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BMJ Open Social integration and loneliness among long-term care home residents: protocol for a scoping review

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ABSTRACT

Introduction Social well-being is associated with better physical and mental health. It is also important for quality of life, including from the perspectives of those living in long-term care (LTC) homes. However, given the characteristics of the LTC home environment and the people who live there, the nature and influence of social integration and loneliness, and strategies to address them. may differ in this population compared with those living in the community. The objective of this scoping review is to provide an overview of the nature and extent of research on social integration and loneliness among LTC home residents, including a summary of how these concepts have been operationalised and any evidence from specific

Methods and analysis This study protocol describes the methods of a scoping review of peer-reviewed literature related to social integration and loneliness among LTC home residents. A literature search was developed by an Information Specialist and will be conducted in MEDLINE(R) ALL (in Ovid, including Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily) and then translated into CINAHL (EBSCO), PsycINFO (Ovid), Scopus, Sociological Abstracts (Proquest), Embase and Embase Classic (Ovid), Emcare Nursing (Ovid) and AgeLine (EBSCO). Two reviewers will independently screen titles and abstracts of articles identified in the search. Two reviewers will then independently review full text articles for inclusion. Data extraction will also be carried out in duplicate. We will engage LTC home community members, including residents, family and staff, to refine the review questions, assist in interpreting the results and participate in knowledge translation.

Ethics and dissemination Ethics approval is not required. We will present findings at conferences and publish in a peer-reviewed journal. Ultimately, we hope to inform future observational and interventional research aimed at improving the health and quality of life of LTC home residents.

INTRODUCTION

Social support, from our family, friends and community, has been recognised for decades as a key determinant of health. 2 Systematic reviews suggest protective effects of social support and social engagement on health

Strengths and limitations of this study

- ► To our knowledge, our review will be the first to systematically summarise published, peer-reviewed articles of observational and intervention studies related to social integration and loneliness among long-term care home residents.
- Our protocol documents a rigorous and transparent methodology.
- Our goal is to identify gaps in the literature and make recommendations for future research.
- Inconsistent terminology is an acknowledged issue in this area of research, particularly for research related to social integration; we have attempted to develop a comprehensive search strategy that encompasses multiple search terms but still acknowledge some relevant journal articles may not
- We are limiting our search to peer-reviewed journal articles published in English and recognise some relevant research will not be included.

outcomes (including mortality,3 cognitive functioning, 4 dementia, 5 and coronary heart disease and stroke⁶) as well as negative health impacts of loneliness.⁷⁸

However, research on the influence of social factors on health has noted limitations including inconsistent terminology, inattention to the multiple aspects of social factors and an incomplete understanding of the biological mechanisms underlying these relationships.⁷ 9-12 A conceptual framework for social integration, proposed by Berkman et al, describes a process whereby macrosocial contexts (ie, cultural, socioeconomic status, politics and social change) influence the development and structure of social networks which in turn provide opportunities for specific psychosocial mechanisms (including social support and social engagement); ultimately, these 'downstream' psychosocial mechanisms may influence health status by buffering physiological stress responses,





imparting positive psychological states and traits and reducing negative health behaviours. Building on this work, Uchino examined evidence for how these social mechanisms influence health through cardiovascular, neuroendocrine and immune function, but also highlighted the potential for reciprocal relationships among the various factors; importantly, social support and social engagement may influence health and vice versa. 10 Loneliness, the separate but overlapping concept describing one's subjective perception of the number or intimacy of relationships, 13 is thought to influence health through neural mechanisms.⁷ While loneliness has generally been considered distinct from social support and social engagement, 45 others have found that perceived isolation (eg, loneliness) may mediate the relationship between these factors and mental health. 11 For consistency, we will hereafter use the term social integration 9 12 to encompass concepts such as social networks, social support and social engagement, and loneliness to denote it as a distinct phenomenon.

