#### **REVIEW ARTICLE**

## Assessing social connection for long-term care home residents: A scoping review of measure content

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#### **Funding information**

This project has been made possible with the financial support of Health Canada, through the Canada Brain Research Fund, an innovative partnership between the Government of Canada (through Health Canada) and Brain Canada, and of the Alzheimer's Association, Grant/Award Number: ARCOM-22-875327

#### Abstract

**INTRODUCTION:** Social connection comprises distinct but interrelated aspects describing how individuals connect to each other. Various measures have assessed multiple aspects of social connection in long-term care (LTC) home populations, but they use inconsistent terminology, making it unclear what aspects are measured. This scoping review describes how social connection is assessed by measures that have been used in LTC home residents.

**METHODS:** This review followed the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines. Two systematic literature searches combining search terms for social connection AND LTC home residents AND measurement properties were conducted in eight electronic databases from inception to April 2022. Included studies reported the development or psychometric testing of measures which assessed social connection in LTC home residents. A content analysis with a deductive-inductive approach was used to analyze the measures' content and an adapted Framework Method was used for data management. Findings report each measure's items and the assessed aspects of social connection. Dementia and non-dementia-specific measures had content, administration, and scoring compared.

**RESULTS:** From 8753 records, 58 studies reporting on 14 dementia-specific and 28 non-dementia-specific social connection measures were identified, including complete measures, subscales, and single items. These measures assessed social network (52.4%), social isolation (11.9%), social interaction (47.6%), social engagement (31.0%), social support (33.3%), social connectedness (21.4%), and loneliness (9.5%). A total of 27 (64.3%) of the measures included more than one aspect of social connection. Dementia-specific measures most often assessed social interaction whereas non-dementia-specific measures most often assessed social network, social interaction, and social support. Dementia-specific measures typically relied on a proxy response, whereas non-dementia-specific measures more often used self-report.

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Alzheimer's Dement. 2024;10:e12488. https://doi.org/10.1002/trc2.12488 **DISCUSSION:** Existing social connection measures in LTC home settings operationalize seven aspects of social connection and differ according to the target population (dementia or non-dementia-specific). These findings will inform future measure selection and development.

#### Highlights

- Social connection is important to long-term care (LTC) home residents' quality of life.
- · Social connection has been assessed by quantifying/describing relationships.
- Existing measures usually assess more than one aspect of social connection.
- · These aspects cover several interlinked observed or experienced domains.
- Dementia and non-dementia-specific measures differ in assessing social connection.

#### 1 | INTRODUCTION

Social connection is an umbrella term encompassing aspects of how individuals connect to each other.<sup>1</sup> It depends on the existence, roles, and qualities of relationships and the sense of connection within these relationships.<sup>2</sup>

Social connection is important to the quality of life of people living in long-term care (LTC) homes.<sup>3</sup> Social connection is associated with health outcomes that include mortality,<sup>4</sup> self-rated health,<sup>5</sup> depression,<sup>6</sup> and anxiety<sup>7</sup> for LTC home residents, and also with dementia risk in the general population.<sup>8</sup> Many LTC home residents experience loss of family/friends, chronic illness, sensory impairments, cognitive impairments, and mobility issues which can negatively impact their social connection.<sup>9</sup> Cognitive impairment and dementia, a term for several diseases that affect memory, thinking, and the ability to perform daily activities,<sup>10</sup> are prevalent in over 50% of LTC residents,<sup>11</sup> and can exacerbate poor social connection as they may impair social processes that are responsible for interpreting information from faces, recognizing the thoughts and feelings of others, displaying empathy, regulating emotions, and behaving within social norms.<sup>12</sup> Social connection may be further impacted by the lack of understanding and stigma towards individuals with dementia.<sup>13</sup> Previous research has tested interventions to address aspects of social connection in LTC residents.<sup>14</sup> However, researchers conceptualize aspects of social connection differently, using terminology loosely, inconsistently, and interchangeably,<sup>15,16</sup> and there is no gold standard approach to measurement leading to problems in interpreting studies of social connection. The LTC home context has specific considerations for the population and setting whereby measures must address relevance, comprehensiveness, and comprehensibility for residents (many of whom are older adults with complex health needs and may be unable to self-report) and staff (who provide proxy-reported data on behalf of residents).<sup>17,18</sup> Previous research has shown low inter-rater agreement between self- and proxy-reported quality of life ratings, whereby proxies typically rate quality of life lower.<sup>19</sup> Despite these measurement challenges, stakeholders-namely people with lived experience of dementia and LTC homes, such as staff, residents, and family members—have emphasized the relationship between social connection and living well with dementia, making it important to assess.<sup>20</sup>

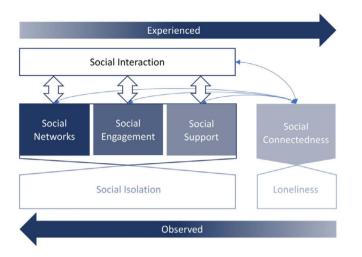
Although measures used to assess social connection in LTC settings have been described.<sup>15</sup> there are no reviews which address how these measures assess the distinct aspects of social connection. Furthermore, it is unclear how dementia-specific measures differ from those designed for wider use among all LTC home residents.<sup>15</sup> To advance conceptual clarity, and in preparation for the future development of a measure to assess social connection in this population,<sup>21</sup> this study will map out the operationalization of social connection within the LTC home setting. This work will offer clinicians and researchers interested in social connection among older adults a framework for examining the literature and developing refined assessments of social connection. The objective of this scoping review is to use a comprehensive literature search and content analysis to qualitatively analyze measures that have been used to assess any aspect of residents' social connection in LTC home settings and describe the characteristics of measures designed for use among residents with dementia. This review aimed to answer the following research questions:

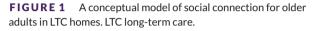
- 1. How is social connection operationalized for measurement in LTC home residents?
- 2. How do dementia-specific measures differ from those developed for broader use among all LTC home residents?

#### 2 | METHODS

#### 2.1 Scoping review approach

This review was conducted in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines,<sup>22</sup> and research was guided by Arksey and O'Malley's<sup>23</sup> scoping review framework. The review protocol was registered on PROSPERO (registration number: CRD42022303526), published<sup>24</sup> and is part of the





"Social Connection in Long-Term Care Home Residents" (SONNET) study.

