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The Psychosocial Needs of People With Dementia Living Alone: A Narrative Synthesis Systematic Review

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Abstract

The number of people with dementia living alone is predicted to double by 2039. People with dementia may live alone through choice and others due to life events like bereavement. There are unique challenges to living alone for people with dementia, their care partners and services supporting those individuals. The current review sought to summarise the psychosocial needs reported by people with dementia who live alone. Searches were completed accessing Academic Search Ultimate, MEDLINE, CINAHL Ultimate, APA PsycArticles and APA PsycInfo. Eligible articles explored the needs or experiences of people with dementia living alone through qualitative or mixed methods. The data was synthesized narratively, and the National Institute of Care and Health Excellence's quality appraisal checklist was used to assess all included studies. Needs were identified across all domains of Kitwood's model; love, identity, attachment, inclusion, occupation and comfort. The data revealed overlapping needs between those with dementia who live alone and those who live with others but importantly, needs that were distinct or exacerbated by living alone with dementia. Specifically, threat to personhood without others to maintain stories about identity and the management of living at home with the recognition that this would eventually end. The heterogeneity of people with dementia who live alone was highlighted and the gaps in the representation of the needs of specific groups in the research were considered such as individuals from the LGBTQ + community. Thus, the need for an intersectional and person-centred approach to future research and clinical practice was discussed.

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Background

It is estimated that in the UK around 120,000 people with dementia live alone, a number predicted to double by 2039 (Alzheimer's Society, 2019). Living alone poses a significant risk for dementia, more so than physical inactivity, hypertension, diabetes and obesity (Desai et al., 2020). People live alone for many reasons, some through choice and others because of bereavement or divorce. Many people who live alone will have support from informal caregivers, but a proportion (around 9% within one study) have no support (Eichler et al., 2016).

People with dementia have described advantages to living alone including, having one's own space, freedom and routines (Dementia Enquirers, 2021). However, research suggests that people with dementia who live alone experience poorer outcomes than those who live with a spouse or family caregiver. Individuals who live alone are less likely to receive a timely diagnosis, and more likely to experience delayed access to, and challenges in navigating social care and other support services (Aspinal et al., 2023). All too often, people with dementia who live alone only come into contact with services when at a point of crisis (Waugh, 2009). Alzheimer's Society identified the gaps in dementia care post-diagnosis between professional and voluntary services with limited access to information, care coordination and planning, and post-diagnostic interventions (Alzheimer's Society, 2022). It is perhaps unsurprising then that people who live alone with dementia are at increased risk of and experience a shorter time to transition into long-term care (Gaugler et al., 2003).

Supporting people who live alone also presents challenges for health and social care professionals in terms of balancing a person's autonomy and rights, alongside assessing safety and managing risk (Witt & Ploeg, 2016). Research highlights the importance of the relationship that professionals establish with the person with dementia (Gilmour, 2004) and the need for support to be flexible and responsive (Waugh, 2009). Providing support to people with dementia who live alone can require professionals to contain a lot of anxiety (from other professionals, services and distance carers), and uncertainty alongside competing views from other professionals and relatives about what is in the best interest of the person with dementia (Gilmour et al., 2003). As a result, researchers have determined that staff providing support to individuals who live alone require highly developed abilities in ethical decision-making, judicious use of discretion, and the ability to navigate complex and uncertain situations (Waugh, 2009). Arguably this highlights the potential role of specialist dementia nursing and case management in supporting this vulnerable population. Understanding the psychosocial needs of people living alone with dementia would be of great benefit to anyone providing support to this population, and can inform and drive policy and intervention development in this field.

To the knowledge of the authors, no reviews have focused on the psychosocial needs of people with dementia who live alone. A review of the availability and effectiveness of non-pharmacological interventions for this population was published recently (Polack et al., 2025), which when read alongside the present review will offer a holistic view of the current situation for people living alone with dementia.

Aim

The aim of this review is to summarise the psychosocial needs reported by people with dementia who live alone across the illness trajectory (diagnosis to death and then bereavement support of carer).

Methods

The protocol for the review (PROSPERO ref: CRD42024517810) was co-created with an advisory board of people living alone with dementia, distance carers, specialist dementia nurses and researchers interested in this area. The need for the review and the resulting review questions arose from the advisory group and members helped to shape the methods detailed below.

Search Strategy and Study Selection

Five electronic databases were accessed, selected due to their relevance for the scope of this review; Academic Search Ultimate, MEDLINE, CINAHL Ultimate, APA PsycArticles and APA PsycInfo. The final search was performed on 15th January 2024.

The development of the search strategy was guided by published reviews relating to the needs of people with dementia and multiple health conditions and the experiences of people with learning disabilities living alone. Search terms relating to living arrangements and dementia were generated. No further categories of search terms were included to acknowledge the broad definition of 'needs'. The final search strategy was designed in collaboration with an academic librarian, and used the following:

> **Terms relating to living situation:** "home environment" OR "solitary liv*" OR "liv* alone" OR "home alone" OR "living situation" OR "living arrangement*" OR "unaccompanied" OR "without care*"
>
> **Terms Relating to Dementia**: Dementia OR Alzheimer*.