Social integration and loneliness have been identified in the context of improving quality of life for those living in long-term care (LTC) homes¹⁴ (similarly defined as nursing homes or care homes), including specifically from the perspectives of LTC home residents. 15 16 However, given the characteristics of both the LTC home environment (ie, shared living space, provision of nursing and personal care, social and recreational programme and so on) as well as the people who live there (ie, mostly over age 65 years 17-19 and with complex healthcare needs, often including cognitive impairment), 18 19 the nature and influence of social integration and loneliness, as well as strategies to address them, may differ in this population compared with those living in the community. This is not to say that increasing age necessarily brings social isolation¹¹ or that LTC homes cannot offer residents opportunities for meaningful social engagement,²⁰ but despite these differences, very little research in this area has been focused on those living in LTC homes.²¹

To our knowledge, there is no systematic summary of the literature related to social integration and loneliness among those living in LTC homes. Mikkelsen *et al*² and Brimelow and Wollin²³ have provided a detailed reviews of the literature on interventions targeting social integration and loneliness among LTC home residents; however, they did not consider evidence from observational studies, nor did they summarise approaches to measuring social integration and loneliness in this population. Victor summarised how measurement of loneliness has been operationalised in this population, but searched only one bibliographic database and limited to studies reporting prevalence of loneliness.²¹

In this paper, we present the protocol for a scoping review on social integration and loneliness among LTC home residents. The objective of our scoping review is to provide an overview of the nature and extent of research on this topic, including a summary of how these concepts have been operationalised as well as any evidence from specific groups within LTC homes. With this information, we intend to identify gaps in the literature and make recommendations for future research.

METHODS

We will conduct a scoping review to examine the literature on social integration and loneliness among LTC home residents. We chose a scoping review for our knowledge synthesis in order to address a broad set of research questions, with a flexible and iterative approach, on a research topic where we expect the limited number of studies will preclude a systematic review.²⁴

Patient and public involvement

During the conduct of this review, we will engage LTC home members, including residents, family and staff, to refine the questions, assist in interpreting the results and participate in knowledge translation. Our study team includes individuals with experience of living and working in LTC homes and we are also extending our involvement to include others at a LTC home, namely:

- 1. Residents' council: an independent, self-determining group made up of only the LTC home residents. Through Ontario's LTC Homes Act, 2007, every LTC home licensee must establish a residents' council at the home.²⁵ The council is intended to represent all residents who reside in the LTC home and provide advice and recommendations to the LTC home on ways to improve care or the quality of life in the home, and to provide peer to peer support as well as plan activities and collaborate with community groups. All residents are invited and encouraged to attend and participate in council meetings. Some are not cognitively able to participate due to impairment, others choose not to participate. The residents' council meets monthly and, on average, approximately eight residents attend the monthly meeting.
- 2. Family council: an organised, self-determining group composed of family and friends of the LTC home's residents. Family council works with residents' family and friends and the LTC home to identify and resolve issues affecting residents' quality of life, plan activities for residents, families and staff, support each other and offer a forum for sharing their experiences, learning and exchanging information. Family councils are included in the LTC Homes Act, which outlines the LTC home's obligations to support the establishment of a council. ²⁶ The family council meets monthly and has a membership of 12 family members.
- 3. Staff meeting: a regular forum for all staff at the LTC home, including nurses, personal support workers, activity and therapy staff, social worker, dietary aides, dietitian, housekeeping staff and management.

We will present to each of these groups twice. At the first meetings, early in the conduct of this study, we will provide an overview the scoping review and ask for discussion and input to refine the research questions (see



Identifying the research questions section). At the second presentations, which will take place after compiling the study data, we will ask for input on interpreting the results (see Consulting with stakeholders section).

Key concepts: social integration and loneliness

For our review, we consider research on social integration 12 to include:

- 1. *Social networks*, that is, size and nature of the social network structure as well as the characteristics of the social ties, and acknowledge that it is these networks that provide opportunities for social support and social engagement.⁹
- 2. Social engagement, that is, taking part in real-life activities with others, ^{9 27} as well as the converse, social disengagement. ²⁸
- 3. *Social support*, that is, instrumental, emotional, appraisal and informational help available, 9 as well as *social isolation*, that is, lack of personal relationships with family, friends and acquaintances on which people can fall back in case of need. 29
- Social capital, that is, features of an organisation that facilitate coordination and communication for mutual benefit, such as interpersonal trust, reciprocity and mutual aid. 12 30

However, acknowledging the diversity of terminology used in this area of research, our search strategy will use a broader list of terms (see online supplementary appendix A). The subjective experience of social integration, including *loneliness*¹³ and *perceived isolation*, ¹¹ are also explicitly included.

