Scoping review of methods for engaging long-term care residents living with dementia in research and guideline development

Caitlin McArthur, Niousha Alizadehsaravi, Adria Quigley, Rebecca Affoo, Marie Earl, Elaine Moody

ABSTRACT

Objectives To describe: (1) methods used to engage long-term care (LTC) residents living with dementia in research and guideline development; (2) the outcomes of engagement; and (3) barriers and facilitators to engagement.

Design Scoping review.

Search strategy We conducted searches in Academic Search Premier (EBSCO), APA PsychInfo (EBSCO), CINAHL (EBSCO), Medline (OVID), Embase (Elsevier), Web of Science and the Cochrane database, and a structured grey literature search in July 2021 and updated in March 2023. We included studies that described or evaluated resident engagement, defined as including residents living with dementia in the process of developing healthcare guidelines or research which could include collaborators or partners in planning, execution or dissemination of the guideline or research. Title, abstracts and full-texts were screened for eligibility by two team members using a pilot-tested process. Data were extracted from included studies independently and in duplicate by two team members using a pre-tested data extraction form. Results were narratively synthesised according to the research question they addressed.

Results We identified three studies for inclusion. Residents were engaged at the beginning of the research projects through interviews, focus groups, and consultations. None of the included articles described the outcomes of engagement. Barriers to engagement were predominantly at the resident level, including impaired verbal communication limiting resident's abilities to participate in discussions, while increased time to support engagement was reported as a barrier at the resident and research team levels.

Conclusions We found a small body of literature describing the engagement of LTC residents in health research and guideline development. Future work should explore alternative methods to engage LTC residents living with dementia, including art-based methods, and the effect of including resident engagement. Guideline developers and researchers should ensure adequate time and human resources are allocated to support engagement.

BACKGROUND

Patient engagement has become recognised as an essential component of health research and guideline development. Health guidelines include evidence-based recommendations for health practice, public health or health policy. Patient engagement is defined by the Canadian Institutes of Health Research as patients becoming partners in the project through active engagement in governance, priority setting, developing the research questions, performing parts of the research, and summarising or sharing the results with target audiences. The goal of patient engagement is to collaboratively build sustainable, accessible and equitable healthcare systems to support positive health changes.

Patient engagement profoundly affects the guideline development and research process by changing the way they are conceptualised, conducted and disseminated. For example, patients can help identify priority health areas, determine if treatment effects are meaningful, weigh risks and benefits of treatment options, analyse cost impacts and assess acceptability and feasibility of

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This is the first synthesis of methods to engage long-term care (LTC) residents living with dementia in research and guideline development.
⇒ Our scoping review identifies gaps in current methods used for engagement of LTC residents living with dementia in research and guideline development and points to strategies for engagement and opportunities for developing new methods in the future.
⇒ Our scoping review provides a description of the evidence available to date, however, we did not assess the quality of the literature as part of our scoping review and cannot comment on the effect of engagement on outcomes.
⇒ We only included studies published in English, limiting our results to English-speaking countries or those who can pay for translation services.
treatments. Patient engagement is essential to developing and conducting useful, patient-centred guidelines and research by acknowledging that patients are experts and are empowered and informed consumers in healthcare decisions. Indeed, patient engagement ensures inclusion of patient-relevant topics, assessment outcome selection and helps to establish institutional policies grounded in respect, trust, reciprocity and co-learning. Although there are many benefits to patient engagement, patient involvement in research and guideline development remains limited. This is especially true for people with perceived and actual communication difficulties, like those living with dementia in long-term care (LTC).

LTC is a home for people who are unable to live independently and require 24-hour specialised care including nursing, personal care, support and/or supervision. LTC residents often live with multiple complex health conditions affecting their physical and cognitive health. As many as 95% of LTC residents require assistance with basic activities of daily living such as grooming, dressing, walking, transferring and feeding themselves. Further, 69% of residents have a primary diagnosis of dementia while 87% experience cognitive impairment resulting from other primary diagnoses like stroke or traumatic brain injury. LTC residents living with dementia are often not included in patient engagement because of difficulty verbally communicating thoughts and feelings. Dementia often leads to vague and empty speech, waning vocabulary, and altered linguistic reasoning and word association patterns, which limits the ability to convey meaning to the researchers and guideline developers.

