

Facilitators and barriers to remaining at home for people with dementia who live alone: a protocol for a systematic review of qualitative evidence

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Review question/objective: This qualitative review aims to gain an increased understanding of the factors that support (facilitators) and challenge (barriers) people who have dementia and live alone in being able to remain living in their own homes. The review will contribute to the development of a complex intervention, inform clinical practice and influence policy development for this population.

Overarching review question: what are the barriers to, and facilitators for, people with a dementia who live alone being able to remain in their own homes?

Sub-questions:

1. What are the factors that support and/or challenge a person with dementia who lives alone?
2. What are the barriers to, and facilitators for, people with a dementia who live alone being able to remain in their own homes from the perspective of people who have dementia and live alone?
3. What are the barriers to, and facilitators for, people with dementia who live alone being able to remain in their own homes from the perspective of people who interact closely with this population, including family, and health and social care workers?

Keywords Alzheimer's disease; dementia; lived experience; living alone; solitary

Background

Dementia is a significant and growing global issue: an estimated 47.5 million people worldwide have dementia and this number is growing annually by 7.7 million.¹ In the United Kingdom (UK) alone, approximately 850,000 people are living with dementia.²

The term dementia refers to a range of progressive cognitive disorders, including the most common types of dementia (Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia), and also those arising from other neurodegenerative disorders and medical conditions (such as Parkinson's disease, Huntington's disease, HIV and Creutzfeldt-Jakob disease). Regardless of the etiology, dementia has considerable health, social and

economic consequences for individuals who receive the diagnosis, their family and friends, and the wider society.¹ Particularly, as dementia progresses, one such consequence is people facing increasing risks of having to leave their home and move into a care home or another institutional setting due to multiple and complex challenges.³ People who have dementia and live alone appear to face an even higher risk of being unable to remain living at home.^{3,4}

Enabling people with dementia to live at home

The World Health Organization and numerous government policies have prioritized the need for people with dementia to be enabled to remain living at home for as long as possible.^{5–8} Estimates are that two thirds of people in the UK with dementia live at home in the community² yet end-of-life statistics for the UK and many other European and non-European countries show that most people with dementia will enter a care home at some point before they die.^{9,10} However, in some countries, such as those in Africa,

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Asia and Latin America, long-term care admission is less common.⁸

There are a number of key drivers behind aims to increase community dwelling for people who have dementia. Firstly, the wider public, and people with dementia more specifically, have expressed a preference to remain living at home.⁸ A UK poll found that 85 percent of people would prefer to live in their own home for as long as possible if they were diagnosed with a dementia.¹¹ Secondly, living at home may enable people to experience a better quality of life through remaining engaged within known social and physical environments.³ Some studies even suggest that people with dementia living at home, or at home for longer, live longer than those admitted into a care home,^{12,13} although there is conflicting evidence on this.¹⁴ Finally, an international systematic review found that enabling people to remain at home has economic and cost advantages, with the direct costs of institutionalized dementia care being on average three times higher than the direct costs for when someone lives at home.¹⁵ In the UK, the estimated total annual social care costs for people with dementia living at home and in residential care are £2 billion and £8 billion, respectively.¹⁶ However, these figures are slightly misleading in that they fail to account for the significant informal costs of the time unpaid caregivers in the community provide to those living at home.^{15,16}

Barriers and facilitators to living at home alone

People with dementia who live alone are particularly at risk of having difficulties managing at home and having to leave their own homes to move into a care environment. Data related to the number of people who have dementia and live alone varies. Population-based studies suggest that approximately a third of people who have dementia and live in the community, live alone.^{17–20} In the UK, in 2010, this group was estimated to comprise 141,460 people.²¹ These people living alone may have family carer support in person or over the phone, but some people appear to have no informal carer support.²¹

A systematic review by Luppá *et al.*³ shows that people with dementia living alone have increased risk of, and a shorter time before, moving to a care home than those who live with a spouse or other caregivers. In the UK, people with dementia who

have a co-resident carer are 20 times less likely than those who live alone to be admitted into a care home.⁴ Miranda-Castillo *et al.* explored the needs of those with a dementia living alone compared to those living with a carer, and found people living alone had significantly more unmet needs, and specifically more unmet needs in areas of “looking after home”, “self-care”, “food” and “accidental self-harm”. It appears plausible that unmet needs faced by this population may contribute to their increased risk of admission into long-term care.

