Older adults’ experiences of loneliness in long-term residential care facilities: a scoping review

Cristina Joy Torgé1,Rosita Nyman2 & Axel Ågren1

1Linköping University, Department of Culture and Society, Division of Social Work, Norrköping Sweden

2Jönköping University, School of Health and Welfare, Jönköping, Sweden

# Abstract

Studies report that 61% of residents living in long-term care facilities (LTCs) experience “moderate loneliness” and 35% “severe loneliness” (Gardiner et al., 2020). However, many of the studies that measure loneliness in LTCs use standardized loneliness scales that do not discriminate between the feelings of loneliness in community and in an LTC context.

The transition to LTC brings about dramatic changes in family- and social life, as well as feelings of being uprooted from one’s home (Börjesson & Torgé 2021). There are also unique risks for social isolation in LTCs, despite ‘round the clock care (Boamah et al., 2021).

The aim of this scoping review is to map available research regarding loneliness and social isolation in LTCs, from the older adults’ perspectives. How do older residents describe their experience of loneliness and social isolation?

Databases within medical fields and social science were used to look for research from 2013-2023 that contain qualitative data of experiences of older adults residing in LTCs in any geographic location. This review includes texts on older adults’ (mean ≥ 60) experiences of loneliness in long-term care facilities (excluding ordinary housing). Articles that evaluate interventions without exploring older residents’ views through qualitative methods will be excluded. Results are presented thematically, and knowledge gaps identified.

Keywords: Loneliness; Social isolation; Long-term care; Qualitative research

# Introduction

It is estimated that, globally, 61% of older adults living in residential- and nursing homes experience “moderate loneliness” and 35% experience “severe loneliness” (Gardiner et al., 2020). In our context of Sweden, surveys on older social care users’ quality of life also reflect this, with 46% of nursing care home residents reporting “suffering from loneliness from time to time” and 24% “suffering from loneliness often” (NBHW, 2022).

Research on nursing homes as a context for everyday life emphasizes the ambiguous nature of residential care facilities and how these affect the dynamics of relationships therein (Torgé, 2020, Börjesson and Torgé, 2021). The transition to nursing homes is also often out of necessity, and the physical location has elements of both public and private space. Although facilities have moved away from the institutional paradigm and now espouse “home-like” surroundings, they also maintain institution-like characteristics such as limited control of physical space, the family being reduced to visitors while living with strangers, and the structure of time around bodily care (Börjesson and Torgé, 2021). Research shows that, paradoxically, there are unique risks for social isolation in nursing homes, even though the older adults are surrounded by care staff around the clock (Boamah et al., 2021). The recent COVID-19 pandemic worsened social isolation, among other ways though visiting restrictions.

Arguments for decreasing involuntary loneliness on a societal level often have their starting point in loneliness as a public health concern. Slogans like “loneliness kills”, however, arguably have limited usability in this context, where residents already have the highest healthcare consumption. Long-term care use is increasingly concentrated on the last years of life (Forma et al., 2017). In Sweden, for example, remaining life expectancy after a move to a nursing home is six to nine months (Törnqvist et al., 2013). Despite this unusual context, the same arguments for reducing loneliness – and the same measures for interventions – are used for older adults across the board, regardless of the group, location, and specific phase of life. Although involuntary loneliness is a problem throughout the life course, its causes, the motives to reduce loneliness, as well as the projected positive effects of interventions perhaps cannot simply be translated from one group to another. Most intervention studies about loneliness in nursing homes, however, merely apply the same principles to community-dwelling older adults to adults in residential care.

One can further critically discuss the kinds of understandings generated in loneliness studies, and whether these are insightful to understand the experiences of loneliness among this group. In Sweden, for example the National Board of Health and Welfare survey simply asks nursing home residents if they “feel lonely”, with the possible answers “never/sometimes/always”. Impenetrable aspects such as existential loneliness, as well as the specific effects of the transition to residential care on one’s social networks, are seldom considered or problematized. Qualitative research on nursing homes bear witness to the dramatic changes in family- and social life which the person undergoes within a short time. Expressions such as “married widowhood” (Braithwaite, 2002) signify the spatial and emotional disconnectedness from meaningful relationships. For a group that is at the end of life living in residential care environments, loneliness interventions premised on health effects or number of social interactions thus also have their natural limitations.