#### 2.2 Conceptual model of social connection

We developed this conceptual model depicting how the aspects of social connection are related to each other (see Figure 1). We built on a model originally proposed by Berkman et al.<sup>25</sup> to explain the relationship between social connection and health and adapted for research in nursing homes by Leedahl et al.<sup>26</sup> We added other aspects of social connection (ie, loneliness, social connectedness, social interaction, and social isolation). These definitions, articulated a priori, will help to ensure social connection is consistently conceptualized throughout the study, including in the study selection and data analysis. Identified measures will be analyzed according to these definitions:

- Social connection: An umbrella term encompassing aspects of how individuals connect to each other.<sup>1</sup> It depends on the existence, roles, and qualities of relationships and the sense of connection within these relationships.<sup>2</sup>
  - Social networks: Web of relationships that surround an individual and the characteristics of those ties.<sup>25,26</sup>
  - Social interaction: An interpersonal process by which individuals in contact temporarily change their behaviors towards each other by a continuous mutual stimulation; this can be verbal and/or nonverbal, positive or negative, and between two or more individuals.<sup>27</sup>
  - Social engagement: Taking part in activities within the communities in which people live. This may include productive activities, social activities, or leisure activities.<sup>25,26</sup>
  - Social support: Exchange of resources between at least two individuals intended to enhance the well-being of the recipient. This may include emotional (expressions of empathy, love, trust, car-

#### **RESEARCH IN CONTEXT**

- Systematic review: We searched eight bibliographic databases, MEDLINE ALL (Ovid), Embase Classic and Embase (Ovid), Emcare Nursing (Ovid), APA PsycInfo (Ovid), Scopus, CINAHL Complete (EBSCOhost), AgeLine (EBSCOhost), and Sociological Abstracts (ProQuest), for published research studies reporting on the psychometric testing or development of a measure which assessed any aspect of social connection in long-term care (LTC) home residents.
- 2. Interpretation: Our findings clarify how social connection has been defined and assessed in LTC home residents and details how dementia and non-dementia-specific measures differ according to content, mode of administration, and scoring options. These results will guide measure selection, and future development of new measures for interventional and observational research targeting social connection.
- Future directions: There are a variety of measures available to assess the aspects of social connection in LTC home residents. Future research should use this study's results to inform choice of outcome measure, taking into account their psychometric properties.

ing), instrumental (tangible help), informational (advice, suggestions, information) and appraisal (information for self-evaluation) support.<sup>28</sup>

- Social isolation: Lack of (or limited) social contact with others.<sup>1</sup>
- Social connectedness: The extent to which one feels that they have meaningful, close, and constructive relationships with others; it is the opposite of loneliness.<sup>29</sup>
- Loneliness: Negative experience resulting from the discrepancy between an individual's desired and actual experience of meaningful connections. This may include emotional loneliness (lack of close intimate attachment to another person, or feeling isolated or alone) or social loneliness (lack of connection with a social network, or feeling left out).<sup>30,31</sup>

While the aspects of social connection are distinct, bidirectional arrows are used to acknowledge that they are related. Our model demonstrates that the aspects of social connection exist on continuums of being experienced by the individual and observed by others. Further, while some aspects of social connection may be objective others are, by definition, more subjective. We will select measures from the literature that have items assessing any of these aspects of social connection. Overall, selected measures will reflect the presence or absence of social connection that LTC home residents experience.

#### 2.3 Comprehensive literature search

Eight electronic databases, MEDLINE ALL (Ovid), Embase Classic and Embase (Ovid), Emcare Nursing (Ovid), APA PsycInfo (OVID), Scopus, CINAHL Complete (EBSCOhost), AgeLine (EBSCOhost), and Sociological Abstracts (ProQuest), were searched for published research studies on psychometric properties of a measure of any aspect of social connection, tested in LTC home residents. Two searches were conducted as recommended by de Vet et al.<sup>18</sup> Searches were developed in MED-LINE ALL (Ovid) and translated into all the other databases (Appendix S1).<sup>32</sup>

Search 1 was conducted from database inception to November 18, 2021 and consisted of (1) the construct of interest, aspects of social connection (as defined above in the conceptual model); (2) the population, LTC home residents (as defined using the international definition, "adults living in residential facilities, whose staff provide help with most or all daily activities and 24-h care and supervision");<sup>33</sup> and (3) measurement properties, using the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) search filter.<sup>34</sup> When possible, limits were applied to focus on human adult studies and journal articles. No date or language limits were applied. Search 2 was conducted from inception to April 5, 2022 and consisted of (1) the construct of interest, names of measures identified from the first search, supplemented with a list of measures used in previous research in this population, identified from systematic reviews of psychometric measurement of linked concepts in LTC homes, or reviews of psychosocial interventions in LTC homes (full list in Appendix S2); (2) the population, LTC home residents; and (3) measurement properties. Reference lists of pertinent review articles were also scanned to identify potential additional relevant studies.

#### 2.4 Study selection

#### 2.4.1 | Inclusion criteria

Studies were included if (1) they reported on a measure that assessed any aspect of social connection, including a subscale(s) or item(s) that were reported separately (eg, a quality of life measure with a social connection subscale); (2) the study aim was to develop or evaluate at least one psychometric property of a measure of social connection; and (3) the population consisted of older adults (mean age of 65 years or older [or at least two thirds of participants were 65 years and older]), of whom at least 2/3 were living in a LTC home (or <2/3 if results were presented for LTC home residents separately).

#### 2.4.2 | Exclusion criteria

Secondary texts, literature reviews, conference abstracts, editorials, and dissertations were excluded as they did not have sufficient detail regarding the study design.<sup>35</sup> Grey literature was excluded as it is

unlikely to report on a measure's development or testing. Studies were also excluded if the complete wording of the measure's items could not be located; extensive effort went into obtaining measures including emailing lead and co-authors (authors were emailed up to five times before search efforts ceased) and looking at studies which used/cited the measure.

#### 2.4.3 | Identifying relevant studies

Citations were imported into Covidence (www.covidence.org) for duplicate removal and study selection. A pilot test of 15 papers (titles and abstracts) was conducted to familiarize reviewers with eligibility criteria. Following the pilot test, titles and abstracts were screened and full-text review was conducted independently by two reviewers (M.L., A.S., or J.B.). Non-English papers were assessed by additional reviewers with relevant language and research expertise. Reasons for exclusion at full-text review were recorded. Reviewers met regularly to compare results. Any disagreements that arose in the screening or full-text review were resolved through discussion.

#### 2.4.4 | Charting the data

Data were extracted independently by two of the three reviewers listed (M.L., A.S., or J.B.) using standardized instructions and a data extraction form which contained the following fields: record ID, author(s), study publication year, study title, population (country, race/ethnicity, inclusion criteria, exclusion criteria, sample size number of residents and homes, gender/sex, age), measure name, mode of administration, and scoring options. Measures were classified as dementia-specific if they were designed exclusively for assessing individuals with dementia or classified as non-dementia-specific otherwise.

#### 2.5 | Qualitative analysis

#### 2.5.1 | Collating, summarizing, and reporting results

The Framework Method was used to manage and analyze the qualitative data of this content analysis.<sup>36</sup> Adaptations were made, summarized below, to accommodate the hybrid deductive-inductive approach that integrates theory-driven codes at first-level coding with datadriven codes at second-level coding.<sup>37</sup>

#### 2.5.2 | Transcription and familiarization

Names of measures and their social connection items were transcribed verbatim in an electronic document, noting the source as dementia or non-dementia-specific as well as mode of administration and scoring options. M.L. kept reflective notes on how items aligned with the aspects of social connection (Figure 1) as well as initial observations of how items from dementia and non-dementia-specific measures differed. Given the codes were predefined (ie, using the aspects of social connection), the analysis proceeded from this stage directly to indexing.