Limiters were applied to identify research available in English and that included a term relating to dementia in the title. Articles were exported to and managed using End Note Version 20. In addition, the reference lists of the included studies were screened to find studies that were not detected in the systematic searches. Forward citation searches of included articles were conducted using Google Scholar.

The research team sought guidance on the inclusion and exclusion criteria from a research advisory group which included people with dementia living alone, informal carers, clinicians and other researchers in the area. Studies were deemed eligible for the review if meeting the inclusion criteria and not violating the exclusion criteria, see Tables 1 and 2.

Each study's title and abstract were screened by the first author to determine potential eligibility. The full-text versions were obtained if it was unclear whether the study met the inclusion criteria. Two authors read all full-text articles and uncertainty regarding study eligibility was resolved through discussion between them.

Data Extraction

The first author extracted and tabulated the information from the eligible studies regarding the year of publication, year of data collection, study country, study population/ sample, study design, number of participants, age and gender of participants, inclusion criteria, phenomena of interest and key research findings. The findings of the research were then coded into different identified needs as identified by Kitwood (Kitwood, 1997) (comfort, identity, inclusion, occupation, love and attachment).

Table 1. Inclusion Criteria and Rationale for the Current Review

Inclusion criteria	Rationale
The participants in the research were people with dementia (as reported by the authors of the papers) who lived alone. Living alone, according to (Office for National Statistics, 2023), refers to a one-person household. The review was interested in people with any type of dementia. In research where clinical professionals, informal or formal carers were participants, results from people with dementia and others needed to be distinguishable	To find papers relevant to the clinical population and where the population of interest were able to share their experiences
Research where people with dementia were included with other clinical or non-clinical populations were only eligible if the study reported results specific to the participants with dementia	
The research focused on the needs and/or experiences of people with dementia living alone as identified in their findings. Needs were defined by Kitwood's person-centred care model (Kitwood, 1997) which included; love, identity, attachment, occupation, inclusion and comfort	To find papers exploring the experience of living alone with dementia or where the results section covered needs specific to this population
The research was an empirical piece of work. Studies that shared the same data set were included when separate analyses were completed within each study, resulting in unique findings	To find research that provided data relating to the needs and experiences of people with dementia living alone and to ensure the data was not duplicated in the review
The research was available in English	To find research in the language used by the research team, to ensure accessibility to the research. The team had no access to translation

Quality Assessment

The quality of studies was critiqued according to the UK National Institute for Health and Care Excellence quality appraisal checklist for qualitative studies (National Institute of Health and Care Excellence, 2012). The studies were assessed on the theoretical approach, study design, data collection, trustworthiness, analysis and ethics which were then summarised into an overall quality grade for each paper. For studies adopting a mix-method design, only the qualitative aspect of the research was included. Studies were graded into three categories of quality:

(++) all or the majority of quality assurance criteria met;
(+) some of the criteria has been fulfilled and the conclusions are unlikely to change due to the criteria that have not been met;
(−) few or none of the checklist have been fulfilled and the conclusions are likely to differ based on the methodological quality of the study.

Studies were not excluded based on their methodological quality instead, was used to contextualise the understanding the findings regarding the influence of potential methodological bias.

Table 2. Exclusion Criteria and Rationale for the Current Review

Exclusion criteria	Rationale
Literature reviews (including protocols), reflection or discussion papers and summaries from research conferences	To find primary empirical research that reported the experiences and views of people with dementia living alone
Research where the participants were not people with dementia. This includes people with other diagnoses such as mild cognitive impairment (MCI), and healthcare staff, informal or formal carers	To ensure that the data analysed was including the experiences of those with dementia living alone
Research that included mixed samples were excluded if they reported findings that were not specific to people with dementia	
Research that used case study or series designs	To find research that reflects the experiences of a group from the population of interest as opposed to individuals

Data Synthesis

A thematic synthesis was applied to the data in three stages (1) coding the text, (2) development of descriptive themes and (3) generation of analytical themes (Thomas & Harden, 2008). Inductive coding was used in stages 1 and 2 to offer interpreted codes for each line of data, subsequent data could either be used as evidence for a pre-existing code or given a new code. As similarities or differences in codes across the data were identified, they could then be organised into a hierarchy of emerging groupings and descriptive themes.

