	<p>To work with their partner as a couple [88]</p> <p>Able to be in charge with supportive interactions [59]</p> <p>Regular visits to family – a vital component integrated into the lives of nursing home residents [87]</p> <p>Strengthened relationships, feeling safe [62]</p> <p>Losing partner after diagnosis; difficult to meet anyone new [62]</p> <p>Being able to express and share feelings was important [32]</p> <p>Dementia brought us closer together [72]</p> <p>The importance of commitment and togetherness [72]</p> <p>Discussing their difficulties in relation to functioning in the work place with their partner [41]</p> <p>Life is given meaning through social interaction with others; it doesn't matter whether the visitor is a friend, a sibling, a child or just another fellow human being, who sits down, talks and listens [86]</p> <p>Social interactions with someone who listens and brings memories and feelings to life makes time pass quicker and life becomes more fun [86]</p> <p>Connectedness to family made life worthwhile [58]</p> <p>Being with peers</p> <p>New social activities and social relations in day care – being part of a group and human being [42]</p> <p>New social interactions with likeminded people reduced isolation [46]</p> <p>Mealtime with others supports identity [47]</p> <p>New activities, interaction and relations through care service [50]</p> <p>Mealtimes together with others is honouring identity [65]</p> <p>Mealtime is a social situation [48]</p> <p>Difficulties with co-residents in institution – avoid persons in order to avoid difficulties [74]</p>

Table 4 (continued)

Category	Change in life	Change in relations	Maintenance of meaningful aspects in life
Condensed meaning units	Positioning by using the pronoun “we” – the we-ness [61] Advised by others not to tell anyone about the Alzheimer disease (AD), but felt no reason to be ashamed [58] Still trying to help others, although ability to help had increased [58]	Being treated paternalistically Treated like a child [43] Important to be treated with respect from health professionals [51] Exclusion and betrayal – dementia has changed how people treat me [54] The experience of others being afraid and unsure about how to behave towards people with dementia [57] Feeling like having a “babysitter” [57] Comfortable inner circle – uncomfortable outer circle; consequences in society and social relations when hearing/using the diagnosis of dementia [66] Being forced versus being able to choose [68] Tension in the family, being nagged for their shortfalls [71] Being ignored and met with disrespect [71] Feeling family members blaming them for causing trouble, but still feeling loved and respected [15] The experience of family conflicts due to suspiciousness [15] Subjected to violations of their rights in the workplace as they were assigned to new work tasks [62] Restricted by relatives’ paternalism Relatives taking over negotiating when they visited the doctor together [40] Relatives paternalism led to conflicts when persons with AD felt dominated or controlled [40] No longer being a participant in the world; feeling like an object [86]	To be accepted as you are when being with others with dementia [81] Helpful to meet like-minded people as themselves [92] Making new friends in the nursing home and mingle with them [87] Participation in religious activities helped to connect with other residents [87] Good to hear that others are likely to experience the disease in the same way [63] Feeling listened to and understood when among peers [58] Feeling connected to others with AD [58]

Results

The analysis revealed three categories: (1) *change in life*; (2) *change in relations*; and (3) *maintenance of meaningful aspects of life*. The categories were further divided into subcategories, which described the extracted meaning from the selected areas highlighted in the included articles, see Table 4.

Change in Life

This category is differentiated into the following subcategories: (a) *new roles and different social status*, and (b) *protecting roles and stabilizing life*. The person's experience of living with dementia was characterized by challenges regarding their roles and social shifts. In addition, the process of adapting to these changes was essential. The adversity of the descriptions presented differs from a position wanting to stop the progression of the impairment to realizing the need for help, accepting the new roles and the changed status, and appreciating the protection and support from family and friends. For the PWD, the social environment and the network represent a stabilizing aspect and help them to avoid thoughts and worries about the possible progression of the disease.

New roles and different social status consist of the declining functional levels that affect the person's position in the family and relations with significant others. In terms of reconstructing roles and identity, the person's experiences of changes in life included the social environment, and the next of kin become more protective than before.

Protecting roles and stabilizing life describe what the person does to compensate for a lack of ability, such as the ability to communicate. The person is trying to normalize the situation and cover up the dementia. Some individuals are trying to spare close relatives from grief.

Change in Relations

This category is separated into the subcategories: (a) *being disconnected*, (b) *being dependent*, (c) *being a burden*, and (d) *being treated*. All of these subcategories are incorporated into a state in the PWD. By using the verb 'being', we have interpreted the statements given as an active presentation, as this is how the PWD describes the changes in relations. The presentation highlights how the person experiences himself/herself, based on the reflection from the surroundings.

