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Self-reported needs and experiences of people with dementia living in nursing homes: a scoping review

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ABSTRACT

Objectives: With rates of dementia continuing to rise, the impetus on improving care for people with dementia is growing. Unmet needs of people with dementia living in nursing homes have been linked with worsening neuropsychiatric symptoms, higher levels of depression, and reduced quality of life. Furthermore, proxy accounts exploring the needs of people with dementia have frequently been shown to be unreliable. Therefore, this literature review aims to explore the self-reported needs and experiences of people with dementia in nursing homes.

Method: A scoping review of the literature was carried out using the databases PubMed and PsycINFO to search for relevant articles according to PRISMA guidelines. Search terms were designed to include both quantitative and qualitative study designs. Thematic synthesis was used to categorise findings into themes related to self-reported needs and experiences.

Results: A total of 41 articles met the eligibility criteria. An analysis of study characteristics revealed more than half of studies used a qualitative design. Thematic synthesis resulted in eight themes: activities, maintaining previous roles, reminiscence, freedom and choice, appropriate environment, meaningful relationships, support with grief and loss, end-of-life care.

Conclusion: Whilst the voice of people with dementia has previously been neglected in research, this review has shown that people with dementia in nursing homes are able to describe their experiences and communicate their needs. The findings in this review have provided a contribution towards guiding evidence-based practice that is tailored to the needs of nursing home residents with dementia.

ARTICLE HISTORY

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KEYWORDS

Dementia; experiences; long-term care; nursing home; subjective needs

Introduction

Historically, people with dementia, and specifically those living in nursing homes, have been excluded from participation in research (Davies et al., 2014). Exclusion from research can be linked with the dominance of the biomedical model and an emphasis on developing pharmacological treatments for dementia. Consequently, researchers have frequently pursued a positivist-based paradigm of research, with participants playing a passive role in clinical trials (Bond & Corner, 2001). Furthermore, involving people with dementia in qualitative research has commonly been disregarded because of the association of dementia with 'dwindling personhood' (Moore & Hollett, 2003), and the view that associated communication and memory problems may affect an individual's ability to share their experiences (Nygård, 2006).

In recent years, research into the needs and experiences of people with dementia living in nursing homes has been recognised as an increasingly valuable field (Milne, 2011). In the United Kingdom, approximately 70% of people living in nursing homes have dementia, which is often in the moderate to severe stages (Prince et al., 2014). Unmet needs of people with dementia living in nursing homes have been linked with worsening neuropsychiatric symptoms of dementia (Cohen-Mansfield, Dakheel-Ali, Marx, Thein, &

Regier, 2015), higher levels of depression (Hancock, Woods, Challis, & Orrell, 2006), and reduced quality of life (Hoe, Hancock, Livingston, & Orrell, 2006). However, research in this field has frequently relied on reports from family members and staff, despite evidence to suggest that proxy accounts are not always reliable (Crespo, Bernaldo de Quirós, Gómez, & Hornillos, 2012; Orrell et al., 2008). Therefore, eliciting the voice of people with dementia in research aimed at exploring their needs is essential for the production of evidence-based guidelines for care delivery in nursing homes, paving the way for improved quality of life amongst people with dementia (Sabat, 2003).

Although literature reviews exploring the self-reported needs of people with dementia have been carried out, these have focussed on those living in the community (Van der Roest et al., 2007; Von Kutzleben, Schmid, Halek, Holle, & Bartholomeyczik, 2012). One review by Cadieux, Garcia, and Patrick (2013) looked at the needs of people with dementia in long-term care, using both proxy and subjective accounts. Their search included quantitative and qualitative studies published between 2000 and 2010. However, their search string did not include specific terms to identify subjective accounts, and consequently, some articles exploring subjective needs and experiences may have been overlooked. The aim of this scoping review therefore, is to

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explore the self-reported needs and experiences of people with dementia in nursing homes.

Method

Scoping review methodology

Due to the broad nature of the research question and the lack of current research in this area, the scoping review was selected as the appropriate methodology for this study (Peters et al., 2015). A scoping review has been described as a form of 'knowledge synthesis' and involves examining the nature and extent of research activity, which is important for determining gaps in the literature and directing future research (Colquhoun et al., 2014). For the purposes of this review, the six-stage framework as described by Arksey and O'Malley (2005) and adapted by Levac, Colquhoun, and O'Brien (2010) has been used to guide the process.

Search strategy

Search strings were discussed amongst the authors (K.S & L.P) and with a librarian. They were then organised according to the PICOS model for constructing search strings for mixed-methods reviews (Methley, Campbell, Chew-Graham, McNally, & Cheraghi-Sohi, 2014). The databases PubMed and PsycINFO were used in the search, which took place during February and March 2018. The search was initially narrowed to include articles published between January 2000 and February 2018 in English, French or Czech, which resulted in a total of 1158 articles. Table 1 shows the exact search string used for each database and the number of articles found.

Inclusion and exclusion criteria

The inclusion and exclusion criteria were initially decided upon by the authors (K.S & L.P) and reviewed during the search process by all authors. Articles of both quantitative and qualitative study designs exploring the self-reported needs and/or experiences of people with a diagnosis of any type of dementia living in a long-term care facility, such as a nursing home or residential home, were included. Those only involving participants with dementia living at

home or in hospital were rejected, as well as studies involving only participants with mild cognitive impairment (MCI) or probable dementia. Studies where participants already had a confirmed diagnosis of dementia were included, as well as those where researchers assessed cognitive impairment using an appropriate test. Those studies using only proxy accounts or observational methods were not included, as these did not seek to obtain views of people with dementia themselves. Finally, conference reports, editorials, books, protocols and dissertations were rejected. The screening process was carried out in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Liberati et al., 2009), as shown in Figure 1.

Critical appraisal

Critical appraisal in mixed methods reviews is currently a developing area. The Mixed Methods Appraisal Tool (MMAT) (Pace et al., 2012) was used as a general guide to assess the quality of articles of all study designs and to exclude any articles with fatal flaws. No studies were considered to warrant exclusion on this basis alone.

Data analysis

A convergent qualitative synthesis was carried out, enabling the transformation of both quantitative and qualitative data into qualitative findings (Pluye & Hong, 2014). In order to transform data, thematic synthesis as described by Thomas and Harden (2008) was used. This involved firstly coding data inductively, according to both the category of needs and the category of experiences. For instance, a number of participants made reference to being bored and to repetitive days, and these topics formed initial codes under the category of experiences. In the second step, similar codes were merged into sub-themes wherever possible. In this case, codes were categorised into the sub-theme 'boredom and monotony'. The same process was undertaken according to the category of needs.

The final stage of thematic synthesis requires the development of 'analytical themes', which address the research question directly. In this example, two authors (K.S & L.P) discussed, developed and sorted sub-themes to form the overarching analytical theme 'activities'. Wherever possible,

Table 1. Exact search strings used for each database and number of articles found.