While the highest number of people living with dementia are community-dwelling, LTC has the highest proportion of residents living with dementia in any care setting. Therefore, any guideline that is developed for LTC and any research conducted in LTC will affect residents living with dementia. Resident-centred care is considered the gold standard approach in LTC that shifts from a traditional biomedical model to a more individualised approach focusing on resident goals. It has been shown to be effective in reducing negative resident outcomes, like behaviour symptoms and psychotropic use. Including the residents’ voice in guideline development and research is one step towards supporting resident-centred care and potentially improving outcomes. LTC residents could be involved in many steps of the research and guideline development process including identifying priority topics and research questions, providing input on resident preferences for treatment, and informing and supporting knowledge translation and dissemination strategies. Topics of care that may require guideline development or research in LTC with resident input include, but are not limited to, fall and fracture prevention, deprescribing, mood, quality of life and social engagement. While previous work has synthesised patient engagement in research related to dementia in general, the vast majority of this work has been done with community-dwelling older adults living with dementia and/or their care partners. Some principles may be transferable to the LTC setting, but many aspects of care for people living with dementia in LTC are unique. For example, a higher proportion of residents living with dementia in LTC will be in the later stages of dementia than in the community and verbal communication will be more impaired. As such, methods for engagement in research and guideline development will need to be different for this population and their appropriateness will depend on their stage of dementia.

The term ‘patient’ in patient engagement is defined by the Canadian Institutes of Health Research as ‘an overarching term inclusive of individuals with personal experience with a health issue and informal caregivers, including family and friends’. In Canada, people living in LTC are referred to as ‘residents’ rather than ‘patients’. Further, ‘person living with dementia’ is the preferred term for a person with dementia. Therefore, from here forward rather than ‘patient engagement’ we will use the term ‘engagement of LTC resident living with dementia’.

To ensure recommendations and guidelines reflect topics and include actions that are important to LTC residents, researchers and guideline developers must overcome communication challenges with LTC residents living with dementia. The best strategies and methods to do this remain unknown. Therefore, the purpose of this scoping review was to synthesise what is known about methods to engage LTC resident with dementia in health research and guideline development and identify gaps in research where new methods may need to be developed. Our specific objectives were to describe the: (1) methods that have been used to engage LTC residents living with dementia in research and guideline development; (2) outcomes of engagement; (3) barriers and facilitators to engagement. We distinguish resident engagement from residents acting as research participants, with our scoping review focusing on the former. While engagement of caregivers and family members may be one way to overcome the challenge of communication for LTC residents living with dementia, we chose to focus on engagement with the residents themselves as this is an area lacking evidence. A scoping review methodology was chosen to capture the breadth of literature on this topic and to include a variety of publication types, as many organisations may have engaged LTC residents but have not published their work in peer-reviewed publications. The results of the scoping review will be used to inform a larger programme of research where LTC residents will be engaged in research and to identify opportunities for improving reporting and implementation of resident engagement in future work conducted in LTC.

**METHODS**

As described in the published protocol, this scoping review was conducted in accordance with the PRISMA extension for Scoping Reviews (PRISMA-ScR).

**Supplemental file 1—PRISMA ScR Checklist**, and the
framework and suggestions proposed by Arksey and O’Malley, and Levac et al.

Research questions
The research team defined three a priori research questions for the scoping review:
1. What methods have been used to engage LTC residents living with dementia in research and guideline development?
2. What are the outcomes of resident engagement?
3. What are the barriers and facilitators to resident engagement?

Patient and public involvement
We received feedback and suggestions on our protocol and interpretation of our results from stakeholders including residents living with dementia and family members in LTC, healthcare professionals (therapeutic recreation specialists, physiotherapists, nurses and healthcare aides) and representatives from the Alzheimer’s Society of Nova Scotia. We met with our stakeholders two to three times over the course of the project to gain their feedback. For the protocol, stakeholders provided input on the inclusion and exclusion criteria, research questions and data items to be extracted. They also provided input on the interpretation of our results, recommendations for resident engagement in future research and guideline development, and mechanisms of disseminating the results.