#### 2.5.3 | Applying the analytical framework

During first-level (deductive) coding, the research team applied the aspects of social connection as previously defined in the literature and which informed the conceptual model. Each item was mapped to a code (ie, aspect of social connection) independently by two researchers (M.P.L., A.S., K.S.M., H.M.O., J.B.). The item's wording, mode of administration, and scoring options were considered in the coding. During this stage, social interaction was added as a distinct aspect of social connection and the "other" code was created to accommodate items within measures which did not align with any of the social connection codes. Inter-coder agreement was calculated. Coding disagreements were resolved through a discussion between all five researchers (M.P.L., A.S., K.S.M., H.M.O., J.B.).

#### 2.5.4 | Charting the data into the framework matrix

A Framework Method table was created to manage and analyze the first-level (deductive) coding. Measures (including those with standalone items) and subscales were assumed to represent a construct and were thus reported and analyzed separately. Rows were labelled with names of measures, columns were labelled as the codes (ie, aspects of social connection) and cells contained items mapped by row and column coordinates.

#### 2.5.5 | Interpreting the data

The data were interpreted in three steps. First, each measure was summarized according to the code(s) to which it was mapped and whether it was mapped to multiple codes; dementia and non-dementia-specific measures were compared by tabulating the presence of codes. Second, second-level coding employing an inductive, data-driven approach was applied to identify and describe themes within codes and compare them across dementia and non-dementia-specific measures. In this step, M.L. independently defined second-level codes and then revised and edited them after discussion with the research team; full consensus on second-level codes was achieved. Third, dementia and non-dementia-specific measures were compared by aspects of social connection assessed, mode of administration and scoring options. Multiple steps were taken to ensure rigor throughout the coding process.<sup>38</sup> Trustworthiness and credibility were ensured by practicing reflexivity, establishing a physical audit trail, peer debriefing, systematically managing data, and examining contrary explanations during data analysis.<sup>39,40</sup>

#### 2.6 Stakeholder consultation

Virtual, 1- to 2-hour, group stakeholder consultations were held on September 15, 2022, February 16, 2023, and three, 30-min one-onone consultations during March 2023. Each consultation was held on Zoom, and the research team took notes throughout. Stakeholders were people with lived experience of dementia and LTC homes and were identified through their involvement with the Canadian Consortium on Neurodegeneration in Aging's Engagement of People with Lived Experience of Dementia (EPLED) program (www.epled.ca)<sup>41</sup> and the UK Alzheimer's Society Research Network. This step provided opportunities for people with lived experience to assist with interpreting data by offering insights outside the realm of research literature.<sup>23</sup> At September's meeting, stakeholders received information and commented on the study methods.<sup>42</sup> During the February and March meetings, stakeholders contributed to interpreting results, particularly Figure 2, as they helped researchers to understand if measures used to assess social connection contain relevant items and if some aspects of social connection are particularly important to assess.<sup>42</sup> These discussions were guided by the questions: (1) Do you feel that secondlevel codes describing the aspects of social connection reflect your personal experiences? and (2) From your experience, are any of these aspects of social connection particularly important to LTC care home residents?

#### 3 | RESULTS

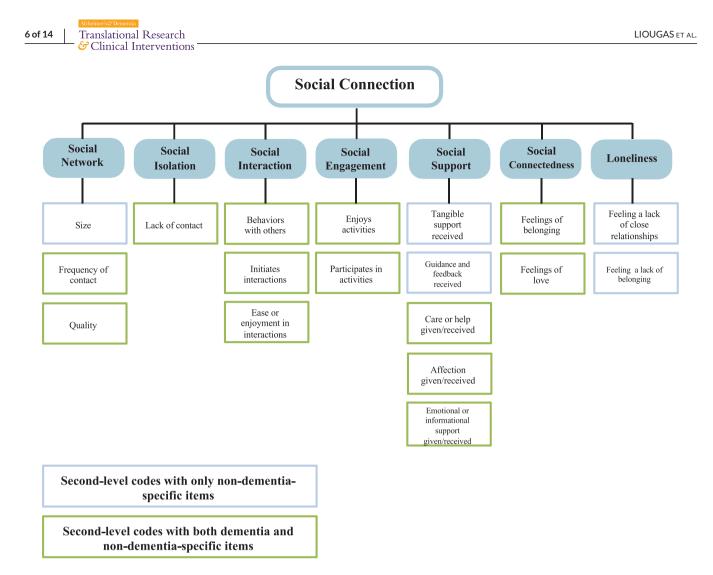
#### 3.1 Search results

The search strategy identified 8753 records, 7223 records from search 1 and 1530 records from search 2. After applying exclusion criteria and removing duplicates there were 55 manuscripts, and three additional manuscripts from reference list searching (Figure 3). A description of study characteristics can be found in Dewan et al.<sup>43</sup>

#### 3.2 Overview of measure characteristics

The 58 studies reported on 31 measures: 11 complete measures, 21 subscales, and 10 single items, each of which was analyzed and reported separately (as 42 measures). One measure had three subscales, three measures had two subscales, and twelve measures had one subscale. Two measures had four single items and two measures had single items. A list of measures and corresponding citations can be found in Appendix S3.

From these measures, 284 individual items were extracted, which were reduced to 266 after excluding duplicates (eg, from successive



**FIGURE 2** Second-level codes describing the seven aspects of social connection. The aspects of social connection are shown across the top in the solid blue boxes. Underneath each aspect are the inductive, second-level codes.

revised versions of measures). There were 14 dementia-specific measures contributing 83 (31.2%) items, and 28 non-dementia-specific measures contributing 183 (68.8%) items.

# 3.3 | Aspects of social connection assessed by measures

Following the double coding of the 266 items (two independent raters, 532 total ratings), an initial inter-rater agreement of 86% was obtained. All researchers reviewed and agreed on the final item coding.

First-level coding, mapping items to aspects of social connection, is summarized in Table 1. Overall, measures most often included social network (52.4%) and social interaction (47.6%), and least often included social isolation (11.9%) and loneliness (9.5%). Of the 14 dementia-specific measures, 57.1% included items related to social interaction. Although none of the dementia-specific measures assessed loneliness, one had items related to social connectedness. Of the 14 non-dementia-specific measures, 64.3% included items related to social network. Each measure captured between one to five aspects of

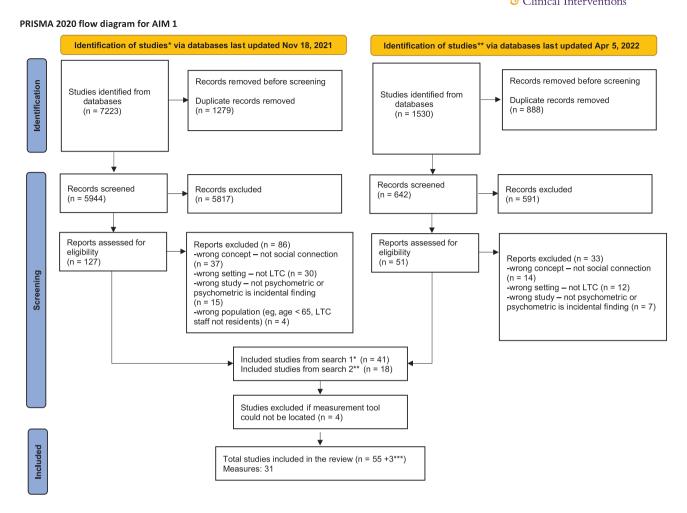
social connection. Overall, 27 (64.3%) of the measures included more than one aspect of social connection.