Cohort studies involving the wider population of people living in the community with dementia identify a number of other predictors of admission to a care home, or “institutionalization”. These include: advancing age³; having a non-spousal caregiver³; increased severity of cognitive impairment^{3,22}; functional impairment or dependency in activities of daily living (ADL)^{3,22}; other co-existing health problems²²; falls²²; presence of behavioral and psychological symptoms of dementia^{3,4,22}; and carer issues and characteristics such as quality of life, sense of burden and carer’s own health issues.^{3,4,22} Whilst there are common risk factors across nations, the reasons for institutionalization have been found to vary, depending on the country, possibly due to differences in culture and dementia care services.²² A recent European-based study within the RightTime-PlaceCare dementia research program reiterated the context-specific nature of decisions around entry into long-term care, and found that whilst higher levels of carer burden and reduced ADL ability are the predictors of institutionalization most common across the nations studied, there are significant variation in needs, and tailored responses are required to enable individuals with a dementia to remain at home.²³

For those with dementia living alone, no cohort studies have been completed to identify their specific predictors of long-term care admission. Even if studies existed, evidence on “predictors” alone would only illuminate part of the issue, and would fail to explain how and why these predictors affect the ability to remain living at home and, how the predictors interact, and would not enable the consideration of how factors could be mediated or altered to improve outcomes. Consideration of barriers and facilitators is therefore required to allow: exploration of meanings, experiences and contexts;

potential development of intervention theory; and the preliminary consideration of intervention implementation issues.²⁴ For the purposes of this review, barriers are factors that have or have the potential to challenge the ability of a person with dementia to remain living at home alone. Facilitators include any factors that have or have the potential to positively affect or support the ability to remain at home. Both facilitators and barriers will be from the perspectives of people who live alone and have dementia, and those who interact closely with them.

A preliminary search for systematic reviews and review protocols confirmed that no reviews on this topic have been completed, are ongoing, or are planned in published protocol format. This was confirmed through database searches within Pubmed, the JBI Database of Systematic Reviews and Implementation Reports, CINAHL Plus (via EBSCOhost), Cochrane Database of Systematic Reviews, PROSPERO, PsycINFO (via ProQuest) and EMBASE (via Ovid).

Given that those who live alone are at increased risk of having to leave their home and at an earlier stage, it is necessary to develop increased understanding of these factors and issues, and to develop effective interventions to extend their ability to remain at home. Initial scoping searches indicate availability of qualitative studies on both the experiences of people who have dementia and live alone,^{25–34} and the experiences and views of people who interact closely with this population, such as health care professionals.³⁵ It is hoped that the synthesis of relevant qualitative evidence in this review will contribute to the development of an intervention to be delivered by occupational therapists as part of a wider research project.

Inclusion criteria

Types of participants

This review will consider studies with a singular focus on people who have dementia and live alone in the community, or people who interact closely with this population.

Dementia: For the purposes of this review, the term dementia includes the most common forms of dementia (Alzheimer's disease; vascular dementia; mixed dementia, such as both Alzheimer's disease and vascular dementia; dementia with Lewy bodies; and fronto-temporal dementia). Studies where the type of dementia has not been specified will also be

included. Included studies must have a primary focus on people described as having dementia, regardless of whether a doctor's diagnosis has been provided. Studies with a primary focus on people with dementia which also include some participants with suspected dementia will be included within this review. However, studies with a primary focus on participants with a suspected dementia will be excluded.

