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EMRAN: Quality of life in care homes: protocol

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**Development and Validation of Quality of Life Measurement Tools Used in Older Peoples' Care Homes: a scoping review protocol**

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East Midlands Research into Ageing Network (EMRAN) is a research collaboration across the East Midlands to facilitate collaborative applied clinical research into ageing and the care of older people. EMRAN was set up with support from NIHR CLAHRC East Midlands.

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## Abstract

### Introduction

There is a high prevalence of frailty and cognitive impairment within care home population. These wide-ranging experiences and needs impact on residents' quality of life. Therefore, measuring Quality of Life (QOL) in residents as part of routine practice could help inform care decisions. This review aims to describe how QOL tools used in care homes have been developed, to describe the extent to which these are grounded in the care home experience, the extent to which the concerns of residents, families and staff are addressed by existing tools, and/or the extent to which these remain unaddressed.

### Method

This review will follow the Joanna Briggs Institute (JBI) guidelines for conducting scoping reviews. All published literature will be searched using bibliographic databases (MEDLINE, EMBASE, PsychINFO, CINAHL, and COSMIN database of systematic review of outcome measurement instruments) and grey literature will be searched using OpenGrey and social care online databases.

Studies will be selected for inclusion based on population- individuals aged 65 years and above; concept- all QOL tools both generic and dementia-specific used in care homes

regardless of the context they have been developed for; and context- care homes- both residential and nursing homes with or without dementia care in any country. Also, reference lists of reviews and included studies will be carried out to identify additional relevant studies. Only papers written in English will be included. Conference abstracts, editorial and commentary articles will be excluded. Articles will be independently screened (at both title/abstract and full text stages) for eligibility by two reviewers. Any disagreement will be resolved by a third reviewer.

Data will be extracted, summarised descriptively and presented in a tabular form under categories that represent the review's objectives. This will include the theoretical frameworks/conceptual models, stakeholder involvement, tool content, intended use of the tool, validation and strengths and limitations of the tool.

## Discussion

A key strength of this review is using a scoping review methodology which is appropriate for the review question because it will provide a descriptive and broad overview on the development of QOL tools used in care homes. Potential limitations include limiting the searches to only studies published in English.

## Introduction

Approximately 420, 000 older people live in UK care homes (1). Care homes, known internationally as long term care facilities or nursing homes, are places where people live and receive care. Care homes with and without nursing are often called nursing and residential homes respectively. Residential homes provide support with personal care. Whilst, nursing homes, in addition to personal care support, also provide 24 hour supervision by a registered nurse for people with more complex health needs.

There is a high prevalence of frailty and cognitive impairment within care home population (2). Most projections suggest that the absolute number of older people who need support in a care home will increase (3). Therefore, there is a need to understand care experiences and outcomes of residents to improve the quality of care provided. One way of doing this is by measuring Quality of Life (QOL).

QOL is defined by the World Health Organisation QOL group as “an individual’s perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (4). On the other hand quality of care refers to the processes required to ensure basic needs are met. Therefore QOL is different from quality of care but correlates with it and is regarded as being an important outcome by residents and relatives (5).

There are a number of QOL tools that exist and have been used for older people (6, 7, 8, 9, 10, 11). Some QOL tools focus on health-related aspects of life affected by a person’s health condition and treatment known as health-related quality of life (10). Whilst others focus on social care related quality of life that refers to the aspects of an individual’s QOL that can be affected by social care (12).

A search for reviews on QOL tools for care homes was done in the Cochrane Database of Systematic Reviews and Medline (OVID) on the 5<sup>th</sup> July 2021 by one of the reviewers (AU). Reviews that looked at different aspects of QOL tools were found. Aspden et al. focused on the measurement properties of these tools (13). This review identified 13 QOL instruments, 5 of which were generic and 8 were disease specific. Most of which lacked information on hypothesis and content validity and none of the tools had any information on hypothesis testing and measurement error. Another review by Hughes et al. that focused specifically on measurement properties of QOL tools for dementia and usability in care homes also found limited information on measurement properties of most of these tools (14). Interestingly, this review also showed that the identified tools may not be feasible or accessible for use in care homes. Additionally, a review by the WE-THRIVE working group focused on identifying measures relating to the concepts of well-being, QOL and personhood that can be used internationally to assess long term care (15). For the concept of QOL, the review identified and recommended three non-dementia specific and three dementia specific tools for use in long term care setting.