Once the first and second stages of coding were completed, deductive coding, based on Kitwood's model of needs in dementia care (Kitwood, 1997), was applied. Deductive coding allowed for the current review to apply Kitwood's model to the population of people with dementia living alone and identify evidence that strengthened, refined or expanded on theoretical knowledge (Fife & Gossner, 2024). In particular, it was identified whether the included studies found any experiences or needs specific to those with dementia living alone regarding their need for love, comfort, inclusion, occupation, attachment and/or identity

Results

Study Selection

The database search identified 1,882 records (see Figure 1). After duplicates were removed (534 records), 1,348 records remained. Each title and abstract of the 1,348 records were screed by the first author and the full texts of 138 records were considered for possible inclusion by the first and sixth authors. Of these, 16 articles were included (see Table 3). We found no additional records in the reference lists of included articles. Figure 1 presents the PRISMA flow diagram.

Sample

Table 3 presents the characteristics of the included studies. Sample sizes ranged from 6-24. Where recorded, the ages of participants ranged from 48 to 100. Participants were identified as having a

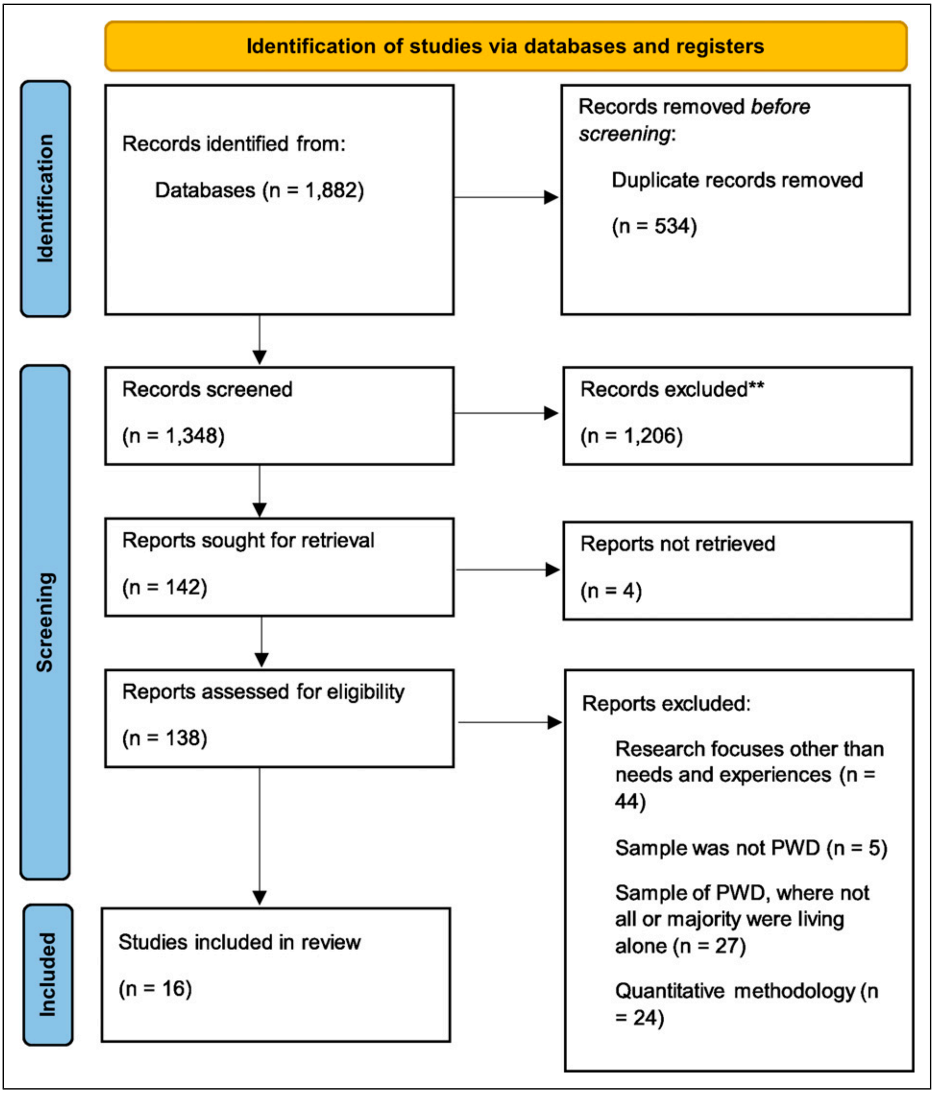

Figure 1. PRISMA Flow Diagram for the Review (Page et al., 2021)

formal diagnosis of dementia in 14 of the studies, with the remaining two stating only that the sample were people “with dementia”. In total, 13 studies were conducted in Europe, two in North America and one in Australia participants.

Study Design

Seven studies had a cross-sectional design, nine longitudinal design.