Six-stage scoping review approach

Our methods follow the six-stage approach described by Arksey and O'Malley³¹ and Levac *et al*⁶²: (1) identifying the research questions; (2) searching for relevant studies; (3) selecting studies; (4) charting the data; (5) collating, summarising and reporting the results; and (6) consulting with stakeholders. We will report our results in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews.³³ Our study team was formed to include experienced clinicians and researchers and an information specialist, all of whom have experience in scoping review methodology.^{34–37}

Identifying the research questions

The research questions proposed at the outset of this scoping review are listed below, but may be revised after consulting with LTC home community members (see Patient and public involvement section).

- 1. How have the concepts of social integration and loneliness been defined and measured in studies of LTC home residents?
- 2. Have social integration and loneliness been addressed in specific individuals and groups within LTC homes (eg, those with impaired communication or cognitive impairment)?

- 3. What factors have been studied for an association with social integration and loneliness among LTC home residents? (this includes studies whereby social integration and/or loneliness are the exposure(s) as well as those where they are the outcome(s))
- 4. What interventions have been evaluated to increase social integration and/or decrease loneliness among LTC home residents? (this includes studies whereby addressing social integration and/or loneliness are part of the intervention and/or assessed as the outcome(s)).

Searching for relevant studies

Published journal articles reporting results of observational and intervention studies will be eligible for inclusion if they report a measure of social integration or loneliness (descriptive, exposure or outcome) in a population of adult residents of LTC homes, 19 38 nursing homes 12 39 or care homes 15 40 (ie, adults living in residential facilities, whose staff provide help with most or all daily activities and 24-hour care and supervision). These terms reflect differences in terminology between countries, but were chosen for their overlap with the international consensus definition of nursing home.⁴¹ Still, our search strategy uses a broader list of terms (see online supplementary appendix A) and studies identified that are judged to meet this consensus definition will also be included. However, our definition will exclude studies carried out strictly in 'board and care homes', sub/postacute care facilities, rehabilitation hospitals, assisted living facilities, retirement homes, skilled nursing facilities, hospices, geriatric hospitals/wards or residential settings specifically for persons with intellectual disability or psychiatric disorders (although we will not exclude these populations living in LTC homes). Most people living in LTC homes, nursing homes or care homes are over age 65 years, ^{17–19} but there are also younger residents; we included only studies in adults (aged 18 years and over) as younger LTC residents represent a very small and clinically distinct population in LTC homes. 42

Studies that explicitly report social integration or loneliness as a domain of a multidimensional construct, for example, quality of life, as well as those reporting psychometric properties of instruments used to assess social integration or loneliness in this population will also be included. Qualitative research will be used to contextualise the review results, but will not be included in the analysis. Publications that do not include original research findings, including expert opinions, editorials, protocols and letters to the editor, will be excluded. Relevant reviews will be retained as potential sources of additional reference records.

We have developed a comprehensive search strategy by first consulting relevant published studies to develop a list of search terms. An experienced information specialist (JBa) reviewed the list of search terms together with the research questions to develop a preliminary search strategy (see online supplementary appendix



A). This strategy was tested and refined in consultation with the study team. The search will first be conducted in MEDLINE(R) ALL (in Ovid, including Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily) and then translated into CINAHL (EBSCO), PsycINFO (Ovid), Scopus, Sociological Abstracts (Proquest), Embase and Embase Classic (Ovid), Emcare Nursing (Ovid) and AgeLine (EBSCO). All searches will be conducted from the databases' inception through to the date the search was executed. Search strategies included the use of text words and subject headings (eg, MeSH, Emtree) related to (1) social engagement, loneliness and (2) LTC, nursing homes, care homes, homes for the aged—limited to human adult populations when possible. Searches were also limited to English language, reflecting reviewers' language facility and practical considerations related to translation costs and time. Searches will be conducted by an information specialist (JBa). Reference lists will be scanned and subject-matter experts will be consulted to identify additional studies. We will not include grey literature. Covidence (www.covidence. org) will be used to manage the review process and Endnote will be used to manage reference lists as well as the deduplication process.⁴³