Database	Search terms	Records identified
PubMed	("Nursing Homes"[Mesh] OR "Residential Facilities"[Mesh] OR "Long-Term Care"[Mesh] OR "Nursing Home*" [Title/Abstract] OR "Residential Facilities" [Title/Abstract] OR "Long-Term Care" [Title/Abstract] AND ("Dementia"[Mesh] OR "Dementia" [Title/Abstract] OR "People with Dementia" [Title/Abstract]) AND ("Self Report"[Mesh] OR "Self Report*" [All Fields] OR "Subjective" [All Fields] OR "Surveys and Questionnaires" [Mesh] OR "Survey*" OR "Questionnaire*" [All Fields] OR "Trial" [All Fields] OR "Interviews" [All Fields] OR "Phenomenological" [All Fields] OR "Qualitative Research" [Mesh]) AND ("Experience*" [All Fields] OR "Health Services Needs and Demand" [Mesh] OR "Quality of Life" [Mesh] OR "Quality of Life" [All Fields] OR "Care Needs" [All Fields] OR "Wellbeing" [All Fields])	750
PsycINFO	(MJMAINSUBJECT.EXACT("Nursing Homes") OR MJMAINSUBJECT.EXACT("Residential Care Institutions") OR MJMAINSUBJECT.EXACT("Long Term Care") OR ab("Nursing Home*") OR ab("Residential Facility") OR ab("Long Term Care")) AND (MAINSUBJECT.EXACT.EXPLODE("Dementia") OR ab("Dementia") OR ab("People with Dementia")) AND (MAINSUBJECT.EXACT.EXPLODE("Self-Report") OR "Self Report*" OR "Subjective" OR MJMAINSUBJECT.EXACT("Surveys") OR MAINSUBJECT.EXACT("Questionnaires") OR "Survey*" OR "Questionnaire*" OR MJMAINSUBJECT.EXACT("Interviews") OR "Interview*" OR "Trial" OR "Phenomenological" OR MAINSUBJECT.EXACT.EXPLODE("Qualitative Research")) AND (MJMAINSUBJECT.EXACT("Experiences (Events)") OR MJMAINSUBJECT.EXACT("Health Service Needs") OR "Care Need*" OR MAINSUBJECT.EXACT.EXPLODE("Quality of Life") OR "Quality of Life" OR MAINSUBJECT.EXACT.EXPLODE("Well Being") OR "Well Being")	408
Total number of records		1158

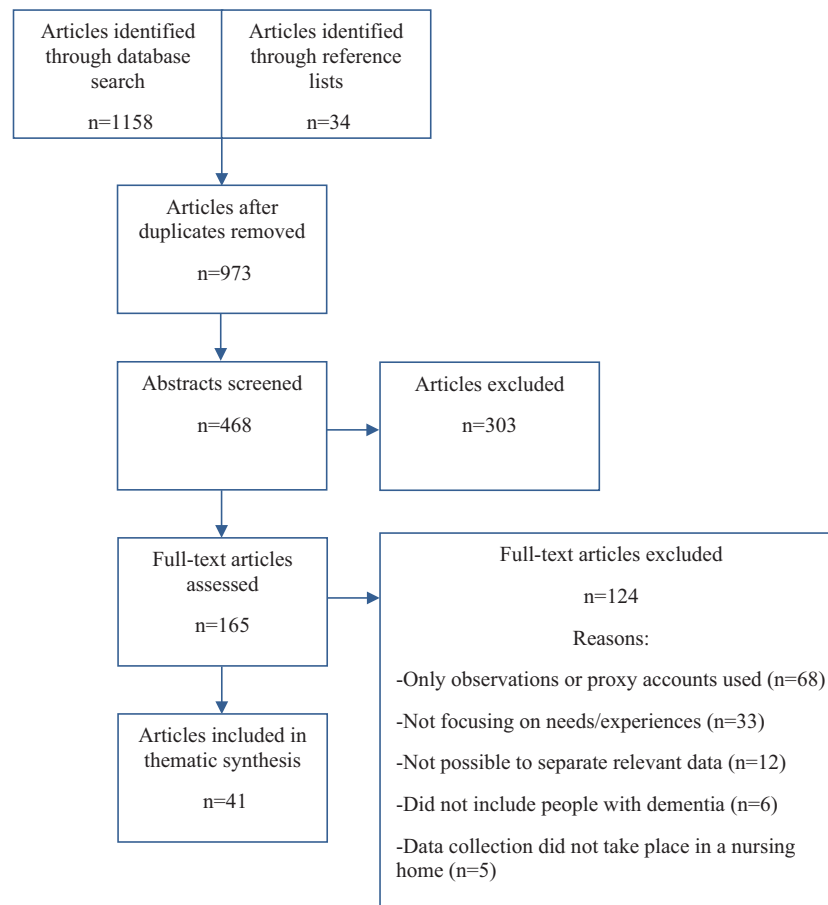


Figure 1. Search flowchart in accordance with PRISMA guidelines.

direct quotes from participants were used for data analysis, rather than the authors' interpretation of what participants had said (Van Leeuwen et al., 2019).

Results

Study characteristics

A total of 41 studies were included in the final synthesis. The most commonly stated aims were to explore participants' experiences ($n=14$); quality of life ($n=10$); perspectives ($n=5$); perceptions ($n=4$); preferences ($n=3$); needs ($n=3$); views ($n=3$); self-report ($n=2$); wellbeing ($n=1$); priorities ($n=1$); requirements ($n=1$); and feelings ($n=1$). Twenty-eight studies used a qualitative design, eight studies used a quantitative design, and five studies used mixed methods. Of the qualitative studies, the majority used interviews ($n=27$), including semi-structured and unstructured or conversational interviews, and one study used focus groups. Of the quantitative studies, five were randomised controlled trials. A number of studies used various methods to collect additional data, including: proxy interviews or focus groups with family or staff ($n=15$); observations ($n=12$); proxy scale ratings or questionnaires completed by family or staff ($n=5$); and data from medical notes ($n=7$). A small number of studies ($n=4$) used stimulus materials, such as photos, symbols or Talking Mats to aid participants' communication during interviews. Finally, details about participants' type of dementia were only described in a small number of studies ($n=10$), whilst severity of dementia was more

commonly described ($n=33$), with approximately half of studies specifying that they included people with severe dementia ($n=20$). In Table 2, we provide a summary of the individual studies.

Themes

Eight themes resulted from thematic synthesis: activities, maintaining previous roles, reminiscence, freedom and choice, appropriate environment, meaningful relationships, support with grief and loss, end-of-life care. Table 3 shows the sub-themes according to both experiences and needs for each of the eight analytical themes.

Activities

One of the most commonly occurring experiences of residents with dementia was boredom, with synonymous expressions such as 'monotonous' days (Harmer & Orrell, 2008) and 'lack of stimulation' (Aggarwal et al., 2003) also conveyed. The effects of boredom were spoken about by one resident who said: 'I get bored here [...] I feel like throwing something at them' (Clare, Rowlands, Bruce, Surr, & Downs, 2008). Participants discussed a number of unstructured activities they enjoyed, such as crosswords, playing instruments, jigsaws, reading and knitting (Harmer & Orrell, 2008; Jonas-Simpson & Mitchell, 2005; Murphy, Tester, Hubbard, Downs, & MacDonald, 2005). However, many participants wished for 'more social interaction' (Popham & Orrell, 2012), and said that they take part in

Table 2. Summary of articles used in thematic synthesis.