Information sources
Licensed databases
Systematic searches for peer-reviewed articles were conducted in the following licensed databases from inception with no language limitations: Academic Search Premier (EBSCO), APA PsycINFO (EBSCO), CINAHL (EBSCO), Medline (OVID), Embase (Elsevier), Web of Science and the Cochrane database. The search strategy used text and indexing terms to capture the key concepts: resident (patient) engagement, research and guideline development and dementia. Concepts combined with the Boolean Operator AND, and the search terms within each concept were combined with OR. Truncation and phrase symbols were used when appropriate, to capture comprehensive results. The search strategy was developed and executed by a research librarian at Dalhousie University. See online supplemental file 2 for the full search strategy.

Grey literature
Guided by the Canadian Agency for Drugs and Technologies in Health Grey Matters Tool, we conducted a grey literature search pertaining to research and guideline development including LTC resident engagement. We used the search terms: long-term care, dementia, research, guideline development, engagement and participation.

Handsearching
We searched the reference lists of included articles for additional relevant citations. We also contacted the researchers and opinion leaders in patient engagement for people living with dementia to gather additional articles.

Eligibility criteria
We included all study designs including qualitative studies, case studies, mixed-methods, prospective, longitudinal, retrospective case–control, randomised controlled trials and quasi-randomised clinical or controlled trials. Studies included LTC residents defined as individuals who reside in a residential home for people who are unable to live independently, requiring access to nursing, personal care, support and/or supervision, with a mean age of 65 years or older and a dementia diagnosis. Included studies described research or evaluate resident engagement, defined as including residents living with dementia in the process of developing healthcare guidelines or research which could include collaborators or partners in planning, execution or dissemination of the guideline or research. We excluded editorials, clinical commentaries, lectures, legal cases, letters, newspaper articles, patient education handouts or unpublished literature, and articles that were not in English.

As we initially expected, we had a small number of articles where LTC residents living with dementia were included in research and guideline development. As defined a priori, we extended our inclusion criteria to capture engagement of LTC residents living with or without dementia, since many residents in LTC have dementia. With this extension, we achieved our a priori defined minimum of at least three articles to synthesise. Thus, we did not extend our inclusion criteria further to capture people living with dementia of any age living in the community.

Selection of sources of evidence
Two team members reviewed the title and abstract of identified articles and applied the inclusion and exclusion criteria outlined above and in the protocol. Full-text articles that met the inclusion criteria were reviewed by the same two team members. Disagreements in the inclusion/exclusion of articles were resolved through discussion with a third team member. The screening process was pilot tested on 5% of articles with no modification required. In accordance with the PRISMA framework, reasons for exclusion of the full-text articles were documented and are reported below. Reviewers used the Covidence software (Veritas Health Innovation, Melbourne, Australia) to organise and manage all aspects of the review (eg, selection, data extraction).

Charting the data
A pilot-tested data extraction form, designed by the research team, was used to extract data. Two team members used the pretested data extraction form to chart the data from the included articles independently and in duplicate. Disagreements were resolved by a third team member. We extracted the following data from each article: study title and country, characteristics of included
studies (aim of study, research question addressed, study design, description of guideline being developed), characteristics of participants (sample size, age, gender/sex, level of cognition, comorbidities, functional status, description of dementia type), research question 1: methods of engagement (type of engagement, stage of engagement, amount of time spent engaged, how many residents engaged, recruitment methods for residents engaged), research question 2: outcomes of resident engagement (resident and research team outcomes, level of engagement and satisfaction, guideline development outcomes, outcome measure used), research question 3: barriers and facilitators to resident engagement (resident level, research team level and organisational level).

Summarising and reporting the findings
To provide an overall summary of the results, we used descriptive statistics to describe the articles, year of publication and country of origin. We further described the results according to the research question addressed as detailed below.