Table 3. Study Characteristics

Author, date, country	Study aim	Sample	Design	Findings	Quality score
Witt et al. (2009) Canada	To understand the meaning of living alone for older people with dementia	8 women, aged 58–87 Diagnosis of mild-moderate Alzheimer's disease or a related dementia Living in the community	Interviews (14 in total six participants interviewed twice) Interpretive phenomenology	Finding explore the spatial experience of living alone, captured as 'living on the threshold'	(++)
Witt et al. (2010) Canada	To understand the meaning of living alone from the perspective of older people with dementia	8 women, aged 58–87 Diagnosis of mild-moderate Alzheimer's disease or a related dementia Living in the community	Interviews (14 in total six participants interviewed twice) Phenomenological analysis	Findings explore the temporal meaning of living alone, including holding onto now and acknowledging the limited time remaining for living alone	(++)
Eades et al. (2018) England	Pilot an outreach programme to enable socially isolated people with dementia to engage with cultural activities in their homes	6 people (3 women, 3 men), aged 70–100 Diagnosis of mild-moderate dementia Living in the community or sheltered housing Also interviewed artists and befrienders	Interviews Thematic analysis	Themes were engagement, reflection on value of previous cultural activities, precariousness and isolation and the importance of being heard	(++)
Frazer et al. (2012) UK	To explore how women who live alone with dementia see themselves and how they cope in their day-to-day lives	8 women, aged 75–95 Diagnosis of Alzheimer's disease and/or mixed vascular dementia Living at home	Interviews Interpretive phenomenological analysis	Themes related to loss, embodiment, adapting, awareness, safety, relationships, exclusion and loneliness	(+)
Gilmour (2004) Northern Ireland	Explore the concepts of risk in the context of the social circumstances of people living alone in a rural area	10 people (2 men, 8 women), aged 74–93 "With dementia" Also interviewed family carers and professionals	Interviews	Findings highlight issues related to assessing and manging risk and both problems and opportunities related to living alone	(+)

(continued)

Table 3. (continued)

Author, date, country	Study aim	Sample	Design	Findings	Quality score
Groen-van de Ven et al. (2016) Netherlands	To provide insight into the decision trajectories of people with dementia	10 people (7 women, 3 men), aged 78–89 Diagnosis of dementia Informal caregivers and people not living alone also interviewed	Repeat interviews over 12 months Multilayered analysis approach combining different analytical methods	Four themes: managing daily life, arranging support, community living and preparing for the future	(++)
Heaton et al. (2021) Wales	To explore the attitudes and approaches to the future of those living alone with dementia	24 people (21 women, 3 men), aged 69–91 Diagnosis of dementia Relatives and friends also interviewed	Repeat interviews over 12 months Framework analysis	People expressed a desire to live at home as long as possible. Participants approached the future by 'holding on' and through 'anticipatory acts'	(++)
Illiger et al. (2021) Germany	To understand the disposition of people living alone with dementia toward the use of care and support services	12 people (2 men, 10 women), aged 65–84+ years Diagnosis of dementia	Interviews Grounded theory	Individual and gender specific differences concerning the use of formal support were evident	(+)
Johannessen et al. (2018) Norway	To examine how people living alone with young onset dementia perceive the course of dementia, their needs and coping strategies	10 people (3 men, 7 women) Diagnosis of young onset dementia, any type (excluding frontotemporal dementia) Aged 49–67	Longitudinal qualitative approach interviews every 6 months for 4 years Grounded theory	People experience changes in their identity over time	(+)
Johannessen et al. (2019) Norway	To explore how people living alone with young onset dementia experience and cope with transitions during the progression of their dementia	10 people (3 men, 7 women) Diagnosis of young onset dementia, any type (excluding frontotemporal dementia) Aged 49–67	Longitudinal qualitative approach interviews every 6 months for 4 years Grounded theory	Two main transitions (1) coping with diagnosis and (2) moving into care	(+)

(continued)

Table 3. (continued)

Author, date, country	Study aim	Sample	Design	Findings	Quality score
Lloyd and Stirling (2015) Australia	To identify unmet service needs	7 people, aged 48–85 Diagnosis of dementia	Interviews Thematic analysis	Four main themes: access to public space, social distance and proximity, changing meanings of space and objects, and imaginative co-presence	(+)
Nygård (2008) Sweden	Explore the meaning and use of everyday technology for people with dementia who live alone	8 people (3 men, 5 women), aged 57–82 Diagnosis of dementia	Repeated interviews and observation Phenomenological analysis	Everyday technology has both practical and existential meaning and helped people to support their perception and presentation of themselves	(+)
Nygård and Starkhammar (2003) Sweden	To map out and describe telephone use among people living alone	10 people (3 men, 7 women), aged 75–87 Diagnosis of dementia	Interviews and observations Comparative data analysis	Findings showed people struggled to use the phone and the strategies they used to try and help themselves were not always reliable	(++)
Nygård and Starkhammar (2007) Sweden	To identify and characterise difficulties with and hindrances to using everyday technology	8 people (3 men 5 women), aged 57-82 Diagnosis of dementia	Repeat interview and observations Comparative data analysis	Barriers to technology use were evident in different domains related to both the person and their context	(+)
Odzakovic et al. (2021) England, Scotland and Sweden	To examine the experiences of people with dementia who live alone, focusing upon how they establish social networks and relationships in a neighbourhood context	14 people (11 women 3 men), aged 62–88 Diagnosis of dementia	Multiple data collection methods including walking interviews, semi-structured interviews, guided home tours and social network mapping Thematic analysis	Themes: making an effort to stay connected, befriending by organisations and facilitated friendships, the quiet neighbourhood atmosphere and changing social connections	(++)