## 3.4 Second-level codes among dementia and non-dementia-specific measures

Figure 2 summarizes second-level codes for each aspect of social connection (see Appendix S4 for complete coding). Aspects of social connection had between one (social isolation) and five (social support) second-level codes.

Social network is the web of relationships that surround an individual and the characteristics of those ties.<sup>25,26</sup> Social network was described by three second-level codes: size, frequency of contact, and quality. "Size" referred to the number of individuals in a resident's social network. "Frequency of contact" referred to the number of contacts (including face-to-face or by phone) between a resident and others in their social network. "Quality" was applied to items assessing perceptions of positive and negative aspects of a resident's relationships with family, fellow residents, LTC home staff and others, providing an

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\*Search 1: social connection AND long-term care (LTC) homes AND COSMIN filter

\*\*Search 2: identified social connection measures from existing systematic reviews and search 1 AND LTC homes AND COSMIN filter \*\*\* Three citations from reference list of included studies

**FIGURE 3** PRISMA flow diagram describing the flow of information from the study search and selection. COSMIN, COnsensus-based Standards for the selection of health Measurement Instruments; LTC, long-term care; PRISMA, Preferred Reporting Items for Systematic reviews and Meta-Analyses.

indication of the strength of the network tie, for example, "Is on friendly terms with one or more residents?".

Social isolation is the lack of (or limited) social contact with others.<sup>1</sup> It was described by one second-level code that referred to items that assessed the lack of contact between a resident and others within their social network or environment, for example, "Cool–Being socially uninvolved, withdrawn".

*Social interaction* is an interpersonal process by which individuals in contact temporarily change their behaviors towards each other by a continuous mutual stimulation; it can be verbal and/or nonverbal, positive or negative, and between two or more individuals.<sup>27</sup> Social interaction was represented by three second-level codes: behaviors with others, initiates interactions, and ease or enjoyment in interactions. "Behaviors with others" included items assessing verbal (talking, asking, answering, speaking, chatting, conversing) and non-verbal (head nod, looking, staring) communication, joy, and humor (smiling, laughing, humor, delight). Items coded as "Initiates interactions" described a resident initiating interactions with others, for example, "He/She seeks

contact with others by greeting people or joining conversations". "Ease or enjoyment in interactions" referred to items assessing a resident's demeanor or response to interactions with or in the presence of others, for example, "Responds positively when approached".

Social engagement involves taking part in activities within the communities in which people live.<sup>25,26</sup> Social engagement was represented by two second-level codes: enjoys activities and participates in activities. "Enjoys activities" was applied to items assessing a resident's pleasure, enjoyment, ease, or satisfaction participating in activities, for example, "Do you enjoy the activities that are offered?". "Participates in activities" referred to items assessing a resident's participation in activities, for example, "To make plans to get together with neighbors or acquaintances".

*Social support* refers to the exchange of resources between at least two individuals intended to enhance the well-being of the recipient and may include emotional, instrumental, informational, and appraisal support.<sup>28</sup> Social support was described by five second-level codes: tangible support received, guidance and feedback received, care or

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**TABLE 1** Aspects of social connection captured in measures of social connection that have been used in long-term care home residents.

	Aspects							
Nama dina ang	Social	Social	Social	Social	Social	Social con-	Lanalta	
Name of measure	network	isolation	interaction	engagement	support	nectedness	Loneliness	Other
Dementia-specific measures								
Alzheimer's Disease-Related Quality of Life (ADRQL)								
Relating to and being around other people			х	Х	Х			
Person's special identity and important relationships	х							х
Dementia Care Mapping (DCM) <sup>a</sup>		Х	X	X				
Dementia Quality of Life (DQOL)								
Feelings of belonging						Х		
Engagement of a Person with Dementia Scale								
Social engagement			x					х
Maastricht Electronic Daily Life Observation (MEDLO) tool								
Social interaction			x					
Social Connectedness Index								x
Social Observation Behaviors Residents Index (SOBRI)								
Social interactions with residents			x					
Social interactions with staff			x					
QUALIDEM								
Social relations	x	х	х		x			
Social isolation		x						х
Quality of Life in Late-Stage Dementia (QUALID) <sup>a</sup>			х					
Quality of Life in Alzheimer's Disease (QoL-AD) <sup>a</sup>	х							
Quality of Life-Alzheimer's Disease scale in Nursing Homes (QOL-AD NH)	х							х
Total number of measures: 14	4	3	8	2	2	1	0	5
Percentage of measures	28.6	21.4	57.1	14.3	14.3	7.1	0.0	35.7
Non-dementia-specific measures								
ICEpop CAPability measure for Older people (ICECAP-O) <sup>a</sup>						х		
InterRAI Self-Report Nursing Home Quality of Life Survey								
Staff-resident bonding	х		х		x			
Personal relationships	x				х	х		
Social life scales	x			х				х
Laurens Well-Being Inventory for Gerontopsychiatry								
Social well-being	x		х	х		х	x	х
Lubben Social Network Scale-Revised (LSNS-R)								
Family	х				х			
Residents	х				х			
Non-resident friends	х				х			
Staff Persons	х				х			
Multidimensional Observational Scale for Elderly Subjects (MOSES)								
Withdrawal	х		х					х

(Continues)

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### TABLE 1 (Continued)

	Aspects							
Name of measure	Social network	Social isolation	Social interaction	Social engagement	Social support	Social con- nectedness	Loneliness	Other
Nottingham Health Profile (NHP)								
Social isolation		х					х	
Nursing Home Adjustment Scale (NHAS)								
Relationship development	х				x	х	х	
Nursing Home Care-related Quality of Life Scale								
Social interaction	х			х				х
Revised Index for Social Engagement (RISE)			x	х				
SAR Foundation's Satisfaction and Quality of Life Scale (SyCV-FSAR)								
Interpersonal relationships	х			x				x
Satisfaction measure for elderly residents in Galicia								
Social interaction	х		x			х	x	
Sociability of Aged Persons	х		x	х	x			
Socially Supportive Activity Inventory (SSAI)	х		x	x				
Social Support Scale in Chronic Diseases (SSCII)			x	х	x	х		х
Social Quality								
Unsettled relationships	х	х						х
Social Well-being Of Nursing home residents-scale (SWON scale)								
Affection			x		x			
Behavioral confirmation					x			х
Status	х		x					
The Index of Social Engagement Scale (ISE)			x	х				х
Time Use			x	х				х
World Health Organization Quality of Life (WHOQOL-BREF)								
Social relations	x				х	х		х
World Health Organization's Quality of Life Questionnaire-version for older people (WHOQOL-OLD)								
Social participation				x				x
Intimacy						x		
Total number of measures: 28	18	2	12	11	12	8	4	12
Percentage of measures	64.3	7.1	42.9	39.3	42.9	28.6	14.3	42.9