Studies with participants with one of the rarer forms of dementia, such as Creutzfeldt-Jakob disease and HIV-associated neurocognitive disorder, will be excluded due to their lesser prevalence and the differing features of the rarer dementias. Studies with participants with other forms of cognitive impairment will also be excluded. This includes, but is not limited to: acquired brain injury, mild cognitive impairment, subjective memory complaints, confusion or delirium or cognitive impairments associated with other conditions such as Parkinson's disease and Huntington's disease.

Age: Participants of interest are primarily those aged 65 years or over, therefore studies with a singular focus on people with dementia who are under 65 years of age will be excluded.

Living alone in the community: For inclusion in this review, all study participants should have their primary residence in the community, and be living alone or at least spending nights on their own. People who live alone and have support visits from paid carers are included within this population. Studies with participants who live with another person, such as a spouse or another family member, or within an environment where there is impromptu access to paid carers or a warden for support 24 hours per day, such as warden controlled housing, extra-care accommodation and care homes, will be excluded. *People who interact closely with people who have dementia and live alone:* This includes family members, friends, informal carers, formal carers, health and social care professionals and significant others who closely work with or support people who meet the inclusion criteria (as provided above) in terms of dementia type, age and living status.

Phenomena of interest

The phenomena of interest are factors that support (facilitators) and/or challenge (barriers) people who have dementia and live alone, including those which affect their ability to remain living at home. Studies providing the perspectives of people with dementia

living alone and people who interact closely with them will be included. Barriers and/or facilitators may be expressed as, but are not limited to, beliefs, experiences, expectations, attitudes or descriptions of behaviors, processes or outcomes.

Context

Studies completed in any setting will be included providing the person(s) with dementia normally have a primary residence in the community and live alone. Settings may include, but are not limited to, community locations, outpatient clinics, and inpatient facilities (for example, those that prepare for return home alone from hospital).

Types of studies

Studies employing qualitative methods will be the primary focus of this review, and this includes qualitative sub-studies that are part of evaluations of predominantly quantitative studies or mixed methods. Studies that use recognized qualitative designs, such as phenomenology, grounded theory, ethnography, action research and feminist research, will be included. Textual documents, such as opinion pieces and letters, will not be eligible for inclusion.

Search strategy

The search strategy for the review aims to identify published and unpublished studies and there will be no limits on search dates. Publications are to be written in English due to insufficient resources within this review to employ translators, and studies sourced and excluded because of language will be recorded.

This review will use a three-phase search approach.³⁶ Firstly, a comprehensive search strategy was developed through an initial limited search of MEDLINE and PsycINFO. PsycINFO was selected as this database appears to contain more literature pertaining to this area of inquiry than CINAHL. This identified key index terms and free-text words within titles and abstracts of relevant articles.

Initial keywords identified include: Population: “dement*” OR “Alzheimer*” AND “liv* alone” OR “solitary” OR “home alone” OR “independent liv*” OR “unaccompanied” OR “social* isolat*” OR “lonel*”.

The resulting search strategy will be used to search for qualitative studies, and will include key

search terms and synonyms, and subject headings (such as MeSH in MEDLINE). The strategy will be developed in consultation with information specialists.

The second phase of the review will be a systematic search of electronic databases using the developed search strategy, which will be altered in line with individual database requirements.

The databases to be searched include:

- MEDLINE (via Ovid)
- EMBASE (via Ovid)
- PsycINFO (via Ovid)
- CINAHL (via EBSCO)
- AMED (via EBSCO)
- Applied Social Sciences Index and Abstracts (ASSIA)
- The Cochrane library (including Central Register of Controlled Trials (CENTRAL), Cochrane Database of Systematic Reviews, and Database of Abstracts of Reviews of Effects (DARE))
- Web of Science (SCI-EXPANDED, SSCI, A&HCI)
- Social Policy and Practice (via Ovid).