Author/Year/Country	Aim	Research type	Number & type of facility	Study design & methods	Study population	Themes
Aggarwal et al. (2003) UK	To explore how people with dementia and their relatives experience dementia and to find out how they perceive and receive care provision.	Qualitative	Residential care settings (number unknown).	Exploratory study with semi-structured interviews using stimulus materials such as photos and expression cards.	17 residents at various stages of Alzheimer's disease.	-Activities -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss -Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships
Bartlett (2007) UK	To explore how men with dementia experience, and deal with, nursing home life.	Qualitative	Specialist dementia care wing of a nursing home.	Phenomenological case study with an unstructured interview.	Mr Brown—a resident with Alzheimer's Disease.	-Activities -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss -Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships
Bauer et al. (2013) Australia	To explore residents' perceptions of the needs and barriers to the expression of sexuality in long-term care.	Qualitative	Six long-term care facilities, including high, low and mixed care facilities.	Naturalistic inquiry with semi-structured interviews.	Five residents with a diagnosis of dementia in its early stages.	-Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss -Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships
Cahill and Diaz-Ponce (2011) Ireland	To ascertain if similarities or differences exist in perceptions of quality of life amongst nursing home residents with different levels of cognitive impairment.	Qualitative	Three nursing homes.	Exploratory/descriptive study using in-depth, semi-structured interviews.	61 residents with a mean MMSE score of 12.6.	-Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss -Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships
Casey et al. (2016) Australia	To describe nursing home residents' perceptions of their friendship networks using social network analysis, and to contribute to theory regarding resident friendship schema, network structure, and connections between network ties and social support.	Mixed methods	Dementia Specific Unit in one nursing home.	Social network analysis (SNA) methods: (i) resident self-report structured interviews with open questions where researchers also showed participants photos of co-residents to identify friends; (ii) self-reports on nonfamily objective social support using the Lubben Social Network Scale-6 (LSNS-6) Friendships Sub-scale; (iii) subjective reports of social isolation measured with The Friendship Scale.	30 residents with mild to severe dementia, according to the Global Deterioration Scale (GDS).	-Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss -Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships
Chung et al. (2016) USA	To explore dementia patients' experiences of a media presentation including images of nature.	Mixed methods	One long-term nursing facility.	Exploratory study with semi-structured interviews exploring participants' views on a DVD set of nature scenes.	23 participants with a diagnosis of mild-severe dementia based on the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV).	-Activities -Reminiscence
Clare et al. (2008) UK	To explore the subjective experience of life with dementia in residential care from the perspective of the person with dementia, and to understand the psychological impact of being in this situation.	Qualitative	Ten care homes, specialised for people with dementia or mixed needs.	Exploratory study with interpretative phenomenological analysis of 283 unstructured conversations between researchers and people with dementia.	Data from 71 residents with a mean MMSE of 10.54 was included in analysis.	-Activities -Reminiscence -Maintaining previous roles -Freedom and choice -Meaningful relationships -Support with grief and loss -Activities -Maintaining previous roles -Freedom and choice -Appropriate environment
Cohen-Mansfield et al. (2000) Israel	To explore the role-identity of residents with dementia, and the potential for utilising their enduring sense of self-identity for enhancing their quality of life.	Quantitative	Two nursing homes.	Exploratory study using close-ended questionnaires.	26 residents with various types of dementia at the mild-severe stage.	-Activities -Maintaining previous roles -Freedom and choice -Appropriate environment
Conradsson et al. (2010) Sweden	To evaluate the effects of a high-intensity functional exercise programme on depressive	Quantitative	Nine residential care facilities, four of which	Cluster-randomised controlled trial where participants either received the intervention in the form of a	100 residents with mild-moderate dementia according to the MMSE.	-Activities

(continued)

Table 2. Continued.

Author/Year/Country	Aim	Research type	Number & type of facility	Study design & methods	Study population	Themes
Cooke et al. (2010) Australia	symptoms and psychological wellbeing among older people dependent in activities of daily living and living in residential care facilities.	Quantitative	Two aged care facilities providing high and low care.	high-intensity functional weight-bearing exercise programme (n = 47), or a programme of activities performed whilst sitting in the control group (n = 53). Outcome measures: depressive symptoms, measured by the Geriatric Depression Scale 15-item version (GDS-15), and psychological wellbeing, measured by the Philadelphia Geriatric Center Morale Scale (PGCMS). Randomised controlled cross-over trial. Participants received the live music intervention (n = 23; at cross-over n = 16) or attended a reading group if in the control group (n = 21; at cross-over n = 15). Outcome measures: self-reported quality of life, measured by the Dementia Quality of Life (DQOL) questionnaire, and depression, measured with the Geriatric Depression Scale (GDS).	47 residents with a diagnosis of early-mid stage dementia or probable dementia according to the MMSE or DSM-IV, and a documented history of agitation or aggression within the last month. Mean MMSE score was 16.51.	-Activities
Cooney et al. (2014) Ireland	To understand people with dementia, staff and relatives' perspectives on reminiscence, its impact on their lives and experience of care and care giving.	Qualitative	Four long-term care settings.	Grounded theory study using unstructured conversations with residents.	Eleven residents with a mean MMSE score of 14.9.	-Reminiscence -Meaningful relationships
De Boer et al. (2017) Netherlands	To compare quality of care, quality of life and related outcomes in green care farms, regular small-scale living facilities and traditional nursing homes for people with dementia.	Quantitative	Three types of nursing homes: green care farms (n = 5); regular small-scale living facilities (n = 9); traditional nursing homes (n = 4). One long-term care dementia residence.	Cross-sectional design with data collected on self-reported quality of life using the Quality of Life-Alzheimer's Disease Scale (QoL-AD).	115 residents with a formal diagnosis of dementia and a mean S-MMSE score of 8.4.	-Appropriate environment
Doyle et al. (2015) USA	To explore the notion of generativity among elders with dementia living in long-term care settings	Qualitative	Four wards in three nursing homes.	Ethnographic study using formal interviews with residents. Exploratory study with interviews with residents.	Three residents: -Daniel-diagnosis of Lewy Bodies dementia, MMSE 11. -Samantha-diagnosis of moderate, non-specific dementia, MMSE 9. -Donna-diagnosis of severe early onset dementia, MMSE 18. 37 residents with mild to moderately severe dementia, according to the GDS.	-Maintaining previous roles -Meaningful relationships -Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss
Droes et al. (2006) Netherlands	To explore to what degree does what people with dementia in nursing homes and meeting centres consider important to their quality of life correspond with how their carers feel about what is important for the quality	Qualitative	Four wards in three nursing homes.	Exploratory study with interviews with residents.	37 residents with mild to moderately severe dementia, according to the GDS.	-Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss

(continued)

Table 2. Continued.