Being disconnected represents the distance from social relations and known activities. The experience of withdrawal, discontinuity, isolation, restricted freedom, and homesickness (for those living in a nursing home) might be present. The distance could be understood as either wanting to be disconnected from others, or others disconnecting them. People around them might not be able to understand and thereby are not able to reach the PWD, or the PWD may feel like he/she is not being treated as a fellow human being and that their contact is restricted.

Being dependent is a consequence of the functional impairment in activities of daily living and reduced cognitive and social function for the PWD. The PWD might experience loss of adult competence at several levels. Family and friends must take on the function as caregiver when the PWD lacks the ability to continue with his/her daily activities.

Being a burden is expressed as the experience of family and friends struggling with them. PWD experience being a burden and being sensitive to the consequences for their caregivers.

The last subcategory, *being treated in paternalistic ways*, consists of how family, friends and healthcare personnel behave towards the PWD. Being treated describes care without choices and the ability to influence the action. The approach might be experienced as lack of autonomy, exclusion, betrayal, and a feeling of being treated like a child.

Maintenance of Meaningful Aspects in Life

The third category revealed two subcategories: (a) *supportive interactions* and (b) *being with peers*. The studies emphasize that both old and new relationships play significant roles in maintaining important aspects of a meaningful life.

Descriptions of the *supportive interactions* incorporate maintenance in terms of adjusting to the situation and accepting the situation. Family and others might give practical and emotional support, and thereby play an essential role. We have selected a statement from one of the articles that puts into words the essence of the supportive interactions: “Family steer me with invisible wheels” [53]. In addition, friendships, family, and engagement in spiritual communities seem to be particularly important.

Being with peers represents the valuable and meaningful dwelling with others in the same situation. On one hand, the common situation for PWD is interpreted as being part of a group that is engaged in the same activities. Being with peers reduces the experience of isolation, shapes a feeling of being accepted as they are, and thereby supports their identity. On the other hand, the companionship in an institution might be difficult, and some individuals avoid specific patients and staff.

Living a Meaningful Life in Relational Changes

An overall synthesis of the categories generated from the included articles reveals the comprehensive understanding and the latent meaning expressed as: *Living a meaningful life in relational changes*. Most of the statements represented a type of relational change. However, the expression of the PWD always seems to incorporate their fulfilment of a meaningful life during the different stages of dementia. The three categories: (1) change in life; (2) change in relations; and (3) maintenance of meaningful aspects in life, all represent the process used by the PWD in terms of shaping their new living situation and their struggle for meaningful relationships in life, despite the dementia-related changes.

Discussion

The aim of this systematic meta-synthesis was to interpret and synthesize PWD’s experiences of lived relations with others. This study shows that relations with others such as family, friends, neighbours, and healthcare personnel are important in the lives of PWD in different ways. The included studies had different perspectives on how social relations might change for individuals with dementia and describe the vulnerable experience of being disconnected from others; being dependent on family, friends, and healthcare personnel; feeling like a burden to close relatives; and being a person who is treated in paternalistic ways. Some of the studies also emphasize the importance of social relationships and what others can do to meet and support the PWD. However, some studies describe that it is important for PWD to protect themselves and describe the efforts they make to stabilize their lives and maintain relationships. Some studies highlight that PWD seem to protect themselves by avoiding challenging social relations.

From the perspective of PWD, the life changes after receiving a diagnosis of dementia involve an altered social status and new social roles. Every person receiving the diagnosis of dementia has a life story, and relations are an essential part of that story. The person is a mother or father, daughter or son, friend, spouse, colleague, and part of a family, a network of friends, and a society, etc. Being in relationships with others is important to our identity and our experience of self. The experience of social relationships is a crucial factor in the quality of life [25]. Relationship with others might give us a sense of security; we feel that we belong to someone, and, in a particular setting, we mean something to other people and we

have particular roles and tasks. Both van Manen [18] and Ricoeur [26] state that a person's life-world constitutes a dialectic between the past, present, and future. When a story is being told, the past will be brought into the present, and from that point of view, an individual will be looking into the future. From this perspective, the life-world does not only represent the "here and now." The present perception of lived relation with others also has a connection to the past and future.