<sup>a</sup>Measures with single items.

help given/received, affection given/received, and emotional or informational support given/received. "Tangible support received" items evaluated when a resident received support that involves a monetary component or value, for example, "Contributed to my income or gave me money". "Guidance and feedback received" described items rating when a resident receives guidance or feedback that may be related to expectations, information, understanding, or recommendations, for example, "Told me who I should ask for assistance". "Care or help given/received" related to items assessing when a resident gives or receives care or help, including assistance, sympathy, and concern, for example, "Takes care of other residents". "Affection given/received" referred to items assessing when a resident gives or receives physical or emotional affection, for example, "I have opportunities for affection or romance". "Emotional or informational support given/received" related to items assessing a resident giving or receiving emotional or informational support that may be related to comfort, private matters, or important decisions, for example, "He/She can be comforted or reassured by others". 10 of 14

**TABLE 2** Overview of mode of administration and scoring option used by dementia-specific and non-dementia-specific measures.

	Dementia-specific N = 14 (100%)	Non-dementia-specific N = 28 (100%)
Designed exclusively for the LTC home context	5 (35.7)	16 (57.1)
<b>Mode of Administration</b> *Some measures had more than one mode of administration, % > 100		
Proxy-report-LTC home staff, proxy-proxy perspective	6 (42.9)	8 (28.6)
Proxy-report-LTC home staff, person-proxy perspective	1 (7.1)	1 (3.6)
Proxy-report-caregiver (family member, friend), proxy-proxy perspective	3 (21.4)	0 (0.0)
Proxy-report—caregiver (family member, friend), person-proxy perspective	0 (0.0)	0 (0.0)
Self-report	3 (21.4)	18 (64.3)
Observational	5 (35.7)	1 (3.6)
Scoring Options *Some measures had more than one scoring option, % > 100		
Dichotomous (yes/no or agree/disagree)	6 (42.9)	10 (35.7)
Five categories options	1 (7.1)	0 (0.0)
4-point Likert scale	4 (28.6)	7 (25.0)
5-point Likert scale	3 (21.4)	12 (42.8)
6-point Likert scale	0 (0.0)	2 (7.1)

Abbreviation: LTC, long-term care.

Social connectedness is the extent to which one feels that they have meaningful, close, and constructive relationships with others.<sup>29</sup> Social connectedness was described by three second-level codes: feelings of belonging, feelings of love, and feelings of close relationships. "Feelings of belonging" referred to items assessing when a resident feels useful, likeable, respected, or accepted, for example, "Being respected/accepted—Do you feel respected by others?". "Feelings of love" referred to when a resident feels or experiences love, for example, "Love and friendship". "Feelings of close relationships" referred to when a resident feels closeness or intimate caring connection with others in their social network, for example, "Another resident here is my close friend".

Loneliness is the negative experience resulting from the discrepancy between an individual's desired and actual experience of meaningful connections.<sup>30,31</sup> Loneliness was described by three second-level codes: feeling a lack of close relationships, feeling a lack of belonging, and overall loneliness. "Feeling a lack of close relationships" referred to items evaluating if a resident does not feel close to, alone to, or isolated from their social network, for example, "I feel there is nobody I am close to". "Feeling a lack of belonging" described items where a resident did not feel or experience a sense of belonging with others as they feel ignored, bullied, like a burden, or having a hard time getting along with others, for example, "I feel I am a burden to people". "Overall loneliness" referred to when a resident experiences general feelings of loneliness, for example, "I feel lonely".

Other was described by seven second-level codes: living environment, loss, behavioral symptoms, mood and life satisfaction, manifest impairments, roles of care home staff, and individual perceptions, characteristics or preferences. These second-level codes may influence and affect a resident's social connection but do not directly assess the level of social connection.

### 3.5 Comparing dementia and non-dementia-specific measures regarding mode of administration (proxy or self-report) and scoring options

Dementia-specific measures most often used a proxy mode of administration. Half (50.0%) of the dementia-specific measures used a LTC home staff member as a proxy respondent. Non-dementia-specific measures often used self-report (64.3%) (Table 2). Most of the proxyreported measures used the proxy-proxy perspective, an approach where the proxy rates from their own point of view. Exceptions were the Quality of Life-Alzheimer's Disease scale in Nursing Homes (QOL-AD NH) and the ICEpop CAPability measure for Older people (ICECAP-O) measures, which used a person-proxy perspective, an approach where the proxy rates from the resident's point of view. Dementia and non-dementia-specific measures used dichotomous, 4-point and 5-point Likert scale scoring options (Table 2). Dementiaspecific measures used a dichotomous response option frequently (42.9%) and non-dementia-specific measures most often used a 5-point Likert scoring option (42.8%).

#### 3.6 Consultations with stakeholders

After reviewing the findings presented in Figure 2, stakeholders identified that the second-level codes describing the seven aspects of social connection largely reflected their experience. They agreed that members of a resident's social network are often family, fellow residents, and LTC home staff and that the presence of these network ties helps to facilitate verbal and non-verbal social interaction, social engagement, social support, and social connectedness. Stakeholders noted

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that the second-level codes describing social isolation and loneliness demonstrated the absence of social connection. Stakeholders highlighted social engagement and social connectedness as particularly important aspects of social connection. Although the other aspects were relevant, the second-level codes describing activity participation, enjoyment in activity participation, feelings of belonging, love, and close relationships were considered most meaningful.

#### 4 DISCUSSION

This review examined 14 dementia-specific and 28 non-dementiaspecific measures that assess social connection among LTC home residents. Through a comprehensive literature search and qualitative analysis, the findings map out the operationalization of social connection measures tested within the LTC home setting. The review presents three key findings. First, social connection has been operationalized using items that align with seven distinct aspects of social connection: social network, social interaction, social engagement, social support, social isolation, social connectedness, and loneliness. Most measures aligned with more than one aspect. Second, data-driven codes describe how the aspects of social connection relate to relationships with family, fellow residents, and LTC home staff. This is through quantifying network size and frequency of contact or through describing interactions with others, activity participation and enjoyment, support given/received, and feelings related to connectedness or loneliness. Third, compared to non-dementia-specific measures which often assessed social network, social interaction, and social support, dementia-specific measures more often assessed social interaction and typically relied on proxy response through a proxy-proxy perspective.