Research question 1: methods of engagement
We described the methods of engagement in table format including the type, timing and duration of the engagement, how many residents were engaged, other stakeholders who were engaged and how residents were recruited. We reported the range, mean and SD of duration of engagement and how many residents were engaged in the narrative of the results section.

Research question 2: outcomes of engagement
Engagement outcomes were described through a narrative report at three different levels: resident, research team and research or guideline development. For example, resident satisfaction with guideline development was an example of an engagement outcome.

Research question 3: barriers to engagement
Guided by the principles of thematic content analysis, we grouped barriers to engaging residents in research or guideline development into themes and reported them in a table by the level at which the barriers exist. A priori, we identified three levels (resident, research team and organisational level). This study does not involve human participants. Research ethics board approval was not required.

RESULTS
Description of studies and resident characteristics
We included 3 of the 8442 articles identified in the initial search (figure 1). No relevant grey literature documents were found. Table 1 provides a description of the studies included and the research questions they addressed. Two articles addressed research question 1 and two addressed research question 3 and all the articles described research rather than guideline development. None of the identified articles addressed research question 2.

The included studies were conducted in the Netherlands, Canada and the UK and were published between 2015 and 2018. One study was described as an explanatory case study, one was qualitative and one employed a mixed methodology. The study by Span et al described development of a web tool for supporting shared decision making, Fortune et al examined challenges experienced by participants with participatory action research, and Bowes et al aimed to co-design living environments for people living with dementia and sight loss.

The characteristics of included participants are summarised in table 1. The number of participants in the included studies ranged from 8 to 51, while gender and age were reported in only one study. Likewise, only the Span et al article described the participants’ level of cognitive impairment as mild to moderate dementia and reported specific dementia diagnoses. Participants’ other comorbidities were not reported in any of the studies.

Research question 1: what methods have been used to engage LTC residents living with dementia in guideline development? (n=2 articles)
For both articles that addressed this research question, data were gathered from the participants living with dementia before the research was completed through semi-structured interviews, focus groups and consultations. Interviews completed in Span et al lasted 30 to 60 min, while Bowes et al did not report the duration of engagement. Convenience sampling was used to recruit participants in one study, while the other did not report their sampling method. Likewise, one study reported that other stakeholders engaged in the project were healthcare providers, caregivers, family members and ‘other interested parties’, while it was unclear if other stakeholders were involved in the study by Bowes et al (table 2).

Research question 3: what are the barriers and facilitators to resident engagement? (n=2 articles)
Barriers reported at the resident level were verbal communication challenges limiting inclusion in discussions, stress, fear, confusion and uncertainty experienced by people living with dementia about the research process, and increased time to support resident engagement. For example, helping residents refocus after distractions and to reassure participants they were not being tested. Indeed, Span et al reported that meaningful participation with people living with dementia took more time than the interviews with other network members.

At the research team level, time was a barrier because research processes including resident engagement can be slow and reintroduction of new resident team members can take additional time at the beginning of every session. Only one facilitator was described by Fortune et al at the research team level, where they found welcoming new team members at each session created an
open and inclusive environment. Finally, at the organisational level human resources to support residents was a barrier, as an increased burden on informal caregivers can limit opportunities for engagement.21

**DISCUSSION**

We synthesised the literature describing engagement of LTC residents living with dementia in guideline development and research and found limited work in this

**Table 1** Characteristics of included participants

<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>Number included</th>
<th>Age, mean (SD)</th>
<th>Sampling technique</th>
<th>Level of cognitive impairment of included participants</th>
<th>Type of dementia</th>
<th>Description of comorbidities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Span et al21</td>
<td>2018</td>
<td>51</td>
<td>74.4 (5)</td>
<td>Convenience</td>
<td>Mild to moderate dementia</td>
<td>N=25 Alzheimer’s disease, N=6 vascular dementia, N=2 Lewy body dementia, N=18 unknown</td>
<td>NR</td>
</tr>
<tr>
<td>Fortune et al22</td>
<td>2015</td>
<td>25</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Bowes et al23</td>
<td>2018</td>
<td>8</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>NR, not reported.</td>
<td></td>
<td></td>
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</tbody>
</table>
area. All included articles described research rather than guideline development, where residents were engaged at the beginning of the project through interviews, focus groups and consultations. None of the included articles described the outcomes of engaging LTC residents living with dementia in the work. Barriers to resident engagement were predominantly at the resident level, including impaired verbal communication limiting resident’s abilities to participate in discussions. Likewise, increased time to support engagement was reported as a barrier across resident and research team levels. Despite the limited body of work available, suggestions for guideline developers and researchers and future work can be gleaned, as described below.