Against this background, we wanted to do a scoping review to map available research regarding loneliness and social isolation in different forms of long-term care facilities, from the older adults’ perspectives. How do older residents describe their experience of loneliness and social isolation?

#  Background

Loneliness and social isolation have been studied as a social problem for a long time, and while acknowledged to be a social problem, it is also a subjective experience. In his pioneering work, Robert Weiss (1973) defined social loneliness as caused by the lack of a social network and not being included in social communities. Emotional loneliness was instead caused by lack of intimate relationships (Weiss, 1973). The second commonly used definition of loneliness was developed by Perlman and Peplau (1981), referring to loneliness as an unpleasant experience occurring when there is a discrepancy between a person’s desired and achieved level of social relations (Perlman & Peplau, 1981). Smith (2012) argues that loneliness among older adults is associated with loss of friends, loss of social status, declining health and loss of a spouse. Therefore, older adults who suffer from losses may be more exposed to negative feelings of loneliness and finding it difficult to change their situation (Taube et al., 2016). While lack of support and lack of social relationships are important markers of loneliness, it does not necessarily cause feelings of loneliness. Conversely, people who live a relatively rich social life can still experience loneliness (Hauge & Kirkevold, 2012).

In public discourse, the dominating idea is that loneliness, illness, being passive and dependent on others is something that should be avoided (Ågren & Pavlidis, 2023; Kiuru & Valokivi, 2022) and strongly associated with the fourth age often seen as the ”dark side” of ageing (Gilleard & Higgs, 2014). There have of course been shifts in views of ageing and old age, from being associated with passivity, decline and frailty, to being a period in life filled with opportunities, activity and self-fulfilment. It is however argued that cultural myths continuously dominate, where older adults are viewed as homogeneous and associated with problems such as illness, decline, death and loneliness (Reul et al, 2022; Tornstam, 2007). On the one hand, while experiences of loneliness are individual and subjective, researchers and welfare professionals rely on social scripts in the construction of loneliness as a social problem and to identify who is lonely (Yang, 2019; Schirmer & Michailakis, 2016). Life course- and age norms also colour how loneliness is framed and interpreted as a problem for different age groups. For instance, media portrayals of involuntary loneliness among older adults are prone to evoke feelings of pity or compassion, to a greater extent than with younger adults (Ågren, 2017). There is also a persisting belief that older adults in general feel lonelier than younger adults (Tornstam, 2007) and thus need to be encouraged to be active. These cultural scripts also dominate in understanding the experience of older people needing long-term care, or who live in facilities such as nursing homes. As individuals in the ”fourth age”, they tend to be the stereotypes of lonely, ill and inactive older adults. This said, the experience of loneliness In LTCs – and if and how this experience differs from the experience of loneliness among other older adults in the community – has not been widely studied, although widely reported as a social problem and a problem concerning long-term care provision.

In this research group, we are interested in the portrayal of loneliness in different contexts.
Predominantly, research on loneliness tends to focus on prevalence, predictors, and correlations between loneliness and various negative health outcomes (see Lim, Holt-Lunstad & Badcock, 2020; Holt-Lunstad et al., 2015; Coyle & Dugan, 2012). There is also a plethora of research on loneliness interventions, and organizations that aim to decrease or eliminate loneliness compete for space in what Rokach (2004) defines as the "loneliness industry". A risk, however, is that "non-old" professionals – care staff, volunteers, politicians, but also researchers – define loneliness (and their solutions) thus not recognising individual differences in feelings of loneliness (Ågren & Cedersund 2020; Estes, 1979), where context and older adults’ own understandings of their loneliness, can play a part.

By attempting to map, describe and thematize the available research in this area, we can know on the one hand, if and in what way older adults in LTCs experience loneliness in this context, and concurrently, also how loneliness research frames the problem of loneliness in LTCs. By focusing on the older LTC residents’ own experiences, one would also be able to engage in a broader discussion in loneliness research, about which understandings loneliness tend to be in focus, and which experiences of loneliness are missed. With this as a background, we designed a scoping review. Below is the protocol for our review:

# Review question

How do older residents in long-term care facilities describe their experience of loneliness and social isolation in scientific literature?