Social connection is a complex, multidimensional concept. In this study, seven aspects of social connection were defined and distinguished from each other in a unifying conceptual model. While it is not necessary for one measure to assess each of the aspects, as with any measure, it is crucial to have items aligned with the construct a researcher intends to measure. For LTC home residents, especially those with cognitive impairment, it may not be feasible, or important from the perspective of key stakeholders, to measure all aspects of social connection. In this population, key considerations for the acceptability and feasibility of measures relate to the time required (eg, questionnaire length) and the appropriate use of proxies.<sup>44</sup> Gräske et al.<sup>45</sup> recommended QUALIDEM for people with mild, moderate, and severe dementia as it took a short amount of time to complete, had few missing values, and good practicability.

The aspects of social connection assessed by measurement items are described by second-level, data-driven codes. Consistent with Siette et al.<sup>46</sup> and Valtorta et al.<sup>16</sup> some items focused on the quantification of the social network size and frequency of contact whereas other items describe quality, interactions with others, activity participation, giving/receiving support, and affection. For the aspect social support, second-level codes generally aligned with the four subtypes of social support described by House et al.<sup>28</sup> which are emotional, instrumental, informational, and appraisal support. However, some of

this study's second-level codes describe social support more generally, such as "Care or help given/received." Overall, second-level codes resonated with stakeholders, in particular social engagement and social connectedness, substantiating the face validity of published measures that have been used with LTC home residents.

There were differences between dementia-specific measures and those developed for broader use in the LTC home. While there are a range of non-dementia-specific measures assessing social network, social interaction, social support, social connectedness, and loneliness, dementia-specific measures most often assess social interaction and there are a limited number of measures for the other aspects. These aspects have important implications for quality of life<sup>47</sup> and overall well-being<sup>48</sup> and so measures should be developed and tested which assess these areas for people with dementia.

Many dementia-specific measures rely on a proxy response. Proxy response is commonly used for individuals with dementia, especially more severe dementia, as cognitive impairment and lack of awareness can limit one's ability to respond to objective measures of social connection, and communication impairments can affect one's ability to self-report their experiences.<sup>49</sup> In this setting, the proxy respondent is most often a LTC home staff member. Previous literature has shown that a LTC home staff proxy may be preferred over a caregiver proxy as the response is not affected by stigma, staff attitudes, or job satisfaction.<sup>50,51</sup> In addition, not all residents have a close contact (eg, family or friend) to respond on their behalf.<sup>52</sup> However, LTC home staff members often adopt a proxy-proxy rather than a person-proxy perspective. The proxy-proxy perspective requires the respondent to answer according to their own perception, whereas the person-proxy perspective requires the respondent to answer based on what they believe the individual would indicate if they were able to do so.<sup>53</sup> McPhail et al.<sup>54</sup> and Leontjevas et al.<sup>55</sup> found that the inter-rater gap between self-report and proxy-report was smaller based on a person-proxy perspective compared to a proxy-proxy perspective. Due to this, the person-proxy perspective is more appropriate in instances when proxy-response is used as a substitute for self-report.<sup>56</sup> Future proxy-reported social connection measures should consider using a person-proxy perspective, especially when assessing social connection in those with more severe cognitive impairment.

Dichotomous, and 4- or 5-point Likert scoring options were used by dementia and non-dementia-specific measures. Dementia-specific measures used a dichotomous response option most frequently and non-dementia-specific measures used a 5-point Likert scoring option most frequently. Grassi et al.<sup>57</sup> demonstrated that measures with dichotomous response options, such as yes/no, are more straightforward and easier for those with cognitive impairment to respond to, leading to smaller amounts of missing data and higher measurement completion rates. However, 4-point and 5-point Likert scale response options allow for greater discrimination and capture finer nuances in individual experience.<sup>58</sup> As over 50% of LTC home residents have a cognitive impairment,<sup>11</sup> a dichotomous response option may be the most appropriate for residents with a more severe subset of dementia.<sup>59</sup> Further testing on scoring options is required. Translational Research

#### 4.1 | Strengths and limitations

This review used an inclusive search strategy to capture the complexity of social connection terminology. However, there are still some limitations. First, this review excluded measures that have not been tested in LTC home settings, and measures that could not be located. It is possible that some relevant social connection measures are therefore missing. However, these are likely to be less used measures which have not undergone any psychometric testing. Second, we excluded measures that may include relevant items, but which do not calculate a subscale of social connection. Without the ability to specifically score social connection these cannot be used in research to specifically evaluate this domain. Third, although non-English measures were included, these measures did not undergo a strict translation process involving forward translation, back translation, expert committee review, and acceptability testing.<sup>60</sup> Instead, non-English measures were coded according to the translator's interpretation. It is possible that some meaning was lost in translation. Lastly, the emergence of second-level codes within each aspect of social connection is a highly subjective process. We strived to reduce the likelihood of this by having second-level codes of each aspect presented to a larger study team who provided independent feedback and input and by practicing trustworthiness and credibility.

### 5 | CONCLUSION

This study identified, described, and analyzed social connection measures that have been used in LTC home residents. Existing measures often operationalize multiple aspects of social connection. Secondlevel codes demonstrate that the aspects of social connection have been measured through quantifications and descriptions that reflect the experience of stakeholders. Dementia-specific measures differ from non-dementia-specific measures as they often assess social interaction rather than social network.

#### ACKNOWLEDGMENTS

The authors thank Fiona Höbler, Postdoctoral Research Fellow, Speech Neurophysiology Lab, University of Michigan; Martine Puts, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto; Michal Misiak, Janin Goldman, and Michaela Poppe, Senior Research Fellow, Division of Psychiatry, University College of London, for their assistance with translating non-English literature. The authors would also like to extend their appreciation and thanks to Jessica Babineau, Information Specialist at the University Health Network, Toronto Rehabilitation Institute, for her assistance in developing and executing the search strategy for this comprehensive scoping review. "This project has been made possible with the financial support of Health Canada, through the Government of Canada (through Health Canada) and Brain Canada, and of the Alzheimer's Association (Re: ARCOM-22-875327). To date, Health Canada has invested over \$130 million through the CBRF which

"Ce projet a été rendu possible grâce au soutien financier de Santé Canada, par le biais du Fonds canadien de recherche sur le cerveau, un partenariat novateur entre le gouvernement du Canada (via Santé Canada) et Brain Canada, et d'Alzheimer's Association (Re: ARCOM-22-875327)." Madalena P. Liougas, Katherine S. McGilton, and Jennifer Bethell are supported by the Walter & Maria Schroeder Institute for Brain Innovation and Recovery. Andrew Sommerlad is supported by the University College London Hospital's National Institute for Health Research Biomedical Research Centre.

#### CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest. "The views expressed herein do not necessarily represent the views of the Minister of Health or the Government of Canada." Author disclosures are available in the supporting information section 1.

"Les opinions exprimées dans ce document ne représentent pas nécessairement le point de vue du ministre de la Santé ou du gouvernement du Canada."

#### CONSENT STATEMENT

Consent for this study was not required.