Author/Year/Country	Aim	Research type	Number & type of facility	Study design & methods	Study population	Themes
George and Houser (2014) USA	of life of the people with dementia they take care of. To explore the subjective experience of residents and staff of a skilled-nursing dementia special care unit who participated in TimeSlips.	Qualitative	One skilled-nursing dementia special care unit in a continuing care retirement community.	Exploratory study with semi-structured interviews with residents during the final week of the TimeSlips intervention.	Ten residents with a diagnosis of dementia at the moderate-severe stage and a mean MMSE score of 6.1.	-Activities
Godwin and Poland (2015) UK	To examine the self-experience of people with moderate to advanced dementia.	Qualitative	Three long-term residential or nursing care homes.	Interpretative phenomenological analysis approach using semi-structured empathetic interviews.	Ten residents with varying diagnoses of dementia, all at moderate to early stages of advanced dementia.	-Activities -Maintaining previous roles -Support with grief & loss
Goodman et al. (2013) UK	To explore how older people with dementia discuss their priorities and preferences for end-of-life care.	Qualitative	Six care homes.	Exploratory study using semi-structured, conversational interviews.	18 residents with dementia, as recorded in their care notes.	-Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss -End-of-life care
Graneheim and Jansson (2006) Sweden	To illuminate the meaning of living with dementia and disturbing behaviour, as narrated by three persons admitted to a residential home.	Qualitative	Residential home for people with dementia and complications that mainly take the form of disturbing behaviour.	Interpretative hermeneutic and phenomenological analysis approach with conversational interviews with each resident.	Three residents: -John-diagnosis of vascular dementia, MMSE 20. -Annie-diagnosis of Alzheimer's disease, MMSE 16. -Philip-diagnosis of Alzheimer's disease, MMSE 20. All three also experienced disturbing behaviour.	-Activities -Maintaining previous roles -Freedom and choice -Meaningful relationships -Support with grief and loss
Guzmán-García et al. (2013) UK	To investigate the effect of introducing a dance-based psychomotor intervention using Danzón (Latin ballroom) for people with dementia in care homes.	Qualitative	Two care homes.	Pilot study using grounded theory methodology. Interviews were carried out twice with residents after six weeks of attending the Danzón Intervention	Seven residents diagnosed with varying types of mild-severe dementia, with a mean MMSE score of 11.71	-Activities
Harmer and Orrell (2008) UK	To explore concepts of meaningful activity, as defined by older people with dementia living in care homes, staff and family carers.	Qualitative	Two homes providing traditional residential care and one home providing dementia residential care.	Exploratory study with three focus groups with participants with dementia using pictures of different activities to facilitate discussion.	17 individuals with a mild-severe diagnosis of dementia as defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM), and with a mean MMSE score of 12.	-Activities -Maintaining previous roles -Reminiscence -Meaningful relationships
Haslam et al. (2010) UK	To investigate the impact of group reminiscence (GR) and individual reminiscence (IR) activities on older adults living in care settings.	Quantitative	Specialised units for people with dementia in 9 residential care homes.	Randomised controlled trial where participants were assigned to one of three interventions: group reminiscence, individual reminiscence, or a group control activity (skittles). Outcome measures: Hospital Anxiety and Depression scale (HADS), Quality of Life in Alzheimer's Disease scale (QoL-AD), Life Improvement scale, and Quality of Life Change scale.	40 residents from specialised units with a general medical diagnosis of dementia.	-Reminiscence
Heggestad et al. (2013) Norway	To investigate how life in Norwegian nursing homes may affect	Qualitative	A special care unit for people with dementia		Five residents with a diagnosis of dementia at various stages.	-Freedom and choice -Appropriate environment (continued)

Table 2. Continued.

Author/Year/Country	Aim	Research type	Number & type of facility	Study design & methods	Study population	Themes
Jonas-Simpson and Mitchell (2005) Canada	experiences of dignity among persons with dementia. To give voice to expressions of quality of life for persons who live with dementia and who reside in long-term care, primarily on locked cognitive support units.	Qualitative	in one nursing home, and a general unit in a second nursing home. Locked cognitive support units and one physical support unit in a long-term care facility.	Interpretative hermeneutical and phenomenological approach using formal interviews. Descriptive study using semi-structured interviews conducted alongside a music or art therapist. Music and art was offered to participants as mediums to further describe their quality of life.	16 participants from the locked support units, and one participant from the physical support unit, all diagnosed with varying types of dementia with mild-severe impairment.	-Meaningful relationships -Support with grief and loss -Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss -Activities -Reminiscence -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss
Kaufmann and Engel (2016) Germany	To examine Tom Kitwood's model of psychological needs and well-being in dementia based on the self-report of individuals with moderate or severe dementia, and to differentiate and elaborate this model in the light of the empirical qualitative data.	Qualitative	Long-term care unit for people with moderate or severe dementia.	Deductive-inductive design using semi-structured interviews with questions based on Tom Kitwood's model of needs.	19 residents with mild-severe dementia and an average MMSE score of 9.41.	-Activities -Reminiscence -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss
Milte et al. (2016) Australia	To describe the meaning of quality residential care from the perspective of people with cognitive impairment and their family members.	Qualitative	3 residential aged care facilities.	Descriptive study with in-depth, semi-structured interviews.	12 residents with mild-severe cognitive impairment. The mean number of errors on the Short Portable Mental Status Questionnaire (SPMSQ) for participants was 7.	-Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships
Mjørud et al. (2017) Norway	To investigate the personal experience of living in a nursing home over time from the perspective of the person with dementia and to learn what makes life better or worse in the nursing home.	Qualitative	Two special care units for people with dementia and 2 regular units across 3 nursing homes.	Interpretative phenomenological hermeneutic approach with unstructured interviews.	12 residents with mild to severe dementia according to the clinical dementia rating scale (CDR). Participants was 7.	-Activities -Reminiscence -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss -End-of-life care
Monroe et al. (2014) USA	To determine if a diagnosis of dementia influenced pain self-reports and pain medication use in a group of verbally communicative nursing home residents.	Quantitative	Long-stay beds in one nursing home.	Comparative study using the seven question structured pain interview derived from the Geriatric Pain Measure comparing outcomes in residents with and without dementia.	45 participants completed the interview. 19 with a diagnosis of mild-moderate dementia, and 26 without dementia. All participants had a minimum of one pain-related diagnosis.	-Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss -End-of-life care
Moyle et al. (2011) Australia	To understand the factors that influence quality of life for people living with dementia in long-term care, including an understanding of how they perceived they were valued.	Qualitative	Four long-term care facilities providing low and high care, as well as dementia-specific care.	Pragmatic, exploratory approach with semi-structured interviews.	32 residents with a dementia diagnosis according to the MMSE and DSM.	-Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships
Moyle et al. (2015) Australia	To describe quality of life as reported by people living with dementia in long-term care in terms of influencers of, as well as the strategies needed, to improve quality of life.	Qualitative	Four aged care facilities.	Descriptive, exploratory design with a case study approach and structured interviews.	12 residents with a diagnosis of varying types of dementia, with MMSE scores in the range of 16-24 indicating mild to moderate dementia.	-Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss -End-of-life-care
Mulqueen and Coffey (2017) Ireland	To explore the preferences of residents with dementia for their end of life care, and nurses' perceptions of these preferences.	Mixed methods	One residential care facility.	Nominal group technique with group discussion and ranking of preferences.	Nominal group of six residents with mild dementia and an MMSE score of 18 or over.	-Meaningful relationships -Support with grief and loss -End-of-life-care

(continued)

Table 2. Continued.