# Inclusion criteria

### Types of Sources

This scoping review considers published scientific articles that report on older adults’ experiences of loneliness, using qualitative methods. We have followed the JBI methodology for scoping reviews. To ensure that we are getting the correct material for the review, the population, concept and context have been discussed and decided beforehand. Texts with participants about 60 years and older will be considered.

### Concept

The concept of interest is loneliness. Social isolation is also of interest to us, as it overlaps with the loneliness concept. We wish to investigate how older adults in this context describe or experience loneliness or the effects of loneliness interventions. Interventions or activities against loneliness that are only evaluated through quantitative surveys / scales, without the use of qualitative methods, will be excluded.

### Context

The context is long-term residential care facilities in any geographical location. Long-term residential care facilities are for example nursing homes, skilled nursing facilities, or similar, which may or may not be needs-assessed housing forms, but where the premise of living there is the need for long-term care, social care and medical care. Texts that are about hospices, halfway houses or hospitals are excluded as these are more institutional in nature and we are interested in the long-term residential care facility as a housing form.

### Methods

### Databases

### Databases within both medical fields and social science were searched for articles. The databases included were: Pubmed, Cinahl (Ebsco), Scopus, PsycINFO, MEDLINE, AMED, Web of Science Core Collection and Academic Search Complete. We limited the search from 2013 onwards and included articles in English and Scandinavian languages.

Our search terms are described in the Appendix. The words contained in the titles and abstracts of relevant articles, and the key words used to describe the articles will be used in the first part of the search strategy, and words contained at any part of the article were used in the second part of the search strategy. The search strategy combines concept (loneliness, social isolation), population (age), context (long-term residential care facilities) and study design (qualitative research) (Appendix 1a). The reference list of the sources will be screened for additional studies not already captured in our search. Google Scholar will also be screened for additional studies not already captured in our search.

All identified sources were collated and uploaded into a citation management system Rayyan, and duplicates were removed.

### Study inclusion and data extraction

*This part is ongoing.*

Members of the research team are independently screening the articles against the inclusion and exclusion criteria for the review. Disagreements will be resolved by discussion and exclusion criteria could be modified as necessary. Abstracts of articles that have not been excluded after discussion will be read by all members of the research team again to further define the eligibility of each article. The relevant articles will then be retrieved in full text and assessed in detail against the inclusion and exclusion criteria. Reasons for exclusion of texts at this stage will also be recorded and reported in the scoping review. The result of the searches and the study inclusion process will be reported in full in the final scoping review, which will include a PRISMA diagram of included studies.

We will extract (systematize) data in the included texts in the scoping review. This data will include age and gender of the participants, the form of long-term residential care facility, study methods (e.g. interviews, focus groups) and key findings relevant to the review question. According to the JBI method guidelines for scoping review, a quality appraisal of the included texts is not required.

### Presentation of results

The included texts will first be descriptively summarised (e.g. year published, type of design, aim, country of origin). We will then identify themes that answer our review questions, and any knowledge gaps in the literature. Tables and figures will visualise the findings and a PRISMA flow diagram will be used to illustrate the search and inclusion process.

*Here is the description of the search at the moment:*

After conducting the search according to the search strategy, we ended up with 1915 articles.

After removing duplicates, we ended up with 554 articles.

We are in the process of screening the articles. Articles in languages other than English and Scandinavian languages have been removed. Review articles, study protocols and theses have been removed.

See Appendix for exclusion reasons.

# References – not yet complete

Boamah, et al. (2021). Social isolation among older adults in long-term care: A scoping review. J Aging and Health, 33(7-8), 618-632.
Börjesson, U. & Torgé, C.J. (2021). “They say this is a home”. The challenge of “home” in residential care settings for old and young. J. Hous. Built Environ. doi: <https://doi.org/10.1007/s10901-021-09877-2>

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Berger, P. L. & Luckmann, T. (1966). The social construction of reality: A treatise in the sociology of knowledge. London: Penguin Books.
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 Braithwaite, D. O. (2002). “Married widowhood”: Maintaining couplehood when one spouse is living in a nursing home. Southern Journal of Communication, 67(2), 160-179.

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 Forma, L., Aaltonen, M., Pulkki, J., Raitanen, J., Rissanen, P., & Jylhä, M. (2017). Long-term care is increasingly concentrated in the last years of life: a change from 2000 to 2011. The European Journal of Public Health, 27(4), 665-669.