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#### REFERENCES

- National Academies of Sciences, Engineering, and Medicine. Social isolation and loneliness in older adults: Opportunities for the health care system. The National Academies Press; 2020. doi:10.17226/ 25663
- Holt-Lunstad J. Why social relationships are important for physical health: a systems approach to understanding and modifying risk and protection. *Annu Rev Psychol.* 2018;69(1):437-458. doi:10.1146/ annurev-psych-122216-011902
- Jing W, Willis R, Feng Z. Factors influencing quality of life of elderly people with dementia and care implications: a systematic review. Arch Gerontol Geriatr. 2016;66:23-41. doi:10.1016/j.archger.2016.04.009
- Kiely DK, Simon SE, Jones RN, Morris JN. The protective effect of social engagement on mortality in long-term care. J Am Geriatr Soc. 2000;48(11):1367-1372. doi:10.1111/j.1532-5415.2000.tb02624.x
- Damián J, Pastor-Barriuso R, Valderrama-Gama E. Factors associated with self-rated health in older people living in institutions. *BMC Geriatr*. 2008;8(1):5. doi:10.1186/1471-2318-8-5
- Drageset J, Eide GE, Ranhoff AH. Anxiety and depression among nursing home residents without cognitive impairment. *Scand J Caring Sci.* 2013;27(4):872-881. doi:10.1111/j.1471-6712.2012.01095.x
- Ahmed D, El Shair IH, Taher E, Zyada F. Prevalence and predictors of depression and anxiety among the elderly population living in geriatric homes in Cairo, Egypt. *J Egypt Public Health Assoc.* 2014;89(3):127-135. doi:10.1097/01.EPX.0000455729.66131.49
- Sommerlad A, Kivimäki M, Larson EB, et al. Social participation and risk of developing dementia. Nat Aging. 2023;3(5):532-545. doi:10.1038/ s43587-023-00387-0
- Boamah SA, Weldrick R, Lee TSJ, Taylor N. Social isolation among older adults in long-term care: a scoping review. J Aging Health. 2021;33(7-8):618-632. doi:10.1177/08982643211004174

- Geneva: World Health Organization. Global action plan on the public health response to dementia 2017-2025. World Health Organization. Published online December 7, 2017. https://www.who.int/publications/i/item/global-action-plan-onthe-public-health-response-to-dementia-2017, 2025
- 11. Matthews FE, Dening T. Prevalence of dementia in institutional care. *The Lancet*. 2002;360(9328):225-226. doi:10.1016/S0140-6736(02) 09461-8
- Desmarais P, Lanctôt KL, Masellis M, Black SE, Herrmann N. Social inappropriateness in neurodegenerative disorders. *Int Psychogeriatr.* 2018;30(2):197-207. doi:10.1017/S1041610217001260
- Moyle W, Venturto L, Griffiths S, et al. Factors influencing quality of life for people with dementia: a qualitative perspective. *Aging Ment Health*. 2011;15(8):970-977. doi:10.1080/13607863.2011.583620
- Mikkelsen ASB, Petersen S, Dragsted AC, Kristiansen M. Social interventions targeting social relations among older people at nursing homes: a qualitative synthesized systematic review. *Inquiry*. 2019;56:0046958018823929. doi:10.1177/0046958018823929
- Madrigal C, Bower E, Simons K, Gillespie SM, Van Orden K, Mills WL. Assessing social functioning during COVID-19 and beyond: tools and considerations for nursing home staff. J Am Med Dir Assoc. 2021;22(10):1989-1997. doi:10.1016/j.jamda.2021.07.022
- Valtorta NK, Kanaan M, Gilbody S, Hanratty B. Loneliness, social isolation and social relationships: what are we measuring? A novel framework for classifying and comparing tools. *BMJ Open*. 2016;6(4):e010799. doi:10.1136/bmjopen-2015-010799
- Smith S, Lamping D, Banerjee S, et al. Measurement of health-related quality of life for people with dementia: development of a new instrument (DEMQOL) and an evaluation of current methodology. *Health Technol Assess*. 2005;9(10):1-93. doi:10.3310/hta9100
- de Vet HCW, Terwee CB, Mokkink LB, Knol DL. Measurement in Medicine: A Practical Guide. Cambridge University Press; 2011. doi:10. 1017/CB09780511996214
- Römhild J, Fleischer S, Meyer G, et al. Inter-rater agreement of the Quality of Life-Alzheimer's Disease (QoL-AD) self-rating and proxy rating scale: secondary analysis of RightTimePlaceCare data. *Health Qual Life Outcomes*. 2018;16(1):131. doi:10.1186/s12955-018-0959-y
- Clare L, Wu YT, Jones IR, et al. A comprehensive model of factors associated with subjective perceptions of "living well" with dementia: findings from the IDEAL study. *Alzheimer Dis Assoc Disord*. 2019;33(1):36-41. doi:10.1097/WAD.0000000000286
- Liougas M, Bethell J, Sommerlad A, et al. Systematic review of measures of social connection used in long-term care home research. National Institute for Health and Care Research. Published online January 14, 2022. https://www.crd.york.ac.uk/prospero/display\_record. php?ID=CRD42022303526
- Tricco AC, Lillie E, Zarin W, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med.* 2018;169(7):467-473. doi:10.7326/M18-0850
- Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol. 2005;8(1):19-32. doi:10.1080/ 1364557032000119616
- Liougas MP, Sommerlad A, O'Rourke HM, McGilton KS, Bethell J. Social connection measures for older adults living in long-term care homes: a systematic review protocol. Syst Rev. 2024;13(1):67. doi:10. 1186/s13643-024-02468-6
- Berkman LF, Glass T, Brissette I, Seeman TE. From social integration to health: Durkheim in the new millennium. Soc Sci Med. 2000;51(6):843-857. doi:10.1016/S0277-9536(00)00065-4
- Leedahl SN, Sellon A, Chapin RK. Assessment of multiple constructs of social integration for older adults living in nursing homes. J Gerontol Soc Work. 2018;61(5):526-548. doi:10.1080/01634372.2018.1451938
- 27. Mabire JB, Gay MC, Vrignaud P, Garitte C, Vernooij-Dassen M. Social interactions between people with dementia: pilot evaluation

of an observational instrument in a nursing home. *Int Psychogeriatr*. 2016;28(6):1005-1015. doi:10.1017/S1041610215002483