First, determining the most appropriate type of engagement for LTC residents is essential to support engagement. Importantly, impaired verbal communication was identified as a barrier, yet the included articles chose verbal activities (ie, interviews, focus groups, consultations) as the type of engagement. While some examples of how residents could be supported to engage verbally were provided (eg, providing time to answer questions), limiting engagement to verbal methods may exclude residents who cannot or are not comfortable contributing verbally. Further, focus groups are not ideal activities for people with communication impairments who may become easily distracted. Innovations in ways to engage LTC residents living with dementia in research can help overcome this barrier. One example could be arts-based methods to support engagement. A qualitative study by Hazzan et al.24 found that an arts-based programme allowed LTC residents with moderate to severe dementia to share their thoughts and opinions and make their wishes known. This is an emerging area of work and has mainly focused on methods to support LTC residents living with dementia as participants in research studies rather than as patient partners to inform and guide the research process. Future work should explore how arts-based methods could support LTC residents to provide their input in research priorities, designing methods and interpretation of results.

A very limited discussion of strategies to support engagement of LTC residents living with dementia was found in only one of the included articles, with suggestions of providing time for residents to respond, conducting meetings in a familiar environment and checking in to see if residents understood. Previous work has underscored the importance of including people with communication difficulties in research, particularly those who are typically excluded or considered vulnerable.25 However, like the results of the current review, there are currently no universally accepted guidelines for the inclusion of people with communication disorders such as dementia in research.26 Work by Kagan et al.27 with adults with aphasia and Bourgeois et al.28 29 with residents living with dementia point to several strategies to improve communication: diversifying communication modalities (eg, provide photos, written material, videos, objects, allow participants to respond by writing or drawing) and having flexibility with which strategy to use, working in a quiet environment, removing sensory barriers (eg, using hearing aids and glasses where necessary), promoting trust and patience in the interaction and ensuring participant understanding (eg, paraphrasing or asking alternate questions).26 The effectiveness of these communication strategies for improving resident engagement and satisfaction with engagement have not been examined to date, but they have been shown to positively affect quantitative and qualitative conservation outcomes.28 Likewise, none of our included articles examined the

### Table 2 Research question 1: what methods have been used to engage LTC residents living with dementia in guideline development?

<table>
<thead>
<tr>
<th>Study, year</th>
<th>Type of engagement</th>
<th>Methods to support engagement</th>
<th>Stage of engagement</th>
<th>Time spent engaged</th>
<th>No of residents engaged</th>
<th>Other stakeholders engaged</th>
<th>Recruitment methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bowes et al, 201823</td>
<td>Consultations and focus group</td>
<td>Conducting work in their familiar environment at their own pace, plenty of time given to comment, and checking that they understood the process</td>
<td>Before guideline development</td>
<td>Not reported</td>
<td>Four for initial consultation, and four for focus group</td>
<td>Healthcare providers, caregivers, family members, ‘other interested parties’</td>
<td>Not reported</td>
</tr>
<tr>
<td>Span et al, 201821</td>
<td>Semi-structured interviews</td>
<td>Not reported</td>
<td>Before guideline development</td>
<td>One-time interview lasting 30–60 min</td>
<td>Five of the 23 participants resided in a long-term care home</td>
<td>Unclear</td>
<td>Convenience sampling</td>
</tr>
</tbody>
</table>

LTC, long-term care.
outcomes of resident engagement. Future work should explore the effect of supportive communication strategies on outcomes of resident engagement such as level of engagement, satisfaction and changes to research process or outcomes resulting from engagement.

