BMJ Open

Methods for the involvement of people living with dementia in research focused on the built environment: a protocol for a scoping review

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To cite: Fahsold A, Roes M, Holle B, *et al*. Methods for the involvement of people living with dementia in research focused on the built environment: a protocol for a scoping review. *BMJ Open* 2023;**13**:e075350. doi:10.1136/bmjopen-2023-075350

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2023-075350).

Received 05 May 2023
Accepted 08 August 2023

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ABSTRACT

Introduction The positive influence of a well-designed built environment in dementia-specific care has been known for several years. Many studies focusing on the built environment have captured the perspectives of people living with dementia. However, it remains unclear to what degree and with which methods these individuals have been actively involved in research especially when attempting to understand their perspective. The planned scoping review aims to (1) synthesise methods and results from research about the built environment according to active involvement of people living with dementia and (2) describe facilitators and barriers to this active involvement to capture their perspectives in research.

Methods and analysis We will use four search strategies: (1) searches in academic databases MEDLINE via PubMed, CINAHL and APA PsycINFO via EBSCO, and Scopus; (2) grey literature searches via Google Scholar; (3) handsearches of non-academic environmental planning and design journals and (4) identifying other publications of key authors in the field. Additionally, backward and forward citation tracking will be performed via reference lists and Google Scholar, respectively. Relevant literature published between 2013 and 2023 will be identified for data extraction and synthesis. One researcher will perform each strategy. Title-abstract/full text-screening will be conducted using Covidence by two researchers. Results will be displayed in a table and through figures illustrating identified facilitators and barriers.

Ethics and dissemination We raised no ethical concerns for the planned scoping review. We will prepare the findings including the identified barriers with long-term care practitioners from our network to identify how changes in practical application methods can be addressed. This dialogue can serve as a basis for including people living with dementia to discuss highlighted barriers when researching their perspectives on the built environment. The scoping review results will be reported in both academic and non-academic journals and at academic conferences.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ A strength of the planned scoping review is its inclusion of literature from different disciplines, such as health research, architecture and environmental planning and design, to address the heterogeneous approaches of research projects and studies.
⇒ A limitation of our scoping review is that we will not be able to systematically assess the quality of the studies that will be included in the data synthesis due to the variety of publication types.
⇒ It is beyond our scope to focus on the beneficial effects of the active involvement of people with dementia in research, but there is an opportunity to identify evidence of this reported by people with dementia as additional information during this review.

INTRODUCTION

Rationale

The relevance of the built environment for dementia-specific care has been known for several years. For example, people living with dementia often wish to remain in their familiar home environments.[1] Adapting these individuals' home environment to their individual preferences and needs can enable them to remain at home as their dementia symptoms progress.[2] Barrier-free design of public environments can also increase social participation[3] and independence[4] of people living with dementia. In the context of long-term care, a wide variety of studies have been conducted to evaluate the effects of environmental changes on residents' quality of life, but the evidence is considered insufficient due to various biases. In their updated Cochrane review, Harrison *et al* reported a reduction in certainty due to selection, performance or attrition bias in intervention studies. They also pointed out that different baseline characteristics and potential residual confounders support this.[5]

Many current design concepts are based on creating a person-environment fit,[6] a design that responds to a rising dependency for support,[7] or a design that supports well-being. When reflecting on environmental design choices, architects, environmental planners and designers, as well as other practitioners,

should anticipate the needs of the persons who interact with the built environment, who might have different abilities and resources.[8] This perspective-taking relies on holistic factual knowledge about how another person will perceive, experience and interact with the built environment (which could be acquired via research evidence) as well as an empathetic concern for the users of the environment (which might be acquired from the practical experiences of the person for whom the environment is designed).[8]