Author/Year/Country	Aim	Research type	Number & type of facility	Study design & methods	Study population	Themes
Murphy et al. (2005) UK	To obtain the views of frail older people with communication impairments using an innovative interviewing methods, Talking Mats™.	Qualitative	Care homes (number unknown)	Exploratory study with semi-structured interviews using the Talking Mats visual framework.	Seven older people with communication difficulties and a diagnosis of dementia.	-Activities -Reminiscence -Freedom and choice -Appropriate environment -Meaningful relationships -Activities -Freedom and choice
Olsen et al. (2015) Norway	To explore the positive and negative experiences of a high-intensity functional exercise program in nursing home residents with dementia, from the perspective of the residents.	Qualitative	One nursing home.	Exploratory study with semi-structured interviews.	Eight residents with mild to moderate dementia, according to the CDR.	-Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships
Popham and Orrell (2012) UK	To determine to what extent the care home environment met the requirements of residents with dementia in the context of the views of managers, family carers and staff, and a standard environmental assessment.	Mixed methods	One large care home with residential, nursing and specialised dementia care; three nursing homes, two of which had specialised dementia beds; and one residential home with no specialised provision.	Exploratory, evaluative study with five focus groups with residents using open-ended questions.	Twenty-five participants with a diagnosis of dementia at the mild-severe stage and a mean MMSE score of 8.8.	-Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships
Powers and Watson (2011) USA	To obtain an understanding of residents' spiritual orientations, practices and preferences; to examine family member and NH staff perceptions of spiritual nurturance and support for residents; and to analyse institutional resources for and approaches to assessing and meeting residents' spiritual needs.	Mixed methods	Three nursing homes providing care for people of all religious faiths, but with mainly the following faith-based affiliations: Catholic, Jewish, and Protestant.	Concurrent nested strategy in which the predominant method was qualitative semi-structured interviews.	47 residents with mild-severe dementia according to the Cognitive Performance Scale (CPS).	-Activities -Support with grief and loss
Serrani Azcurra (2012) Argentina	To investigate whether a specific reminiscence programme is associated with higher levels of quality of life in nursing home residents with dementia.	Quantitative	Two nursing homes.	Single-blinded, parallel-groups randomised controlled trial where participants in the intervention group received the reminiscence therapy; an active control group where participants received counselling and informal social contact; and a passive control group where participants received unstructured social contact. Outcome measures: Quality of life measured by the Self Reported Quality of Life Scale (SRQoL).	135 residents diagnosed with Alzheimer's Disease according to the DSM-IV, with a mean MMSE score of 13.9.	-Reminiscence
Tak et al. (2015) USA	To describe types of current activity involvement and barriers to activities reported by nursing home residents with dementia.	Qualitative	Nursing homes (number unknown)	Ethnographic study with semi-structured interviews.	37 residents with a range of mild-moderate dementia and a mean MMSE score of 16.4.	-Activities -Maintaining previous roles -Appropriate environment -Meaningful relationships -Support with grief and loss
Tan et al. (2013) Australia	To explore the perceptions and experiences of aged care residents with mild dementia on the deaths of co-residents.	Qualitative	Three aged care facilities, two of which providing low care, and one	Exploratory study with two rounds of semi-structured interviews.	23 residents with mild dementia according to the Psychogeriatric Assessment Scale (PAS) and the	-Activities -Maintaining previous roles -Appropriate environment -Meaningful relationships -Support with grief and loss

(continued)

Table 2. Continued.

Author/Year/Country	Aim	Research type	Number & type of facility	Study design & methods	Study population	Themes
Thein et al. (2011) UK	To explore the personal experience of people with dementia of moving into a care home.	Qualitative	providing both high and low care. Ordinary or specialist dementia residential and nursing homes (number unknown).	Exploratory study with semi-structured interviews with participants before and five weeks after their move into the care home.	CDR, and with a mean MMSE score of 22. 18 individuals with a diagnosis of dementia in the moderate stages.	-Freedom and choice -Meaningful relationships -Support with grief and loss
Travers et al. (2013) Australia	To conduct a randomised controlled trial of dog-assisted therapy for people with dementia living in aged care facilities using validated instruments of mood, quality of life, and psychosocial functioning.	Quantitative	Three residential aged care facilities, all caring for residents with high and low care needs.	A multicenter randomised controlled trial where participants were randomly assigned to either the dog-assisted therapy group (n = 27) or human-therapist (control) group (n = 28). Outcome measures: Quality of Life-Alzheimer's Disease questionnaire (QOL-AD); the Medical Outcomes Study 36-Item Short Form Health Survey (SF-36); and the Geriatric Depression Scale Short Form (GDS-SF).	55 residents with a diagnosis of mild-moderate dementia, according to the Modified Mini-Mental State Exam (MSE-3MS), with a mean MSE-3MS score of 58.1 in the dog-assisted therapy group, and 59.8 in the control group.	-Activities
Van Zadelhoff et al. (2011) Netherlands	To investigate experiences of residents, their family caregivers and nursing staff in group living homes for older people with dementia and their perception of the care process.	Qualitative	Two group living units located on the grounds of a large-scale nursing home.	Naturalistic inquiry with semi-structured, in-depth interviews.	Five residents with a diagnosis of dementia ranging from moderate to severe and a mean MMSE score of 10.	-Maintaining previous roles -Appropriate environment
Wiersma and Pedlar (2008) Canada	To examine the experiences of older adults with dementia while they were in long-term care and while they were in a summer-camp setting.	Qualitative	Locked cognitive support units in one long-term care facility and one summer camp setting with cabins for 4-6 residents and 2-3 staff.	Exploratory study with conversational interviews at three different phases: (i) during the 3 months prior to going to camp; (ii) during the 4 days of camp; (iii) during the month after the camp.	Ten residents with dementia, mostly World War II veterans, seven of which participated in all three phases, and three of which participated in phase one only.	-Freedom and choice -Appropriate environment -Meaningful relationships

Table 3. Specific experiences and needs according to each theme.