(continued)

Table 3. (continued)

Author, date, country	Study aim	Sample	Design	Findings	Quality score
Svanström and Sundler (2015) Sweden	To elucidate the phenomenon of living alone with dementia and having a manifest care need	Six people (5 women, 1 man), aged 80–90 "with dementia"	Field notes from 32 visits plus 11 interviews Phenomenological analysis	Finding share feelings of loneliness, longing for other people and feelings of boredom	(+)

Quality Assessment

All the studies included either met the majority of the quality assurance criteria (n = 7) or fulfilled some of the criteria where conclusions were unlikely to change where criteria had not been met (n = 9). Quality assessments of each study are included in Table 3.

Across the studies there was a notable lack of reflexivity reported by the authors. Reflexivity is considered essential in qualitative research given the researcher position as the "primary instrument" in data collection and analysis (Watt, 2007, p. 82). The practice of reflexivity demonstrates an awareness of one's own values and beliefs as part of the research, strengthening transparency and credibility of the findings (Patnaik, 2013). Only four of the studies explicitly discussed the role and relationship of the researcher in the research (Lloyd & Stirling, 2015; Svanström & Sundler, 2015; Witt et al., 2009, 2010).

Despite many of the studies having multiple authors, it was at times unclear whether more than one coder had been involved or to what extent they had each been involved in the data analysis. Additionally, when there was more than one coder involved, studies did not report how disagreements were resolved. The use of multiple coders is a technique used to improve data trustworthiness and can contribute to the richness of interpretations (Sweeney et al., 2013).

Psychosocial needs

All studies in the review reported at least one dimension of unmet needs: love (n = 2), comfort (n = 11), identity (n = 8), occupation (n = 4), inclusion (n = 11) and attachment (n = 4).

Love. Feeling loved and accepted is essential for all wellbeing. Kitwood (Kitwood, 1997) argued we all need to feel loved and to love someone. Some people who live alone have a support network nearby and this enabled them to feel loved, for example in the study by Illiger, Walter and Koppelin, one participant stated, '*because my son lives nearby, I feel very safe here*' (28, p.1306). The support provided by families who lived nearby was often described as acts of love, some participants described caring through the generations, having cared for their own parents as their children now cared for them (Illiger et al., 2021).

However, many participants who lived alone did not feel loved, and expressed a longing for other people and someone to share their day with, such as a *'spouse to come home from work and eat dinner '* with (24, p.115). In the study by Johannessen et al., one participant was exhausted by struggling to manage everyday tasks alone and *'longed to be looked after'* (29, p.6). In the study by Frazer and colleagues (Frazer et al., 2012), a female participant described a desire for romantic intimacy.

Where studies described limited contact with children and families it was not always clear whether changes in relationships to limit contact had occurred before the onset of dementia, or because of dementia (Frazer et al., 2012). Some participants described not wanting to be a burden on their families (Illiger et al., 2021; Witt et al., 2010), difficulty maintaining contact was also an issue for some participants because they didn't know peoples' addresses or couldn't use the phone without support (Nygård & Starkhammar, 2003).

Some participants shared a deep love and appreciation for their home, which held important memories of feeling loved and of loved ones. One participant spoke about how his family home gave him a strong connection to his late wife, as he could sense her presence in the home they once shared together (Lloyd & Stirling, 2015).

Comfort. People with dementia need physical and emotional comfort, to feel safe in their environment. For many people the home provided a source of safety and comfort (Svanström & Sundler, 2015), at least in the early stages of their dementia (Witt et al., 2009). Many participants expressed a strong desire to stay living at home independently until they died, although notably in the study by Heaton and colleagues (Heaton et al., 2021) only two participants had told their family about their wish to die at home. Taking a day at a time and not looking too far ahead was a common coping strategy that provided comfort (Heaton et al., 2021; Witt et al., 2010). Having good financial resources was perceived as key to being able to remain at home in comfort (Illiger et al., 2021).

Frustration (Eades et al., 2018), embarrassment (Frazer et al., 2012) and low mood (Johannessen et al., 2018, 2019) were all threats to emotional comfort. However, as dementia progressed it was feelings of anxiety that posed the main threat to participants sense of comfort. People feared making mistakes for fear that would mean they could no longer live alone (Witt et al., 2009) . Risk incidents associated with living alone related to participants safety, started soon after diagnosis (Groen-van de Ven et al., 2017). Participants were aware of the risks to living alone including risk of fires whilst cooking, getting lost when at alone and forgetting if one had eaten (Groen-van de Ven et al., 2017; Illiger et al., 2021; Nygård, 2008; Witt et al., 2010).