Regarding the first-hand experiences of people living with dementia in perceiving, experiencing and interacting with the built environment, to our knowledge, little research evidence appears to be currently available. One reason for this could be that people with dementia might experience involvement in research in terms of adhering to strict time schedules and project plans, due to the very nature of the time-restricted funding period of most research projects. Another reason could be that studies seldom provide detailed reporting on participatory research approaches,[9 10] and researchers are not well prepared to interact with people living with dementia.[11] Past healthcare studies have often relied on so-called proxy persons,[12] such as relatives or caregivers, whose perspectives may differ, with subtle or stronger nuances, from those of people living with dementia. Although people living with dementia advocate for their own active involvement,[13–16] it may currently be unclear for researchers, about how they might capture the perspectives of people living with dementia, especially in instances where limited resources are available during the planning and (re)design process of a study.[8] If studies do include methods to capture the perspectives of people living with dementia, it is valuable to take a closer look at how and to what extent these perspectives have been considered. As we know from previous collaborations with planners, designers and architects, including the perspectives of the future users of a planned built environment can be very valuable information for the design and planning process. We think that taking into account the perspectives of people living with dementia in regard to the built environment they live in can enrich the planning and design process, because it directly relates to their life-world, everyday life and environment they live in.

As the definition of the term 'environment' varies from discipline to discipline, it is necessary to explain the current scope of our understanding of space. There are models of environments for different care settings that serve to explain the intersectionality between social, organisational and physical environments.[17] In this protocol for a planned scoping review, when we will use the term 'built environment', rather than space or place. Here, the term refers to human-designed, built or redesigned environments.[18] The built environment in which people living with dementia live may change as the disease progresses, for example, from a living arrangement at home to living in a long-term care facility. For this reason, we will focus on including diverse living environments that primarily serve the purpose of living and accommodation. Hence, we will exclude environment types that primarily serve other functions and that people interact with for a short time or in a temporary manner (such as healing, rehabilitation or day care environments). Living environments that will be included in the scoping review can, for example, be private homes, assisted living accommodations, residential care facilities or long-term care environments.[19]

A good environmental design can also be regarded as an element of person-centred care,[20–22] a view that we will also follow for the planned scoping review. The combination of a good environmental design and person-centred care approach can support the individual preferences and needs of persons living in and interacting with the built environment, such as choosing social contact or privacy, moving independently and safely, being oneself, and having a sense of place and personal control.[22] Regarding research evidence for design principles and guidelines, a wide range of systematic assessment tools have been developed[23] and published across disciplines. These tools can support practitioners in the implementation of design principles across different care settings.[24]

It is relevant to note that prior research exists that can be categorised as being related to our research interest. For example, the methods commonly used to involve people with dementia in environmental studies and related outcomes have been mapped in an existing systematic review.[25] Furthermore, there are two PROSPERO registered projects for systematic reviews that either focus on the participation of residents with dementia in long-term care research[26] or address the involvement of patients living with dementia in environmental design research.[27] With our planned review, we intend to add additional insights to the existing knowledge in the literature by focusing on the following additional aspects: When we refer to 'active participant involvement' or 'active research involvement', we mean taking into account the perspectives of people living with dementia during collecting data (ie, not via proxy persons) and with this aim to primarily provide situations where people living with dementia can decide which data are of relevance and how to heed their voices.[14] We deem it relevant to explore reported methods for capturing first-hand perspectives of people living with dementia regarding the built environment in which they live. One reason is that the perception, experience, cognition and behaviour of people living with dementia can change due to the symptoms of dementia. A proxy perspective of researchers, relatives or professional caregivers may not correspond completely with the first-hand perceptions and lived experiences of people living with dementia. This particular focus of interest (capturing perspectives via methods of data collection) differs from a more comprehensive involvement in the sense of participatory research approaches (where people living with dementia might be directly involved as coresearchers, involved as research partners and/or affect research decisions).[28] Along with this, we will remain open to diverse

methods, which means that we will include studies that rely on both informal and formal observations, interviews and conversations, or other descriptions of methods that may foster perspective-taking.