Analytical Theme	Experiences Sub-themes	Needs Sub-themes
Activities	Boredom & monotony Isolation & loneliness Belonging Wellbeing Mobility & independence Quality of life Exclusion	Unstructured activities e.g. crosswords, playing instruments, jigsaws, reading and knitting. Facilitated activities in group settings e.g. music sessions, bingo, dancing, group storytelling, pet therapy, reading group, regular exercise classes. Opportunities to attend religious ceremonies. Activities tailored to individual preferences and abilities.
Maintaining previous roles	Boredom & monotony Loss of identity Comfort Coping Feeling appreciated Purpose	Opportunity to contribute to domestic tasks around the home. Opportunity to engage in altruistic activities within the home and in the wider society. Involvement in sharing ideas and knowledge.
Reminiscence	Boredom & monotony Quality of life Wellbeing Improved staff relationships Comfort Hope Empowerment Loss of identity	Opportunities to share memories with others through photographs or newspaper clippings. Reminiscence sessions involving staff. Watching clips of familiar places.
Freedom & choice	Restriction Quality of life Frustration Disempowerment Lack of choice Loss of identity	Listening to or playing music. Going home and attending family events. Support and freedom to access the garden. Control over daily routines. Choice over what to eat. Choice over which room to sit in. Facilities to prepare a drink/snack when hungry. Respect for individual preferences.
Appropriate environment	Isolation & loneliness Mobility & independence Confusion Ownership Privacy	Living near family or in a familiar area. Good relationships with staff. Internal environment that does not increase risk of falls. Internal environment that is not confusing. Access to personal space. Key to room. Family photos in room. Opportunity to bring larger familiar items from home. Spaces encouraging interaction. Accessible external spaces & gardens.
Meaningful relationships	Comfort Isolation & loneliness Exclusion Restriction Frustration Abuse Loss of identity Anxiety Confusion	Routines conducive to forming friendships. Positive relationships with staff. Spending time with family. Assistance to maintain relationships outside of the home. Reassurance of family visits. Staff acceptance of sexuality & intimacy.
Support with grief & loss	Coping Loss of identity Confusion Fear Loss of hope Isolation & loneliness Loss of purpose Mobility & independence Comfort	Informed about the death of a fellow resident. Opportunity to attend funerals. Afternoon tea in memory of residents. Pre-move visit. Known person in the home to talk to. Religious or spiritual support.
End-of-life care	Comfort Pain	Peaceful surroundings. Appropriate pain relief. Presence of family. Surrounded by familiar possessions. Effective communication. Familiar staff providing care. Appropriate environment according to wishes (hospital/home). Religious or spiritual support.

activities as a way of socialising with others (Tak, Kedia, Tongumpun, & Hong, 2015).

Preferred facilitated activities occurring in group settings included: music sessions (Mjørud, Engedal, Røsvik, & Kirkevold, 2017), dancing (Guzmán-García, Mukaetova-Ladinska, & James, 2013; Tak et al., 2015), bingo (Cahill & Diaz-Ponce, 2011); pet therapy (Travers, Perkins, Rand, Bartlett, & Morton, 2013), and group storytelling (George & Houser, 2014). A reading group was shown to increase

feelings of belonging (Cooke, Moyle, Shum, Harrison, & Murfield, 2010), and residents experienced improvements in wellbeing (Conradsson, Littbrand, Lindelhöf, Gustafson, & Rosendahl, 2010) and increased mobility, independence and self-esteem from regular exercise classes (Olsen, Wiken Telenius, Engedal, & Bergland, 2015). Practicing of religion was also linked with improved quality of life (Dröes et al., 2006; Powers & Watson, 2011), with residents wishing to attend church services (Mjørud et al., 2017; Moyle,

Fetherstonhaugh, Greben, Beattie, & AusQoL Group, 2015), and take part in 'life-long religious practices' within the home (Tak et al., 2015).

Activities should also be tailored to the individual (Moyle et al., 2015). Specific barriers to partaking in activities included deterioration in hearing and sight, arthritis, and lack of staff, transport and space in the home (Moyle et al., 2015; Tak et al., 2015). For those residents at a more advanced stage of dementia, engaging in 'simple pleasures', such as having an ice cream and a chat were described as enjoyable activities (Cahill & Diaz-Ponce, 2011).

Maintaining previous roles

A number of participants from various studies described feeling sad about the loss of roles, as portrayed by the following example: 'I used to be a famous teacher, a psychologist, now I am nothing' (Cohen-Mansfield, Golander, & Arnheim, 2000). Participants described feeling of 'little value' (Moyle et al., 2011), and many still had a desire to contribute to the home or society (Godwin & Poland, 2015; Jonas-Simpson & Mitchell, 2005). This could be achieved through engagement in domestic tasks such as tidying their rooms (Kaufmann & Engel, 2016). However, some participants were happy to be relieved of the responsibility of domestic tasks (Godwin & Poland, 2015; Van Zadelhoff, Verbeek, Widdershoven, Van Rossum, & Abma, 2011).

Altruism was also important for some residents, providing occupation, as well as comfort (Doyle, Rubinstein, & de Medeiros, 2015; Kaufmann & Engel, 2016). This may take place within the home, as explained by one participant, who said the best thing about her day was 'chatting with other people, hearing their complaints and their worries and trying to give them a little advice' (Moyle et al., 2015). This was echoed by other participants who said they cope better with their own situation by helping others (Clare et al., 2008). Residents also feel appreciated when staff asked for their knowledge about a subject (Graneheim & Jansson, 2006). Finally, one participant reported how being involved in altruistic activities benefitting the wider society, in this case crocheting baby clothes for hospitals, gave her 'purpose in life' (Tak et al., 2015).

Reminiscence

Reminiscence was described as a meaningful activity (Harmer & Orrell, 2008) and led to a sustained improvement in quality of life amongst participants in one trial (Serrani Azcurra, 2012), although these results were not replicated in a trial investigating reminiscence therapy and wellbeing (Haslam et al., 2010). Residents enjoy reminiscence sessions that involve staff, as they feel they are taking more of an interest in them, which in one study led to increased interaction during activities of daily living (Cooney et al., 2014). Residents also gain consolation from reflecting on things they have done in the past, which provides hope that life may be like that again (Kaufmann & Engel, 2016). Furthermore, reminiscence provides a means to reflect on things they can still do (Clare et al., 2008).

Tools for reminiscence included 'photographs, recordings and newspaper clippings' and subsequent group discussion (Serrani Azcurra, 2012). Films showing familiar

places were enjoyed by some participants (Chung, Choi, & Kim, 2016). However, such reminders could bring back both happy and sad memories (Mjørud et al., 2017). In particular, photographs may remind individuals of what they have lost (Murphy et al., 2005).

Freedom and choice

As with boredom, an experience of a restriction was common. Residents described staff as 'controlling' (Moyle et al., 2011), and said that their quality of life would improve if they could do more of what they pleased (Dröes et al., 2006). When asked what they would like to do but were not allowed to, participants answered: music, going home, and attending family events (Cohen-Mansfield et al., 2000). Lack of freedom to leave the home was noted as a source of frustration across a number of articles (Cahill & Diaz-Ponce, 2011; Goodman, Amador, Elmore, Machen, & Mathie, 2013; Milte et al., 2016; Popham & Orrell, 2012), and being prevented from simply going for a walk in the garden was associated with lower ratings of quality of life (Dröes et al., 2006). World War II veterans living in locked cognitive support units in one nursing home described them as prison camps (Wiersma & Pedlar, 2008); an experience echoed by a number of others residing in general nursing homes (Moyle et al., 2015; Olsen et al., 2015). However, in a home where the doors were not locked, one resident still felt restricted because staff did not have time to assist him to go outside (Heggestad, Nortvedt, & Slettebø, 2013).