Because LTC residents living with dementia may be experiencing communication difficulties for a variety of reasons (eg, dementia stage, expressive aphasia), researchers and guideline developers should not assume a ‘one size fits all’ approach to choosing which strategies to employ. Instead, researchers and guideline developers should assess the individual resident’s communication needs, preferences and strengths and determine the most appropriate communication strategy to facilitate their engagement. For example, arts-based methods may be more appropriate for residents living with more severe stages of dementia, where verbal communication is difficult or no longer possible while supported verbal communication strategies (eg, increased processing time, images provided to support meaning) may still be appropriate for those in earlier disease stages.

Finally, engagement of residents living with dementia was described as taking time and requiring human resources to support communication. Indeed, previous work suggests that providing adequate time for people with communication difficulties to respond is important. In LTC, additional human resources may be required by the home to support residents to travel to the location of the interaction, whether the activities take place in (eg, walk or wheelchair resident to an activity room) or outside (eg, assist resident with transportation) of the home. Further, a trusted care partner may be able to help with interpretation and provide context of the resident’s communication (eg, understanding facial expressions or verbalisations, relate seemingly unrelated stories to previous life events). Guideline developers and researchers wishing to engage LTC residents living with dementia in their processes are urged to ensure adequate planning for time and resources to fully support meaningful interactions. Likewise, funding agencies should budget for these activities to reduce the burden on participants and caregivers, particularly those who belong to equity deserving groups.

There are similarities between our results and work completed synthesising patient engagement with people living with dementia in the community. Like our results, Bethell et al found that very few studies conducted in the community assessed the impact of patient engagement and that barriers included time and resources. In contrast, fewer studies conducted with community-dwelling older adults identified impaired verbal communication as a limitation for patient engagement. Because those living in the community with dementia are generally in earlier stages of the disease process, their verbal communication is usually less impaired than those in LTC. Thus, strategies to enhance and support verbal communication, or alternative to verbal communication, are especially important for patient engagement in LTC.

Our scoping review is the first to synthesise what is known about engagement of LTC residents living with dementia in guideline development and research. A limitation of our work is that we only included articles in English, limiting the review to English-speaking countries or to researchers who have funds for translation services. We only included studies where participants were 65 years or older, meaning we could have excluded articles where participants experienced early onset, atypical forms of dementia or indigenous populations where chronic diseases like dementia may present much earlier than 65 years. However, the primary reason we excluded articles was that they were not conducted in LTC, and we did not exclude any articles that were conducted in LTC where participants were aged less than 65 years. Thus, we feel confident we did not miss any articles by applying this inclusion criterion. As work progresses in this area, we suggest future authors consider including younger populations. The study conducted by Span et al included both LTC residents and community-dwelling older adults living with dementia. Since we did not specify a priori that articles must describe LTC residents and community-dwelling older adults separately, this article met our inclusion criteria and was included in the scoping review. The results of the study by Span et al and thus the results of our scoping review could be affected by the fact that most of their participants were living in the community. However, we were able to extract the data collection methods that were used for all participants in this study, including those in LTC, and the results were consistent with the other two studies included in this review. As per our a priori protocol, we did not assess the quality of the literature included in our scoping review, limiting our ability to comment on the effect of engagement on outcomes. Although our review only included three articles, our results identify important gaps and suggest opportunities for future work in engagement of LTC residents living with dementia in health research and guideline development.

CONCLUSION
We found a small body of literature describing the engagement of LTC residents in health research and guideline development. Residents were engaged at the beginning of the research projects through interviews, focus groups and consultations. Barriers to engagement were predominantly at the resident level, including impaired verbal communication limiting resident’s abilities to participate in discussions, while increased time to support engagement was reported as a barrier at the resident and research team levels. Future work should explore alternative methods to engage LTC residents living with dementia, including arts-based methods and the effect of including resident engagement. Guideline developers and researchers should ensure adequate time and human resources are allocated to support engagement.
REFERENCES