Whenever applicable, in this protocol for the planned scoping review, we follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses-Extension for Scoping Reviews (PRISMA) checklist.[29]

Objectives

The objectives of our planned scoping review are (1) to synthesise methods and results in research about the built environment according to the active involvement of people living with dementia and (2) to describe facilitators and barriers to the active involvement of people living with dementia to capture their perspectives in research.

A thorough literature review may identify methods of active research involvement referring to specific aspects of the built environment that could inform future studies and help reflect on methodological choices in ongoing research projects. This knowledge could also help to meet the demands of short project timescales and the increased time requirements for involving people with cognitive impairments.

METHODS AND ANALYSIS

The study started in December 2022 and will be completed in May 2024. Whenever applicable, the planned scoping review will follow the methodological recommendations of the Joanna Briggs Institute.[30] To operationalise our research questions, we used the 'participants-concept-context (PCC)' mnemonic to ensure that each search component is differentiated from the other components.[31]

Eligibility criteria

To answer the two research questions, a broad review of the literature will be conducted, following the inclusion and exclusion criteria outlined in table 1. In terms of the PCC mnemonic, for participants, we will include sources of evidence regardless of the described method for assessing 'dementia'; this choice ensures that individuals in long-term care settings will be adequately represented.[32] In terms of concept, we will exclude studies focusing primarily on topics other than the built environment. In terms of context, we will exclude studies carried out in settings that do not primarily serve the purpose of living (ie, accommodation and daily living).

Search strategies

Strategy 1: searches in academic literature databases

To identify academic, peer-reviewed publications, we will search the MEDLINE academic databases via PubMed and CINAHL and APA PsycINFO databases via EBSCO, as well as Scopus.

To prepare individual search strings for the databases, we followed the procedure described by Nordhausen and RefHunter in their RefHunter V.5.0.[33] We considered key terms based on an evidence-based design.[23] As our work is often guided by the design principles of Mary Marshall and Fleming and colleagues,[3 19 34] we explored the use of relevant terms from their publications, such as 'good visual access' or 'familiarity'. In some cases, these

Table 1 Overview of the eligibility criteria

	Inclusion criteria	Exclusion criteria
Participants	Persons living with dementia (no need for a reported medical diagnosis)	Cognitive impairment of the study population as a secondary characteristic
Concept	Involvement in data collection in studies/research projects on the built environment	Involvement in other studies/research projects
Context	Various forms of housing (including indoor and outdoor spaces) either with or without a specific focus on dementia, for example, ► home-based care ► long-term care ► assisted living ► residential care ► public outdoor environments	Settings that do not serve the primary purpose of housing, for example, ► acute care, hospitals ► rehabilitation ► psychiatry ► hospices
Period of publication	2013–2023	Before 2013
Sources of evidence	Literature including empirical research reporting, for example, ► original research articles ► PhD theses and other dissertations ► project reports (including pre-occupancy and post-occupancy evaluations) ► non-academic articles	Literature without empirical research reporting, for example, ► study protocols ► theoretical papers without empirical components ► books (electronic or printed)
Publication language	English, German, Dutch	Other languages

terms were too specific; in other cases, we integrated their concepts broadly, such as by using the term 'safety' (see online supplemental tables 1–4). Relevant terms were first searched for the individual search components according to the PCC mnemonic and expanded the search by using suitable keywords from the individual thesauri provided by the databases. Then, we combined the different terms and keywords for the respective databases using Boolean operators and applied limitations using search filters. AF and SK created the initial search strings, which were then checked by BH and MR with awareness of the PRESS Peer Review of Electronic Search Strategies guideline statement.[35] As recommended by Cochrane Training, a final check of the search strategies was carried out by a library information system specialist.[36] All search strings for the electronic databases are listed in online supplemental tables 1–4.