Several participants experienced a sense of disempowerment (Moyle et al., 2011), and a lack of choice (Aggarwal et al., 2003) in other areas of their lives. Residents stated that they should have control over their daily routines and not have to fit in with 'the status quo' (Milde et al., 2016). This included choosing: what to eat (Aggarwal et al., 2003); whether to have a bath or shower (Murphy et al., 2005); which room to sit in (Popham & Orrell, 2012); and what time to go to bed (Jonas-Simpson & Mitchell, 2005). Residents would also like to prepare a drink or snack when they are hungry (Heggestad, Nortvedt, & Slettebø, 2013), with one participant suggesting that there should be a small kitchen in the home for their use (Popham & Orrell, 2012). Participants also wished to be respected as a person with individual preferences (Milde et al., 2016). For instance, in one study, although staff addressed almost all residents by their first name, only 70% of participants who expressed an opinion were happy with this (Cohen-Mansfield et al., 2000).

Appropriate environment

There were varied reports as to whether nursing homes were a homely environment. Reasons for feeling 'at home' included living near family or near where they used to live, and good relationships with staff. Those with mild dementia were more inclined to consider a nursing home homely compared to those at a more advanced stage (Cahill & Diaz-Ponce, 2011). Participants discussed several needs in relation to their built environment, including the need to navigate areas without risk of falls (Dröes et al., 2006) or confusion, particularly for those at advanced stages of dementia (Bartlett, 2007). Participants also appreciated

access to 'personal space' (Popham & Orrell, 2012), which promotes a sense of ownership (Moyle et al., 2015), and fulfils the need for time alone (Kaufmann & Engel, 2016). However, some residents lacked privacy and disliked that strangers could enter without permission (Dröes et al., 2006). As a result, some said they should be provided with a key (Milte et al., 2016; Heggstad, Nortvedt, & Slettebø, 2013). Within their rooms, family photos were important for combatting loneliness (Mjørud et al., 2017). When asked about other objects they would have liked to bring, participants mentioned: furniture, carpet, and plants (Cohen-Mansfield et al., 2000).

The type of home may also play an important role in meeting individuals' needs, such as group living homes, which were found to encourage interaction (Van Zadelhoff et al., 2011). As regards to the outdoor environment, participants wished for accessible external spaces (Moyle et al., 2011) and gardens (Bartlett, 2007), which were found to be important in maintaining independence and ownership (Moyle et al., 2015). Green care farms were also explored. However, no statistically different quality of life scores were found when green care farms were compared with traditional nursing homes or small-scale living facilities (De Boer, Hamers, Zwakhalen, Tan, & Verbeek, 2017).

Meaningful relationships

A number of participants spoke about the importance of relationships, and gaining comfort through human contact (Kaufmann & Engel, 2016). Fear of loneliness was discussed, specifically amongst those residents with advanced dementia (Cahill & Diaz-Ponce, 2011; Mjørud et al., 2017). In one study, a male participant highlighted how as a man it was harder to make friends, partly because there were a lot more women in the home (Moyle et al., 2011). Furthermore, in one dementia specific unit, no residents reported having a friendship within their unit, compared with non-dementia specific units (Casey, Low, Jeon, & Brodaty, 2016). Participants frequently described frustrations with fellow residents, disliking how they shout or hurt others (Bartlett, 2007; Murphy et al., 2005; Wiersma & Pedlar, 2008). Some residents felt that routines kept in the home were not conducive to forming friendships, as most went to bed early (Moyle et al., 2011).

As regards to relationships with staff, Cahill and Diaz-Ponce (2011) found that they are especially important for those with mild-moderate dementia. Some residents described positive relationships with staff (Mjørud et al., 2017). However, others described their relationships as 'economic' (Bartlett, 2007), and said that staff could be difficult to find, manhandled them, and treated them like patients (Goodman et al., 2013; Milte et al., 2016). Relationships with family also continue to be significant (Dröes et al., 2006; Harmer & Orrell, 2008; Tak et al., 2015). Spending time with family provided opportunities for 'meaningful conversations', as well as reminding individuals about their existence outside of the care setting (Moyle et al., 2011). Losing contact with family was mentioned as a 'key source of anxiety' for residents, particularly when first moving into the home, and they may require staff to assist them to maintain contact (Milte et al., 2016), including through the use of Skype (Moyle et al., 2015). Participants felt that their families were not visiting them

enough, which was particularly common amongst those at an advanced stage of dementia, who often wrongly believed family had not visited them when they had (Cahill & Diaz-Ponce, 2011).

Finally, a small number of participants talked about how they missed intimacy (Bauer et al., 2013; Dröes et al., 2006). In one study, nursing homes were not considered to be conducive to expressions of sexuality, with residents fearing negative reactions from staff and gossip. Residents found talking to staff about sexual needs too personal, and viewed staff as 'strangers' (Bauer et al., 2013).

Support with grief and loss

Individuals residing in a nursing home are likely to experience the loss of fellow residents. However, Tan, O'Connor, Howard, Workman, and O'Connor (2013) found that 70% of residents with mild dementia in their study were not concerned about being around people dying. Instead, they were unhappy about not being told about the death of a resident, and felt that all residents should be informed together. As regards to funerals, 40% of participants in this study indicated that they would have liked to have attended a funeral of a resident they were close to. Furthermore, participants appreciated the idea of an afternoon tea in memory of residents who had died.

Residents may also experience loss in regards to their former lives and identities (Cahill & Diaz-Ponce, 2011; Mjørud et al., 2017). A number of participants expressed confusion and fear about why they were in the nursing home (Clare et al., 2008). Others wished to go home, with one participant describing how she had taken to walking down corridors so she would become strong enough to live with her daughter (Goodman et al., 2013). Other residents disliked living in the home so much that they felt they had no future, with three residents in one study saying that they wished for their lives to end. Notably, two of these residents said that they had not been able to talk this way with anyone except the researcher (Goodman et al., 2013). However, Thein, D'Souza, and Sheehan (2011) found that most of the 18 participants they interviewed after their move liked their new homes, which was in part linked with having undertaken a pre-move visit, as well as having a 'known person in the home'.

Participants also described a 'loss of function', leading to a 'loss of purpose'. For instance, a decline in physical independence led one resident to express: 'I can't help anybody else in here, what's the point of it all' (Goodman et al., 2013). Support for residents may be provided in the form of a pastor (Powers & Watson, 2011) or other 'spiritual rituals' (Kaufmann & Engel, 2016), which were identified as providing comfort during difficult times.