Gardiner, C., Laud, P., Heaton, T., & Gott, M. (2020). What is the prevalence of loneliness amongst older people living in residential and nursing care homes? A systematic review and meta-analysis. Age and ageing, 49(5), 748-757.
 NBHW (National Board of Health and Welfare). (2022). Vägledning för att förhindra ofrivillig ensamhet bland äldre personer. Socialstyrelsen.

 Torgé, C. J. (2020). “Being in-Between”: Spouses That Cohabit With and Provide Care for Their Partners in Nursing Homes. Journal of Applied Gerontology, 39(4), 377–384. <https://doi.org/10.1177/0733464818803007>

Törnquist, A., Andersson, M., & Edberg, A. K. (2013). In search of legitimacy–registered nurses’ experience of providing palliative care in a municipal context. Scandinavian journal of caring sciences, 27(3), 651-658."

# Appendices

### Appendix I: Search strategy

AB=abstract TI=title N=near

|  |  |  |
| --- | --- | --- |
| #1 | AB (lonel\* OR social isolation)1 |  |
| #2 | TI (lonel\* OR social isolation) |  |
| #3 | AB ("nursing home” " OR “nursing care home” OR “residential care” OR “long-term care facility” OR “longterm care facility” OR “LTC” OR “senior housing”)1 |  |
| #4 | TI ("nursing home” " OR “nursing care home” OR “residential care” OR “long-term care facility” OR “longterm care facility” OR “LTC” OR “senior housing”)1 |  |
| #5 | 1 OR 2 |  |
| #6 | 3 OR 4 |  |
| #7 | 5 AND 6 |  |
| #8 | TX (old OR elder\* OR geriatric\* OR aged OR “older adult\*” OR aging OR ageing OR senior) |  |
| # 9 | 7 AND 8  |  |
| # 10 | TX (qualitative OR interview\* OR narrative OR “focus group\*”) |  |
| #11 | TX ((“semi-structured” OR semistructured OR unstructured OR informal OR “in-depth” OR indepth OR “face-to-face” OR “open-ended” OR “open ended”) |  |
| #12 | 10 OR 11 |  |
| #13 | 9 AND 12 |  |

1MeSH terms have also been taken into account.

The exclusion criteria

|  |  |
| --- | --- |
| **Exclusion criteria** | **Add Reason** |
| Community dwelling, living at home | Wrong context |
| Short-term housing, Halfway house | Wrong context |
| Hospice or hospital | Wrong context |
| Mean age <60 years | Age |
| Depression | Not loneliness concept |
| Only professional views\*\* | Wrong group (\*\*include if there are older adults’ perspective as well) |
| Only caregivers’ perspective\*\* | Wrong group (\*\*include if there are older adults’ perspective as well) |
| Observational/Cross-sectional (quantitative) | Wrong design |
| Reviews  | Wrong design  |
| Randomized studies | Wrong design |
| Study protocol | Wrong publication type |
| Conference abstract | Wrong publication type |
| Bachelors’ or masters’ theses | Wrong publication type (\*\*\*Doctoral theses have been marked in the review and may be included) |
| Retracted studies | Retracted |

### Data extraction instrument

JBI template source of evidence details, characteristics and results extraction instrument, with adjustments for this scoping review

|  |  |
| --- | --- |
| **Scoping review details** |  |
| Scoping review title:  |  |
| Review objective:  |  |
| Review question:  |  |
| **Inclusion/exclusion criteria** |  |
| Population |  |
| Concept |  |
| Context |  |
| Type of text (e.g. published/unpublished, reports) |  |
| Type of data collection (e.g. interview, focus groups) |  |
| **Source details and characteristics**  |  |
| Citation details (e.g. author/s, date, title, journal, volume, issue, pages) |  |
| Country |  |
| Context (e.g. living situation, environment) |  |
| Participants (e.g. age, gender, number) |  |
| **Details/results extracted from source of texts** (in relation to the concept of the scoping review) |  |
| *Definition of loneliness / Aspects of loneliness studied* |  |
| *Definition of social isolation / Aspects of social isolation studied* |  |
| *Key findings*  |  |