Strategy 2: Google Scholar search

To search for grey literature more specifically (ie, research or project reports), we will use Google Scholar. As illustrated by Briscoe *et al*,[37] search strategies for academic databases must be simplified to perform a reasonable search in Google Scholar.

To find suitable search terms to include in the search process, different combinations of search terms corresponding to the components of the PCC mnemonic were entered into the search mask, and the first 25 hits were reviewed in terms of their fit to the research question by one researcher (AF). Three search strategies revealed promising results in the review process (see online supplemental table 5). The number of searched Google Scholar pages will be set to 35 pages per search to address the listing of grey literature after 20 pages, as described in the literature.[38] Thus, approximately, 1050 hits (titles and displayed information including metadata) will be screened by one researcher (AF). Matching hits will be entered into an Excel sheet based on the available bibliographic information.

Strategy 3: handsearches of non-academic magazine articles

Research projects and studies on the built environment include multidisciplinary but not always interdisciplinary approaches. To prevent a selection bias towards studies from the fields of medicine and healthcare research by the search strategies presented previously, publications by architects, environmental planners and designers will have to be targeted more precisely. For individuals in these professions, contributions to non-academic journals (mostly without being indexed in databases) represent the primary strategy of knowledge dissemination. For this reason, a handsearch of selected non-academic magazines based on the criteria described in table 1 will be conducted by one researcher (SK). Journals will be chosen based on an online catalogue that lists titles of non-academic journals, newspapers and databases in printed or electronic form, primarily for German-speaking countries but also with a few international sources.[39] One researcher (SK) will search for the German terms for 'architecture', 'dementia' or 'environmental design', with the filters set to 'online free access', '2013–2023', and German/English (Dutch is not an option in the filter). She will also search for the term 'dementia' on the websites of the magazines and databases that are identified and will screen the content of published magazine articles, when possible.

Additionally, we asked two architects from our professional network about whether they know additional non-academic, international magazines based on the criteria; this yielded four additional magazines that will be screened. All magazines will be reviewed, and articles fulfilling the inclusion criteria will be listed in the Excel sheet mentioned in the Search strategy 2 section.

Search strategy 4: searching for grey literature by key authors in the field

To detect further grey literature, we will include a specific search of publications by key authors focusing on the built environment. For this purpose, bibliographic information of the included records (from search strategies 1–3) will be checked for multiple publication by one author using Endnote V.20.[40] Key authors will be identified as persons authoring at least five of the included records (independent of first or coauthorship). Subsequently, one researcher (AF) will search for publications by these persons. Given that we will not be able to predict which author profiles will be found on which media, we will use an open search and consult researchgate.net, their

Table 2 Preliminary data charting framework

Item	Content
Study characteristics	► Title ► Author ► Year of publication ► Country/site of study ► Aim/objectives ► Study design (if applicable) ► Research questions
Participants	► Participants (eg, degree and form of dementia, age, ability to communicate, involvement of relatives in the study, demographic variables) ► Factors that hinder and promote the active involvement of people living with dementia in research about the built environment (primary or secondary focus)
Methods of involvement	► Ways that researchers make involvement possible ► Ways to participate in data collection ► Summary of data collection ► Applied assessment tools
Environment	► Setting (eg, home, assisted living facilities, residential long-term care facilities) ► Environmental features or design principles of interest

Google Scholar profiles, and their institutional/personal homepages, according to the availability of these online sources. The bibliographic information of appropriate articles will be entered into the Excel sheet.

Additional ways of searching for literature

To obtain further publications on methods presented in the included records (especially for included grey literature), we will use both backward citation tracking via reference lists and forward citation tracking using Google Scholar, performed by one researcher (AF), for the included full texts from search strategy 1.[41]

Source of evidence selection

For search strategy 1, identified records will be imported into Covidence[42] and will be checked automatically for duplicates. Subsequently, two researchers (AF and SK) will perform a title-abstract screening of the records independent of each other. Similarly, full-text screening will be conducted, and the reasons for exclusion will be listed.