End-of-life care

Needs at the end of life were explored in two studies. Mulqueen and Coffey (2017) found that, amongst six participants with mild dementia, comfort and peace were ranked most important at this stage. Participants wished to be 'pain free, worry free' at the end of their lives, with 'quiet and peaceful surroundings'. This included not being moved to hospital. Presence of family was ranked second in importance, followed by 'my own things', where

participants said being in their own room surrounded by familiar items, such as family photos, would provide comfort. Fourthly, residents highlighted the need for effective communication, hoping that staff would not withdraw from them. In particular, residents would like familiar staff to care for them.

Goodman et al. (2013) qualitatively explored the preferences of 18 residents with dementia for end-of-life care. There were mixed feelings regarding place of death, with one resident expressing preference for the nursing home. However, another said that she would prefer to go to hospital as she felt that there people 'especially take an interest in your feelings'. As regards to religious needs, one resident said he would like to see a priest. Another participant emphasised that she would prefer to talk to a particular staff member about any concerns she may have, more so than her children, who she worried about upsetting.

Residents with dementia may also have varying needs as regards to pain relief. Although it was not specified whether participants were receiving end-of-life care, Monroe et al. (2014) found that nursing home residents with dementia reported more intense levels of pain than those without dementia. However, participants were less likely to tell staff about pain, and less likely to report that nursing home staff asked about their pain.

Discussion

This scoping review provides new evidence concerning the needs and experiences of people with dementia in nursing homes, a previously underrepresented population in research. One of the most commonly occurring needs in the literature was the need for activities. However, participants emphasised the need for activities that are tailored to their abilities and interests. This is a challenge for nursing homes where often 'personal preferences are constrained by the needs of others' (Bruce & Schweitzer, 2008). Obtaining a life history when an individual first moves into the home has been suggested to ensure all aspects of care are personalised. This should be followed by a thoughtful approach to replicating activities, in a way that evokes 'the "feel" of an activity enjoyed in the past, without engendering any anxiety about performance' (Bruce & Schweitzer, 2008).

One particular activity explored in the literature was reminiscence. There was conflicting evidence regarding the impact of this activity on quality of life and wellbeing. Schweitzer and Bruce (2008) propose a 'creative communication-based approach' to reminiscence, underpinned by a person-centred philosophy. For instance, this approach involves listening to individuals tell their stories in a respectful manner, and avoiding questioning information that may seem factually incorrect.

The need for freedom was another common theme amongst participants in this review. In particular, low quality of life ratings were linked with a lack of access to the outdoor environment. Although restricting access to the outdoor environment reduces risk from a staff perspective, it limits activities and prevents the 'possibility of building relationships which might enhance the person's life' (Fossey, 2008). Furthermore, access to the outdoor environment has been shown to have a number of health benefits

for people with dementia, including reducing neuropsychiatric symptoms (Heyn, Abreu, & Ottenbacher, 2004), restoring circadian rhythm, and increasing levels of vitamin D (Pollock & McMair, 2012), linked with a reduction in falls (Bischoff-Ferrari et al., 2009). One potential solution to this dilemma is to introduce 'dementia-friendly outdoor environments' (Mitchell & Burton, 2006). Preliminary recommendations for which include environments that are 'familiar, legible, distinctive, accessible, comfortable and safe' (Mitchell & Burton, 2006). For example, flat paving and regular seating intervals.

Under the theme of 'meaningful relationships', frustrations with fellow residents, and staff were described, as well as a loss of contact with communities and families. These findings may suggest the need for a movement towards 'relationship-centred care', as explored by Nolan, Keady, and Aveyard (2001), who argue that relationships play an important role in determining quality of life, in particular by maintaining 'identity and personhood' (Davies & Nolan, 2008). Participants also described feeling unable to talk to staff about sexual needs. In their study exploring the attitudes of nursing home staff, Ward, Vass, Aggarwal, Garfield, and Cybyk (2005) found that staff commonly avoid this topic during the assessment process as they find it 'problematic'. The authors suggest that staff should be trained in how to broach this topic, and develop an understanding of the way in which sexuality forms an important part of personhood.

As regards to end-of-life care, only two studies in this review specifically addressed this area of need, and in both studies, there were mixed opinions amongst participants about the preferred place of death. This stresses the requirement for future wishes to be discussed, which may take the form of advance care planning (ACP), a process where patients determine their preferences for future care (Robinson et al., 2012). ACP has been shown to reduce inappropriate hospitalisations for people with dementia. However, the ACP process should be commenced in the early stages of dementia before loss of capacity (Robinson et al., 2012).

Implications

This study has shown that people with dementia in nursing homes, including those at a more advanced stage, are able to voice their experiences and needs, which has implications for education, practice and policy in the domain of dementia care planning, provision and evaluation in this setting. Firstly, wherever possible, nursing homes should involve people with dementia in the planning of their care at all stages, including for end of life. Furthermore, the themes and sub-themes presented in this paper have provided a possible evidence-based framework to guide nursing homes in the process of person-centred assessment and care planning for people with dementia. Thirdly, people with dementia should be given the opportunity to contribute to the evaluation of their care.

Future research

This study has also provided a means to identify gaps in the literature and future research priorities. More research

addressing the needs of this population in relation to reminiscence, sexuality and intimacy, and end-of-life care is required. Furthermore, only one study specifically exploring the spiritual needs of people with dementia was identified. Spiritual needs have been found to be neglected in research, despite the role that spirituality has been shown to play in providing a source of comfort for people with dementia, and the way in which spiritual needs determine a range of other needs, such as end-of-life care (Higgins, 2013).

Secondly, due to the broad nature of dementia, needs of individuals according to various types, as well as stages of the condition should be explored. Finally, as regards to methods used in the studies, observations and proxy accounts were commonly used to complement self-reports. Although it has been said that triangulation increases confidence in drawing conclusions from data in dementia research (Black & Rabins, 2007), the researcher should consider that different sources of data may actually introduce 'different perspectives' (Nygård, 2006). Table 2 provides a brief description of methods and additional tools used to collect data. However, a review exploring methods used to elicit the experiences and needs of people with dementia in more detail could provide a valuable source of information for researchers developing their own studies in this area.

Limitations

Only two databases were used to search for articles, hence some articles may have been missed, including grey literature. Restriction to articles in English, French and Czech may also mean that results are more representative of a European or Western perspective.

Conclusion

With rates of dementia continuing to rise, the impetus on improving care for this population is growing. Whilst the voice of people with dementia has previously been neglected in research, this review has shown that people with dementia in nursing homes are able to describe their experiences and communicate their needs. A total of eight themes were identified across the articles used in this scoping review, providing evidence that people with dementia have a wide variety of needs which, as developed by Kitwood (1997), span significantly further than physical needs alone, to include psychosocial and environmental needs. However, this review is only a starting point towards guiding evidence-based practice, and has highlighted a number of gaps in the literature. In particular, further research is required to investigate needs according to the type and stage of dementia, as well as needs in relation to reminiscence, sexuality, spirituality, and end-of-life care for people with dementia in nursing homes.

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