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- House JS. Work Stress and Social Support. Addison-Wesley Pub. Co; 1981.
- O'Rourke HM, Sidani S. Definition, determinants, and outcomes of social connectedness for older adults: a scoping review. J Gerontol Nurs. 2017;43(7):43-52. doi:10.3928/00989134-20170223-03
- Prohaska T, Burholt V, Burns A, et al. Consensus statement: loneliness in older adults, the 21st century social determinant of health? BMJ Open. 2020;10(8):e034967. doi:10.1136/bmjopen-2019-034967
- Weiss RS. Loneliness: The Experience of Emotional and Social Isolation. MIT Press; 1974.
- 32. Rethlefsen ML, Kirtley S, Waffenschmidt S, et al. PRISMA-S: an extension to the PRISMA Statement for Reporting Literature Searches in Systematic Reviews. *Syst Rev.* 2021;10(1):39. doi:10.1186/s13643-020-01542-z
- Sanford AM, Orrell M, Tolson D, et al. An international definition for "nursing home". J Am Med Dir Assoc. 2015;16(3):181-184. doi:10.1016/ j.jamda.2014.12.013
- Terwee CB, Jansma EP, Riphagen II, de Vet HCW. Development of a methodological PubMed search filter for finding studies on measurement properties of measurement instruments. *Qual Life Res.* 2009;18(8):1115-1123. doi:10.1007/s11136-009-9528-5
- Mokkink LB, De Vet HCW, Prinsen CA, Patrick DL, Alonso J, Bouter LM. COSMIN risk of bias checklist for systematic reviews of patient-reported outcome measures. *Qual Life Res.* 2018;27(5):1171-1179.
- Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol*. 2013;13(1):117. doi:10.1186/ 1471-2288-13-117
- Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. *Int J Qual Methods*. 2006;5(1):80-92. doi:10. 1177/160940690600500107
- Nowell LS, Norris JM, White DE, Moules NJ. Thematic analysis: striving to meet the trustworthiness criteria. Int J Qual Methods. 2017;16(1):1-13. doi:10.1177/1609406917733847
- Patton MQ. Qualitative Research and Evaluation Methods. 3rd ed. Sage Publications; 2002.
- 40. Lincoln YS, Guba EG, Pilotta JJ. Naturalistic inquiry. *Int J Intercult Relat*. 1985;9(4):438-439. doi:10.1016/0147-1767(85)90062-8
- Snowball E, Fernandez Loughlin R, Eagleson H, et al. Engagement of people with lived experience of dementia advisory group and crosscutting program: reflections on the first year. *Res Involv Engagem*. 2022;8(1):28. doi:10.1186/s40900-022-00359-5
- Pollock A, Campbell P, Struthers C, et al. Development of the ACTIVE framework to describe stakeholder involvement in systematic reviews. J Health Serv Res Policy. 2019;24(4):245-255. doi:10.1177/ 1355819619841647
- Dewan N, Sommerlad A, Chapman H, et al. Assessing social connection for long-term care home residents: systematic review using COnsensus-based Standards for the selection of health measurement INstruments guidelines. *Alzheimers Dement*. 2024;e12492. doi:10. 1002/trc2.12492
- 44. Sheehan B. Assessment scales in dementia. Ther Adv Neurol Disord. 2012;5(6):349-358. doi:10.1177/1756285612455733
- 45. Gräske J, Verbeek H, Gellert P, Fischer T, Kuhlmey A, Wolf-Ostermann K. How to measure quality of life in shared-housing arrangements? A comparison of dementia-specific instruments. *Qual Life Res.* 2014;23(2):549-559. doi:10.1007/s11136-013-0504-8
- Siette J, Pomare C, Dodds L, Jorgensen M, Harrigan N, Georgiou A. A comprehensive overview of social network measures for older adults: a systematic review. Arch Gerontol Geriatr. 2021;97:104525. doi:10. 1016/j.archger.2021.104525

- O'Rourke HM, Duggleby W, Fraser KD, Jerke L. Factors that affect quality of life from the perspective of people with dementia: a metasynthesis. J Am Geriatr Soc. 2015;63(1):24-38. doi:10.1111/ jgs.13178
- Carpenter BD. Family, peer, and staff social support in nursing home patients: contributions to psychological well-being. J Appl Gerontol. 2002;21(3):275-293. doi:10.1177/073346480202100301
- 49. Ready RE, Ott BR. Quality of Life measures for dementia. *Health Qual Life Outcomes*. 2003;1(1):11. doi:10.1186/1477-7525-1-11
- Spector A, Orrell M. Quality of life (QoL) in dementia: a comparison of the perceptions of people with dementia and care staff in residential homes. Alzheimer Dis Assoc Disord. 2006;20(3):160-165. doi:10.1097/ 00002093-200607000-00007
- Hoe J, Hancock G, Livingston G, Orrell M. Quality of life of people with dementia in residential care homes. *Br J Psychiatry*. 2006;188(5):460-464. doi:10.1192/bjp.bp.104.007658
- Chamberlain SA, Duggleby W, Fast J, Teaster PB, Estabrooks CA. Incapacitated and alone: prevalence of unbefriended residents in alberta long-term care homes. *Sage Open*. 2019;9(4):215824401988512. doi:10.1177/2158244019885127
- Hutchinson C, Worley A, Khadka J, Milte R, Cleland J, Ratcliffe J. Do we agree or disagree? A systematic review of the application of preference-based instruments in self and proxy reporting of quality of life in older people. *Soc Sci Med.* 2022;305:115046. doi:10.1016/j. socscimed.2022.115046
- McPhail S, Beller E, Haines T. Two perspectives of proxy reporting of health-related quality of life using the euroqol-5D, an investigation of agreement. *Med Care.* 2008;46(11):1140-1148. doi:10.1097/MLR. 0b013e31817d69a6
- Leontjevas R, Teerenstra S, Smalbrugge M, Koopmans RTCM, Gerritsen DL. Quality of life assessments in nursing homes revealed a tendency of proxies to moderate patients' self-reports. *J Clin Epidemiol*. 2016;80:123-133. doi:10.1016/j.jclinepi.2016.07.009

- Pickard AS, Knight SJ. Proxy evaluation of health-related quality of life: a conceptual framework for understanding multiple proxy perspectives. *Med Care.* 2005;43(5):493-499. doi:10.1097/01.mlr. 0000160419.27642.a8
- 57. Grassi M, Nucera A, Zanolin E, Omenaas E, Anto JM, Leynaert B. Performance comparison of Likert and binary formats of SF-36 version 1.6 across ECRHS II adults populations. *Value Health*. 2007;10(6):478-488. doi:10.1111/j.1524-4733.2007.00203.x
- Sabbagh MN, Malek-Ahmadi M, Kataria R, et al. The Alzheimer's questionnaire: a proof of concept study for a new informant-based dementia assessment. J Alzheimers Dis. 2010;22(3):1015-1021. doi:10. 3233/JAD-2010-101185
- Kane RA, Kling KC, Bershadsky B, et al. Quality of life measures for nursing home residents. J Gerontol A Biol Sci Med Sci. 2003;58(3):M240-M248. doi:10.1093/gerona/58.3.M240
- 60. Cha ES, Kim KH, Erlen JA. Translation of scales in cross-cultural research: issues and techniques. J Adv Nurs. 2007;58(4):386-395. doi:10.1111/j.1365-2648.2007.04242.x

#### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Liougas MP, Sommerlad A, O'Rourke H, et al. Assessing social connection for long-term care home residents: A scoping review of measure content. *Alzheimer's Dement*. 2024;10:e12488. https://doi.org/10.1002/trc2.12488