A more generalised sense of anxiety was also described, including a fear for the future; *'I am very afraid for the future'* (34, p.484) and *'morning anxiety'* (34, p.486) characterised by a fear about the day to come. Johannessen and colleagues (Johannessen et al., 2019) described how for one participant life became increasingly frightening, this escalated into feelings of panic when the doorbell rang. Interestingly in the longitudinal follow up reported in Johannessen and colleagues, this lady's anxiety was resolved upon moving into nursing care where she felt comforted by a sense that *'somebody was there'* (34, p.486). One participant used alcohol to try and escape and *'shut it all out'* (29, p.6).

Technology was often introduced to mitigate risks, but this was not always well received. One participant had an alarm installed in her home after going out at night but subsequently reported feeling like *'a prisoner inside her home'* (37, p.655). For some, technology provided a false sense of security as people confused its functions and overestimated its capability to keep them safe (Nygård & Starkhammar, 2007), with one participant believing a falls sensor would keep her safe when out and about.

Identity. Individuals with dementia living alone have often experienced numerous losses during their lives which can pose threats to their identity, these might include the loss of a spouse and the loss of relationships with their children (Frazer et al., 2012). Dementia then brings additional losses, the loss of a cognitive abilities for a lady who had never married or had children but focused on her career was a challenge to her identity (Frazer et al., 2012). The loss of a driving license and so a car for those living alone and trying to maintain independence was felt to be a significant loss to identity (Witt et al., 2009).

However, the main threat to identity for those living alone was not having others to affirm their sense of personhood. Svanstrom and Sundler (Svanström & Sundler, 2015) noted how for people living alone identity becomes fragmented as memories of who we are as people become vague, unless these memories are shared and reaffirmed through interactions with others. One participant feared losing a sense of who they were entirely and becoming *'an empty shell'* (29, p.7). Some participants felt that they got their identity back when they moved into care and were around other people (Johannessen et al., 2018).

Participants expressed a strong sense of identity in their home; *'I definitely have strong ties to . . . this home. This is where my children were born and raised'* (26, p.276). Participants were aware that they would not be able to remain at home alone indefinitely, and some feared leaving their home more than dying, because of its central role in their identity (Witt et al., 2010).

Participants spoke about actively managing threats to their identity and key to this was the ability to continue to make their own decisions, to look after themselves and to feel a sense of control over their lives and their futures (Frazer et al., 2012; Johannessen et al., 2018; Witt et al., 2009).

Occupation. The importance of occupation, being engaged in meaningful activities, is crucial to our sense of purpose and worth in life. People need to feel that they can still accomplish things (Frazer et al., 2012).

For some people who live alone *'home is the centre of my life'* (26, p.276). Whereas others described having no choice but to seek meaningful occupation at home due to no longer driving and living in rural areas (Johannessen et al., 2019). For those living alone managing activities of daily living (household chores, medications, home administration) took on a prominent role in occupying most of people's time (Groen-van de Ven et al., 2017). For some managing their own household was a source of pride and provided meaning and structure to their life, whereas one participant described *'I keep very busy doing nothing'* (10, p.22). There was a suggestion of some gender differences in the value placed on household tasks (Illiger et al., 2021). However, as dementia progressed, housework became *'uncontrollable'* (28, p.6) and people felt overwhelmed and exhausted by it.

There were polarised views about the value of TV as a source of occupation and it's use to *'break the silence'* (23, 37, p.659) . The same was true of technology which provided some participant's most significant sources of occupation giving *'meaning and rescue'* (Nygård, 2008) but for others was a source of stress and fear, to be avoided at all costs (Nygård & Starkhammar, 2007). Distance carers often put pressure on people living alone to use technologies for occupation and to retain connection (Nygård & Starkhammar, 2007).

For some participants shopping was an important everyday activity because it provided a chance to see people (Witt et al., 2009). Time outdoors provided structure and meaning *'I like to walk. You have to do something'* (10, p.22). A desire for usefulness was also expressed (Gilmour, 2004). Significant challenges for people who live alone to engage in activities outside of the home included having nobody to *'spur them on'* to act (24, p.12) and finding their orientation to time, difficult on occasions (Nygård, 2008).

A lack of meaningful occupation was commonly reported as a challenge by people living alone with dementia. Participants across studies described life as *'empty'* (24, p.8), *'boring'* (28, p.1307), and *'meaningless'* (34, p.485). In the study by de Witt and colleagues, one participant described *'living alone in a dead house'* (26, p.278). This phenomenon was most noticeable as dementia progressed and energy levels decreased, activity levels reduced, and participants described *'a sense of inner emptiness'* (24, p.7). When people struggled to occupy themselves, time would pass slowly, each day felt the same and some people would sleep to pass the time (Svanström & Sundler, 2015). The evenings were noted to be particularly difficult (Illiger et al., 2021).