Records identified by search strategies 2 and 3 and additional search efforts (ie, searches for key authors and citation tracking) will first be collected in Endnote V.20,[40] and those with an abstract will be uploaded to Covidence,[42] where they will first be checked for duplicates and for further screening as performed in strategy 1.

To apply the eligibility criteria to peer-reviewed articles as well as to project reports and magazine articles with a common understanding, a pilot screening of 20–30 records will be carried out independently by two researchers (AF and SK) using different sources of evidence.[43] If there is disagreement regarding the inclusion of literature throughout the screening process (title-abstract and full text screening), both authors will discuss these cases and attempt to reach an agreement. If an agreement cannot be reached, a decision will be made jointly by all coauthors. The selection process for the literature review will be documented using the PRISMA flow chart.[44]

Data extraction

Data extraction is planned using the data charting framework shown in table 2, which follows the methodological recommendations of the Joanna Briggs Institute.[45] One researcher (AF) will initially extract data from two articles (from search strategy 1 and search strategy 3) to pilot the extraction process using Microsoft Excel. Subsequently, the coauthors will review the extracted content for consistency and accuracy regarding the two research questions. Following potential modifications, data extraction will be performed by one researcher at a time and reflected during the process of data extraction with the project team.

Data synthesis

Two researchers will perform the initial synthesis of the data (AF and SK). The results will be discussed with the coauthors regarding the two research questions. We will present the findings in text and tables. In addition, we plan to develop a graphic representation to describe and conceptually map recurring environmental aspects and overlapping methods used in the included studies.

Patient and public involvement

We will discuss our findings with practitioners from residential long-term care facilities and involve long-term care professionals from our network. The aim is to evaluate the barriers and facilitators to the involvement of people living with dementia to determine whether they can be addressed through changes in practical application methods. Recognising the vulnerability of different groups of people, we want to prepare as effectively as possible for future consolidation within a funded project. This dialogue can serve as a basis for including people living with dementia in discussions regarding highlighted barriers when researching their perspectives on the built environment and taking into account their different capacities for getting involved into research.

Ethics and dissemination

We raised no ethical concerns for the planned scoping review. Long-term care practitioners from our network will be invited to participate in the scoping review based on their expertise to provide practice-oriented reflection. The themes of our analysis will be published in both scientific (healthcare research focus) and non-academic journals relevant to architects, environmental planners and designers to reach the previously identified diverse populations involved within these disciplines. Additionally, we will present the topics at (inter)national conferences and include them in future project planning and grant applications.

Contributors AF and SK designed the scoping review and drafted the planned process. MR and BH critically revised and substantially supervised this process. AF and SK prepared the initial draft of the protocol, MR and BH revised the manuscript. All authors have read, reviewed and approved the final manuscript.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

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Supplementary Material – Protocol SR-MethoDe-BE

Supplementary table 1. Search for MEDLINE via PubMed

Search No.	Terms/Keywords
#1	Dementia[Title/Abstract]
#2	Alzheimer*[Title/Abstract]
#3	“Pick disease”[Title/Abstract:~0]
#4	“Lewy body”[Title/Abstract:~0]
#5	Dementia[MeSH Terms]
#6	**#1-#5/OR**
#7	“Physical environment”[Title/Abstract:~0]
#8	“Built environment”[Title/Abstract:~0]
#9	Environment design[MeSH Terms]
#10	Safety[MeSH Terms]
#11	Small?size[Title/Abstract]
#12	“Wayfind*[Title/Abstract]
#13	“Spatial layout”[Title/Abstract)
#14	“Familiar*”[Title/Abstract]
#15	accessibility, architectural[MeSH Terms]
#16	orientation, spatial[MeSH Terms]
#17	social interaction[MeSH Terms]
#18	community integration[MeSH Terms]
#19	social engagement[MeSH Terms]
#20	Home?like[Title/Abstract]
#21	outdoor[Title/Abstract]
#22	quiet room[Title/Abstract]
#23	floor[Title/Abstract]
#24	dining room[Title/Abstract]