Taking account of the differences between living in care home and living elsewhere, a tool that is context-cognisant and –sensitive for use in care homes is one which can:

- Take account of the concerns of residents, and their relatives, and how these change over time as residents approach the end of life.
- Accommodate the role and perspectives of staff in determining and understanding quality of life
- Reliably account for what matters to residents around quality of life.

The reviews conducted hitherto have provided evidence on what QOL tools could be used in care homes based on their measurement properties, expert consensus and initial surveys of feasibility and usability. However, to our knowledge, no review has described how these tools were developed to provide evidence on whether they are sufficiently context-cognisant or sensitive to legitimately be deployed in care homes. Therefore, this review aims to describe how QOL tools used in care homes have been developed, to describe the extent to which these are grounded in the care home experience, the extent to which the concerns of residents, families and staff are addressed by existing tools, and/or the extent to which these remain unaddressed. To help guide the development of a care home specific QOL measure. Hence, this review will specifically answer the following questions:

- What are the theoretical frameworks or conceptual models that guide the development of QOL tools for care homes?
- Who (residents, relatives, staff carers and expert panel) were involved in the development of QOL tools for use in care homes? How were they involved?
- What are the contents of these tools? (what aspects of QOL are being measured and what items are chosen to represent these)?
- What are the data collection methods and analysis used to establish QOL?
- How are these tools intended to be used?
- To what extent have the measurement properties of these tools been assessed?
- What are the strengths and limitations of these tools?

## Methods

This review will follow the Joanna Briggs guidelines for conducting scoping reviews (16). Scoping reviews can be used to identify the types of evidence available in a given area, to assess how research is conducted on a specific topic, explain key concepts or definitions in the literature, to examine the key factors relating to a concept, and to explore gaps in the literature (17). Although similar to a systematic review in using a rigorous and transparent approach to identifying the available evidence relating to a research question (18). However, unlike a systematic review, it does not aim to answer clinically meaningful questions that can help inform practice or provide evidence on the effectiveness of a treatment, intervention or practice. Also, they do not critically appraise and synthesise the available evidence but rather provide a descriptive overview of the literature (17, 18). Therefore, a scoping review will be appropriate for this review

because it will provide a descriptive overview of the available literature on the development of QOL tools used in care homes.

## **Inclusion criteria**

### *Population*

This review will focus on older people (with and without dementia) aged 65 years and over who live in care homes. This age limit was chosen because most databases have limiters by age categories. Therefore by using this age limit, searches will only be limited to older populations and will not include care homes for people with intellectual disability- who are not the focus of this review, due to different consideration around quality of life and the difference in context between care homes for those with intellectual disability and those for older people.

### *Concept*

Quality of life instruments used in care homes for older people. Tools included will be those developed specifically for use in care homes as well as tools developed elsewhere but used in care homes. Tools included will be both self-reported and proxy-reported instruments measuring either health or social care related quality of life or both. Also, both generic and dementia specific tools will be included. Tools for specific conditions other than dementia will be excluded because these are not as prevalent as dementia and do not influence QOL score completion in the same way as cognitive impairment.

### *Context*

Care homes or equivalent long term care facilities in other countries. This includes both residential and nursing homes, with or without dementia care, in any country. It does not include acute, community, rehabilitation, or long-term care hospitals.

### *Type of studies*

Both quantitative and qualitative studies will be included. Reviews will not be included but their reference lists will be searched for relevant studies. Only studies written in English will be included. Studies that have an abstract but not article in English will be excluded, because abstracts may not contain a detailed description sufficient to address the review questions.

## **Information sources**



The following bibliographic databases will be searched for published literature: MEDLINE, EMBASE, PsychINFO, CINAHL and COSMIN database of systematic review of outcome measurement instruments. For grey literature, the OpenGrey and social care online databases will be searched.

### **Search strategy**

This will be based on the concept and context components. Search terms for these components were derived using previous reviews (13, 14, 15), keywords of identified papers, and index terms. The search strategy was developed by combining the words that represent each component using the Boolean operator OR then combining the components by the Boolean operator AND as follows:

1. Quality of life OR QOL OR health related quality of life OR HRQOL OR HRQL OR SCRQOL OR social care related quality of life AND;
2. Surveys and Questionnaires OR Scale OR measurement OR Questionnaires OR Survey OR instrument OR outcome assessment OR outcome measure OR self-report OR self-assessment OR tool AND;
3. Care homes OR residential care OR Long-term care OR geriatric long-term care facilities OR assisted living OR old age homes OR homes for the Aged.