Inclusion. Feeling included is essential for our wellbeing, participants discussed their right to be heard (Eades et al., 2018) and the importance of camaraderie and being part of something (Frazer et al., 2012).

Participants described striving for *'normality'* (36, p.491) and taking action to remain included but this could be difficult without support (Odzakovic et al., 2021). Some people with dementia sought out places to be around others, even strangers, such as cafes and parks (Odzakovic et al., 2021). For others it was their window that provided a connection to the outside world (Odzakovic et al., 2021). For people with young onset dementia, who may have been at work prior to diagnosis, the transition to being at home alone was significant and brought a sense of exclusion from friends of similar ages who continued working (Johannessen et al., 2019).

Indeed, Eades and colleagues (33, p.11) theme *'community engagement / isolation'* reflects the desire and value of community but also captures the sense of anxiety and precariousness that exists around maintaining a sense of inclusion when living alone with dementia. Many challenges to inclusion reported are common to dementia such as decreased mobility, declining confidence and loss of a driving licence (Eades et al., 2018; Frazer et al., 2012; Lloyd & Stirling, 2015). For individuals with dementia living alone, social losses which are a feature of most people's experience post-diagnosis, were even more significant.

In the study by Frazer and colleagues (Frazer et al., 2012) participants shared feeling excluded from society and a sense of abandonment. Participants described feeling *'invisible'* (30, p.279). A sense of *'outsideness'* and not belonging led some people to retreat into their homes (26, p.281). In the study by Svanstrom and Sundler (Svanström & Sundler, 2015) participants described feeling so alone that they felt they were no longer a part of the world and left with a sense of *'personal extinction'* (23, p.1809).

Loneliness and isolation were commonly reported across studies. However, a sense of solitude (different from loneliness) was valued by some and as a source of freedom and privacy because it allowed people to maintain a sense of independence and self-reliance (Odzakovic et al., 2021).

Attachment. Kitwood (Kitwood, 1997) believed that our connections in life significantly impact our well-being. As humans we all want to feel connected to something or someone. That might be through close relationships or broader community attachments.

The *'need to belong'* (30, p.12) included a desire to be with likeminded people and do things together with others. Participants described how life had more meaning when it was shared with another person (Svanström & Sundler, 2015). Participants expressed a longing for other people to talk with and to bring their memories and feelings to life (Svanström & Sundler, 2015). In the study by Svanstrom and Sundler, participants described feeling like a *'human being again'* when with others (24, p.10).

Sources of connection and attachment included neighbours (Frazer et al., 2012; Odzakovic et al., 2021) and friends, indeed for some participants, friends often had a much more prominent role than family members (Frazer et al., 2012), particularly for people with dementia who had no children (Odzakovic et al., 2021). Participants without children focused their attachments on one or two key relationships (Odzakovic et al., 2021).

For participants who did have supportive family relationships, these relationships often facilitated broader connections to neighbours and friends, for example, one participant said, *'because my children go to the church then Father Peter visits me at home as often as he can'* (37, p.654).

Another source of attachment and social support for some participants came from charities and day services, where staff members were seen as friends rather than professionals (Odzakovic et al., 2021). Whereas home carers helping with meals and domestic tasks were often not seen as a source of social interaction or attachment, indeed many participants didn't remember they had such support (Johannessen et al., 2018; Lloyd & Stirling, 2015; Svanström & Sundler, 2015).

There were a number of barriers to connection, that are common to people who do not live alone with their dementia, including impact of cognitive changes making social interactions too demanding, and the *'social retraction'* of others as a result of the diagnosis (29, p.4). However, for people living alone an additional barrier included a need to cover up and hide difficulties from others because to admit difficulties would risk losing their independence (Frazer et al., 2012; Witt et al., 2009). For example, one participant stated *'you've got to trust and understand the people you're being open with and asking for help, because I have seen too many cases where they overreact'* (26, p.279). Another participant presented their outer image of coping so well, that their children did not believe their diagnosis (Johannessen et al., 2018). Further practical issues, including problems with using the telephone (Nygård & Starkhammar, 2003), also impacted on the ability to connect to others.

Where some participants outlined efforts to maintain existing relationships and established new ones in response to their depleted social networks, others struggled to do this and became isolated. Feelings of isolation and loneliness were a common theme, where participants described *'longing for company'* (24, p.15), indeed one participant described talking to her teddies for company (Lloyd & Stirling, 2015). In the de Witt and colleagues' study (Witt et al., 2009), some participants had become so isolated that they now perceived the world and others to pose a threat, with one participant stating, *'I don't care if the . . . king comes or if the queen comes or whoever it may be, I will not open my door anymore.'* (26, p.283).