Supplementary Material – Protocol SR-MethoDe-BE

#25	kitchen[Title/Abstract]
#26	furnish*[Title/Abstract]
#27	Large scale[Title/Abstract]
#28	home environment[MeSH Terms]
#29	gardens[MeSH Terms]
#30	personal space[MeSH Terms]
#31	light[MeSH Terms]
#32	paint[MeSH Terms]
#33	color[MeSH Terms]
#34	**#7-#33/OR**
#35	**#6 AND #34**
#36	*Filter applied: Period of publication: 10 years*

Supplementary table 2. Search for CINAHL via Ebsco

Search No.	**Terms/Keywords**
#1	AB dementia
#2	AB alzheimer*
#3	AB pick W1 diseas*
#4	AB lewy W1 body
#5	MH dementia
#6	**#1-#5/OR**
#7	AB physical W1 environment
#8	built W1 environment
#9	MH built environment
#10	MH facility design and construction
#11	MH safety

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#12	AB small-size or AB small W1 size
#13	AB orientation
#14	AB wayfind*
#15	AB familiar*
#16	AB interaction W1 space
#17	MH sensory stimulation
#18	AB engagement
#19	MH architectural accessibility
#20	MH cognitive orientation
#21	MJ nursing home design
#22	MJ interior design
#23	AB color
#24	AB paint
#25	AB light
#26	AB architecture
#27	AB kitchen
#28	AB room
#29	AB floor
#30	AB home-like OR AB homelike
#31	AB garden*
#32	**#6 AND #32**
#33	**#42 NOT #43** Limiters - Published Date: 20130101-20231231;

Supplementary Material – Protocol SR-MethoDe-BE

Supplementary table 3. Search for APA PsycInfo via EBSCO

Search No.	Terms/Keywords
#1	AB dementia
#2	AB alzheimer*
#3	AB pick W1 diseas*
#4	AB lewy W1 body
#5	MH dementia
#6	**#1-#5/OR**
#7	AB physical W1 environment
#8	AB built W1 environment
#9	MH built environment
#10	MH facility design and construction
#11	MH safety
#12	AB small-size or AB small W1 size
#13	AB orientation
#14	AB wayfind*
#15	AB familiar*
#16	AB interaction W1 space
#17	MH sensory stimulation
#18	AB engagement
#19	MH architectural accessibility
#20	MH cognitive orientation
#21	MJ nursing home design
#22	MJ interior design
#23	AB color
#24	AB paint

Supplementary Material – Protocol SR-MethoDe-BE

#25	AB light
#26	AB architecture
#27	AB kitchen
#28	AB room
#29	AB floor
#30	AB home-like or AB homelike
#31	AB garden*
#32	**#7-#31/OR**
#33	**#6 AND #32**
#34	Limiters: Publication Year: 2013-2023

Supplementary table 4. Search for Scopus

Search No.	**Terms/Keywords**
#1	TITLE-ABS-KEY (dementia)
#2	TITLE-ABS-KEY (alzheimer*)
#3	TITLE-ABS-KEY (pick W/0 diseas*)
#4	TITLE-ABS-KEY (lewy W/0 body)
#5	**#1-#4/OR**
#6	TITLE-ABS-KEY (built W/0 environment)
#7	TITLE-ABS-KEY (physical W/0 environment)
#8	TITLE-ABS-KEY (environment* W/5 design)
#9	**#6-#8/OR**
#10	**#5 AND ##9**
#11	**Limits:** PUBYEAR > 2012 AND PUBYEAR < 2024

Supplementary Material – Protocol SR-MethoDe-BE

Supplementary table 5. Search for Google Scholar

Search No.	Terms/Keywords
#1	dementia AND built environment AND involvement
#2	dementia AND built environment AND project
#3	dementia AND built environment AND research