The reference lists of included studies will also be screened for additional studies.

### **Study selection**

Five reviewers will be involved in study selection. Two reviewers will independently screen both the title/abstract and full text articles. Any disagreement will be resolved by a third reviewer. All results will be managed in Rayyan. The selection process will be documented using the Adapted PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart for scoping reviews.

### **Data extraction**

The following information will be extracted from articles by reviewers using a standardized data extraction form: author(s), year of publication, country of origin, setting (residential or nursing), sample size, study design, data collection methods, analytical approach, resident and stakeholder involvement, theoretical framework or conceptual models used, content of the tool (domains and items), intended use of tool, measurement properties assessed and strengths and limitations of the tool.

## Data analysis and presentation

Data will be summarised descriptively mapping the extracted data under the following categories: theoretical framework; stakeholders' involvement; tool content; data collection methods and analytical approaches; the intended use of the tool; validation; and strengths and limitations of the tool. Free text entries will be categorised under broad headings which will be iteratively modified as articles are reviewed. Where clear categories emerge, the number of articles under each category will be counted. For both those variables where clear categories emerge, and those where they do not, illustrative verbatim quotes from articles will be collated and stored under the relevant categories. Iterative changes to categories will be made by agreement of at least two members of the research team, with all decisions reviewed by the wider team at regular meetings. All extracted data and results will be presented in tables.

## Reporting

This review will be reported in accordance with the PRISMA extension for scoping reviews (PRISMA-SR) checklist (18). Data will be reported using descriptive statistics- count and proportions- to summarise the data where categories are established. Other findings will be reported narratively under the seven main areas of enquiry.

## Discussion

One of the strengths of using a scoping review methodology is that it is systematic and provides a broad overview on a topic area. Therefore, it is an appropriate choice for this question. Another strength is that this review will help describe and identify gaps in the development of QOL tools used in care homes which can help guide the development of a care home specific QOL tool.

A potential limitation of this review is limiting the search to only papers written in English. Therefore, there is a risk that important papers may not be published in English and will be missed. This is shown by previously published work that shows that the bulk of the literature in English comes from the US, the Netherlands and UK (19). Whilst subsequent reviews have shown a sizeable literature from non- English-speaking countries which is not captured in the English literature (20). Another limitation is that grey literature databases are less comprehensive than bibliographical databases and there is always, therefore the chance of missing important non-academic publications. However, the literature around QOL in care homes has been largely scholarly and therefore it is highly likely that it will be substantially captured by the approaches taken.



Furthermore, the voices of care home residents and their carers may or may not be well captured by the published literature in this field. Though limited by what is available in the published literature and finding out the extent to which these important stakeholders have been involved in the work is an important objective for this review.

## Dissemination

Findings from this review will be published in a peer-reviewed journal and presented at national and international conferences. A lay summary of the findings will also be produced and disseminated to members of the lay public via the Applied Research Collaboration (ARC) website and tweeted on twitter. The findings will inform an ongoing PhD fellowship and will be used to inform interview studies with care home residents, their families, and staff, to inform the development of a context-cognisant and –sensitive approach to describing quality of life in care homes.

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## Competing Interests

None

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## Appendix

### *Search strategy- Medline (Ovid)*

1. exp "Quality of Life"/
2. ("Quality of life" or QOL or HRQOL or HRQL or SCRQOL).ti,ab.
3. ("Quality of life" or QOL or HRQOL or HRQL or SCRQOL).mp.
4. 1 or 2 or 3
5. exp Nursing Homes/
6. exp Homes for the Aged/
7. ("care home\*" or "residential care" or "longterm care" or " long term care" or "assisted living" or " homes for the aged" or "old age home\*").ti,ab.
8. 5 or 6 or 7
9. exp "Surveys and Questionnaires"/
10. (Survey\* or Questionnaire\* or Scale\* or measurement\* or Questionnaires or instrument\* or "outcome assessment\*" or "outcome measure\*" or "self-report\*" or "self assessment\*").ti,ab.
11. 9 or 10
12. 4 and 8 and 11
13. limit 12 to "all aged (65 and over)"
14. limit 13 to english language
15. 14 and exp "Quality of Life"/