To accompany electronic database searching, grey literature will be searched. Key websites will be reviewed (including Alzheimer’s Disease International; Alzheimer’s Society, UK; Alzheimer’s Association, USA; Alzheimer’s Australia; Alzheimer Scotland; and Alzheimer Society of Canada). Other grey literature will be searched, including theses on EThoS and ProQuest Dissertations and Theses Database, and conference proceedings through Web of Science Conference Proceedings Citation Indexes (CPCI-S and CPCI-SSH).

To identify other relevant planned or ongoing research, clinical trials will be identified through searching the World Health Organization International Clinical Trials Registry (this includes ISRCTN) and clinicaltrials.gov. The Cochrane Dementia and Cognitive Improvement Group comprehensive register of dementia trials (ALOIS) will also be searched.

The third phase of the search will be a backwards citation search where the reference lists of included articles will be reviewed for additional studies. Forwards citation searching, for papers citing the included studies, will also be completed.

Studies sourced through this process will be stored and managed using Endnote X7 software. The

details of database, grey literature and other searches completed will be recorded.

Assessment of methodological quality

Studies retrieved will be checked for duplications, and any duplicates will be removed and recorded. Two reviewers will independently screen studies at each stage of screening, using the predefined inclusion and exclusion criteria within the protocol. Any differences in results between reviewers' decisions will be discussed after each phase of screening, and if disagreement persists, a third reviewer will be consulted. Initial screening of publications will be on title and/or abstract and for any papers not excluded at this stage, the full texts will be sought and screened. Those excluded at the full text stage will be tabulated in the appendix and the reason(s) for exclusion recorded. Endnote X7 software will be used to record initial and full text screening inclusion and exclusion decisions.

Qualitative studies meeting the inclusion criteria after full-text screening will be assessed independently by two reviewers for methodological validity prior to inclusion in the review, using the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix I).³⁶ Disagreements between the reviewers will be discussed, and if disagreement persists, a third reviewer will be consulted.

Data extraction

Qualitative data will be extracted from papers included in the review using the standardized data tool from JBI-QARI (Appendix II).³⁶ The data extracted will include specific details about the phenomena of interest, populations, setting, study methods, and outcomes of significance to the review question and specific objectives.

If there appears to be missing data, authors of the studies will be contacted and requested to provide further information.

Data synthesis

Qualitative research findings will, where possible, be pooled using JBI-QARI. This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings rated according to their quality, and categorizing these findings on the

basis of similarity in meaning. These categories are then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice. Where textual pooling is not possible the findings will be presented in narrative form.

To allow the potential exploration of differing viewpoints, from the perspective of people who have dementia and live alone and also people who interact closely with them, study findings from the different populations will initially be analyzed and categorized separately. The extent to which the different populations' perspectives are combined within the synthesized findings is dependent on the categories identified, and the process used by the authors will be described within the review.

The synthesis and reporting of the review data will be guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement and will include a PRISMA flowchart.³⁷

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Appendix I: Appraisal instruments
QARI appraisal instrument

JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

Reviewer Date

Author Year Record Number

	Yes	No	Unclear	Not Applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is there congruity between the research methodology and the research question or objectives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Is there congruity between the research methodology and the methods used to collect data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is there congruity between the research methodology and the representation and analysis of data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there congruity between the research methodology and the interpretation of results?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there a statement locating the researcher culturally or theoretically?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the influence of the researcher on the research, and vice-versa, addressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Are participants, and their voices, adequately represented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include Exclude Seek further info.

Comments (Including reason for exclusion)

Appendix II: Data extraction instruments
QARI data extraction instrument

JBI QARI Data Extraction Form for Interpretive & Critical Research

Reviewer Date

Author Year

Journal Record Number

Study Description

Methodology

Method

Phenomena of interest

Setting

Geographical

Cultural

Participants

Data analysis

Authors Conclusions

Comments

Complete Yes No

Findings	Illustration from Publication (page number)	Evidence		
		Unequivocal	Credible	Unsupported

Extraction of findings complete Yes No