Selecting studies

Prior to embarking on the study selection process, the entire study team will test the eligibility criteria by reviewing and discussing a sample of 20 retrieved citations. The purpose of this discussion will be to identify and clarify any issues related to eligibility and thereby refine the screening process and increase consistency among reviewers. We will not quantify inter-rater agreement at this stage. Then, in the first phase of study selection, two reviewers will independently screen article titles and abstracts to identify potentially relevant studies for inclusion. Any disagreements will be resolved by a third reviewer. Reviewers will meet throughout the abstract review process to discuss and refine the search strategy, as required. In the second phase of study selection, two reviewers will independently review full articles for inclusion. Any disagreements will be resolved through discussion and/or by a third reviewer.

Charting the data

The data items that will be extracted from each study are provided in table 1, recognising this list may be updated during the data abstraction process and after consultation with LTC home community members. Prior to commencing data extraction, the entire study team will independently test the data extraction form in five studies, then meet to discuss any discrepancies or necessary alterations to the form. We will not quantify interrater agreement at this stage. Next, two reviewers will extract data from all included studies. Any disagreements will be resolved through discussion and/or by a third reviewer. Given the objectives of the review, no formal quality assessment of the studies will be undertaken.

Table 1 Data items extracted from studies included in the scoping review

scoping review	
Category	Data items to be extracted
Publication characteristics	First author.Publication year.Source of funding.
Study characteristics	 Objective. Design (eg, psychometric, cohort, cross-sectional, randomised controlled trial and so on).
Characteristics of LTC homes	 Setting described (eg, LTC home, nursing home, care home and so on). Number included in study. Country and state/province. Additional information provided (eg, ownership, rural, size/number of beds, population served and so on)
Characteristics of LTC home residents	 Number. Age. Sex. Additional information provided (eg, other demographic and clinical characteristics and so on).
Measurement of social integration and loneliness	 Description used (eg, social support, social engagement, social participation, social networks, loneliness and so on) and definition provided. Instrument/method used to assess. Source (eg, self-report, staff-report, family report). Study usage (eg, psychometric properties, descriptive, exposure or outcome).
LTC long-term care	

LTC, long-term care.

Collating, summarising and reporting the results

To meet our study objectives, we will present: (1) study characteristics summarised numerically with frequency and percentage statistics; and (2) a narrative synthesis and mapping of the results.^{31 32} We will take an iterative approach to reporting our results, whereby the first author will report consolidated results back to the entire study team; this forum will allow the team to review the results, seek clarification, suggest refinements and offer insights on the findings. These preliminary results will then be prepared for broader input through stakeholder consultation.

Consulting with stakeholders

Preliminary results will be reported to LTC home community members, including residents, family and staff, in a workshop format. The purpose of these consultations will be to contextualise results by incorporating perspectives of lived experience. For these consultations, the preliminary results will be presented then participants will be asked to provide feedback (see Patient and public involvement section).



ETHICS AND DISSEMINATION

Our scoping review will offer an overview of research related to social integration and loneliness among LTC home residents. This protocol documents our rigorous and transparent methodology. Ethics approval is not required.

Once complete, we will present our findings and research recommendations at national and international conferences as well as publish in a peer-reviewed journal. We will engage LTC home community members, including residents, family and staff, in these and other knowledge translation efforts. We expect that by identifying methods to define and measure social integration and loneliness, groups that may call for special consideration, and potential approaches for improving social integration and loneliness in this population, we will inform future observational and interventional research aimed at improving the health and quality of life of LTC home residents. Inexpensive, widely available and non-invasive measures are needed for research related to social engagement and health44 and, given the relevance for those living in LTC homes, these measures may represent important, patient-centred outcomes for research in this population. Given the acknowledged health impacts of social integration and loneliness, coupled with the large and growing population living in LTC homes, 19 research in this area has the potential for important impact at both the individual²¹ and societal level.

Contributors JBe conceived the study and drafted the protocol. JBa developed and will conduct the literature search. RG, AI, KSM, RC-C, RK, BS and DS provided input throughout the protocol development, including planning and implementing the scoping review's methods and parameters. All the authors were involved in revising this protocol manuscript and approved the final version.

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