Discussion

This review highlights the psychosocial needs of people with dementia living alone, with many of the needs described being common to people with dementia living with a care partner. However, living alone did present distinct challenges, including practical challenges (orientation to time, using the telephone to stay connected and in having someone to prompt the initiation of activities) and risks. Perhaps most notable was the increased threat to personhood because of the lack of other people to support and maintain an individual's sense of identity. This is reflected in the recent review of non-pharmacological interventions for people with dementia who live alone (Polack et al., 2025), where interventions promoting social interaction and meaningful relationships was identified as being of potential benefit. The level of exclusion experienced by some individuals living alone was profound and distressing to read, for some people this was compounded by masking or camouflaging difficulties (Perry et al., 2022) for fear of losing their home and independence. The relationship and meaning ascribed to the home where people lived alone was complex, for some their home was imbued with memory and was an intrinsic to their identity, for others their home was or had become frightening and suffocating. Research to understand the meaning of home should be extended to people living alone.

One important reflection is that people who live alone with dementia are not a homogenous group. For some individuals living alone was a choice and these individuals valued their independence and sought to maintain a sense of control and autonomy. For others living alone occurred following multiple losses or in the context of strained family relationships which confounded and complicated experiences of ageing and dementia. Individuals who lived alone with the support of families appeared to have more attachments, and felt more secure and loved. Research with older adults without dementia, has identified that individuals living alone can have equal and at times higher levels of wellbeing than those with others, highlighting the importance of access to diverse social networks as an influencing factor (Djundeva et al., 2019). An intersectional approach must be adopted in future research and to allow services to tailor support. For example, this review highlighted challenges related to rurality and living alone and socioeconomic status but did not reflect LGBTQ + populations which is an omission given LGBTQ + older adults are more likely to live alone and have smaller support networks (Guasp, 2011). Moreover, people in our advisory group highlighted the challenges of living alone with dementia and multiple health conditions and having to manage medication regimes and appointments which was not evident in the literature.

This review highlights support needs in relation to advocacy, education, practical support, emotional support and future care planning. Moreover, the review demonstrates the need for building trusting relationships, assertive engagement and a sensitive assessment, all suggesting that a case management approach could be beneficial. In the recent review of non-pharmacological interventions for people living alone with dementia (Polack et al., 2025), the case management model was highlighted as having a positive impact for this population, although implementation barriers have restricted adoption. More research is needed to understand how specialist nurses can ensure that their support is accessible and beneficial to people who live alone. Terminally ill cancer patients in the UK who live alone are less likely to receive care from community specialist palliative care nurses than those who have a family (Addington-Hall & Altmann, 2000Addington-Hall & Altmann, 2000). Research examining specialist nursing support often excludes those living alone without giving a rationale. In order to identify ways in which specialist nurses can support people living alone, in a meaningful way, solutions must be co-produced with those living alone as experts by experience.

It is important to acknowledge the limitations of our review. We did not include studies which explored the views of people with dementia alongside the views of those with MCI, and as a result draw conclusions on a smaller literature base. For example, the Living Alone with Cognitive Impairment project (Graham et al., 2021) and work focused on ‘ageing solo’ with early dementia and MCI (Lowers et al., 2024) were excluded from this review. This decision was informed by our advisory group who felt strongly that dementia presented different challenges to MCI, and is particularly pertinent to the focus of this review on living alone, as the key criteria that distinguish MCI from dementia according to diagnostic guidelines are preservation of independence in functional abilities and lack of significant impairment in social or occupational functioning (Langa & Levine, 2014).

The review only found a small number of studies, and a key reason for this may be that people with dementia are often excluded from research when they do not have a carer to facilitate involvement (Aspinal et al., 2023; Medeiros et al., 2022). Whilst the majority of studies stated explicitly that participants had a diagnosis of dementia, two did not clarify whether there was a diagnosis (stating only that their sample contained people “with dementia”). Further, authors often did not differentiate or state sub-types of dementia, and members of our advisory group felt that some types of dementia presented different issues related to living at home which should be explored, for example challenges to mobility and balance. Studies did not always clarify whether people were living alone without support or with carers living at a distance, suggesting the heterogeneity and intersectionality in this population must be acknowledge and explored. It is noteworthy that the majority of the studies (13 out of 16) were conducted before the COVID-19 pandemic which has had long term impacts on dementia support services and local communities. The research focused on people living alone who were at home and out in the community, however, none attended to the experiences of people living alone in acute hospital settings. Furthermore, more longitudinal studies are needed, particularly given the fears for the future many people described and to explore needs across the changing circumstances of those living alone.

In conclusion, whilst it is useful to describe the needs of people with dementia living alone, it is also vital that we also highlight their agency. People actively employed a range of coping strategies and practical solutions, whilst being realistic about the future. Research should explore the character strengths and virtues (Power, 2015) of individuals with dementia living alone so that interventions can be developed to facilitate and support these. Describing needs is not enough, we must develop solutions to support and engage people who live alone.

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