The phrase *living a meaningful life in relational changes* describes the essence of the PWD experience of lived relations with others. When close relations change, life will change. When life changes, close relations will change. When an individual has dementia, his/her life will be different in several ways. The present is characterized by uncertainty. A new situation has emerged, changing daily life in different ways. The future is "blurry", and one does not know what to expect or count on, which is not exceptional for PWD. Others experiencing diseases with serious repercussions on their lives, for instance a severe stroke, might describe the same uncertainty about the future. What makes it particularly challenging for many PWD is that there will be parts of their lives that they no longer will remember. The continuity between past, present, and future, the "life line," could be understood as a chain at risk of breaking. How social relations face the changes and adapt to them, can be essential for the PWD's experience. When PWD are no longer capable of maintaining important aspects to live a meaningful life, others might help them do so. Social relations might 'patch up' the gaps by reminding the PWD and maintaining essential aspects from the past, thereby strengthening the chain. The perspective of the life story is an important aspect of a person-centred approach in dementia care by taking into account that the person has been and still is a part of a social context [27–29].

Dementia will change the cognitive capacity and often the physical capability and naturally lead to a decreased ability to perform activities and to participate in different ways. These changes in capabilities often cause changes in the way the surroundings relate to or count on the PWD. PWD might feel stigmatized [30] and are not able to distance themselves from the changes that are occurring. They live with and within the changes and might experience being different in their own and others' eyes. Living with dementia could be considered as a tremendous stress factor in life. The person struggles for a sense of coherence to cope with stress. According to Antonovsky, the sense of coherence consists of three elements: (1) *comprehensibility*, including predictability and understanding; (2) *manageability*, including skills and the ability to manage; and (3) *meaningfulness*, including a belief that things in life are interesting, worthwhile, and that there are good reasons and purposes for things to happen [25, 31]. Additionally, Antonovsky emphasizes the element of meaningfulness as the most important aspect [25]. Our findings show that other persons have an essential impact on the experience of meaning for PWD. Therefore, the changes due to dementia, social relations, and the meaning of life are intertwined aspects. The findings are in accord with the theory of van Manen, highlighting that meaningfulness and the grounds for living are found within the experience of relations with others [18, 31]. Both van Manen and Antonovsky underscore that meaningfulness in life may influence how a person addresses stress. Many PWD postpone telling others about their disease because of the stress and feelings they experience when they receive the diagnosis of dementia. However, one of the most recently published articles highlights the importance of openness and telling others about the diagnosis, which might give hope for a more transparent society [32].

Studies have shown that the numbers of social connections are less important than *how* the person experiences the quality of the relationships [6, 33, 34]. Therefore, one has to be aware of the fact that not every relation is a good relation. Good relationships could be a buffer against symptoms of anxiety and depression. Poor relationships might have the opposite effect. Relational meaningfulness might be a stabilizer, shaping continuity and

protecting against expressions such as agitation [35]. Several studies emphasized the aspect of being with others with dementia, which could be an expression of equality, comfort or safety. When they are with others with dementia, PWD are not supposed to be more or perform more than they are capable of doing. PWD feel accepted as they are and are listened to and understood.

Implications for Practice

Family and healthcare personnel have to be aware of their important roles as supportive persons, enabling PWD to continue living a meaningful life. Understanding and accepting the cognitive changes in a family member or a friend suffering from dementia could be difficult and is a continuous process along with the progression of the disease. There is a need for information, education and counselling of family and friends, as well as health personnel. Emancipation and person centeredness should be the key concepts guiding the care provided to sustain the PWD's feelings of still being involved in their own life in the present and also in the future.

Strengths and Limitations

We have performed a systematic meta-synthesis with transparent descriptions of the selection process for the included articles. However, we acknowledge that a completed overview is not attainable, despite our approaches. The value of both individual reviewers and the use of pairs of researchers to evaluate the studies has to be accredited.

Conclusions

This systematic meta-synthesis shows that relations with others are important in the lives of PWD. The three categories revealed from the 63 articles, change in life, change in relations, and maintenance of meaningful aspects in life, are intertwined and essential for sustaining the lifeline for PWD. The comprehensive meaning is understood as the expression: *Living a meaningful life in relational changes.*

Acknowledgement

We thank university librarian Marit Gjone Sandsleth for providing essential help and advice on the computer-aided search, and Professor Emeritus Knut Engedal for his valuable comments on the preparation of the manuscript.

Disclosure Statement

The authors declare that they have no conflicts of interest.

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