Older persons’ perceptions and experiences of community palliative care: a systematic review of qualitative evidence protocol

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Review question/objective: The objective of this systematic review is to identify and synthesize the best available qualitative evidence on how older persons perceive and experience community palliative care. The specific question is: What are older persons’ perceptions and experiences of community palliative care?

Keywords Community palliative care; experiences; older persons; perceptions; qualitative systematic review protocol

Background

With populations aging around the globe, the need for palliative care for older persons is becoming a significant public health issue.1,2 In developed countries, age-specific death and chronic illness and related disabilities rates tend to be higher in older age groups.1–3 Prevalent chronic conditions for older persons include cancer, arthritis, osteoporosis, diabetes mellitus, cardiovascular disease, stroke, asthma, chronic kidney disease, dementias, including Alzheimer’s disease and mental health conditions such as depression.4–6 In Australia, the cause of 90% of all deaths in 2011 is attributed to chronic diseases.4,5 According to the Australian Institute of Health and Welfare, from 2007 to 2008, 78% of older persons in Australia reported having a chronic disease.4–6 In 2009, 49% of older Australians living in the community aged 65–74 years and 70% of those aged 85 years or over reported having to cope with five or more chronic diseases.4,6

The Korean Declaration on Hospice and Palliative Care 20057 and the Joint Declaration and Statement of Commitment on Palliative Care and Pain Treatment 20088 proclaim that palliative care and relief of pain and suffering are universal human rights for every adult and child with a life-limiting disease, and that these must be provided according to the principles of equity. Research literature, however, shows that access to community palliative health services may be inequitable, with older, male, unmarried persons, persons without home carers, and persons from lower socio-economic groups, ethnic minority populations or with non-cancer life-limiting conditions less likely to access such services.9 Further, despite their increased need for palliative care, older persons have poorer access to palliative care services than persons in younger age groups and those experiencing cancer.1

According to the World Health Organization, “palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”10(p.1)

Many older persons live in the community and prefer to receive palliative care and die in their own homes.11 “A palliative approach, specialist palliative care service provision and end-of-life care are major forms of palliative care for older persons.”12(p.37) A person-centered palliative care approach aims to provide palliative care in the chosen environment of...
the person receiving such care. A seamless, efficient, coordinated, collaborative and holistic community palliative care approach for older persons involves service delivery by multiple agencies and multidisciplinary teams of healthcare professionals. Community palliative care is defined as palliative care “provided in an older person’s home, including a retirement village setting, or similar, but excluding residential aged care facilities”. Coordinated case management/care, integrated care, consumer-directed care and specialist palliative care are the four main models of palliative care service provision. These different models of care, however, are applied differently across and within different countries and contexts. For example, the case management model of care is commonly used in Australia, whilst the integrated care model is more commonly used in North America. The specialist palliative care model has been commonly used for providing palliative care for persons with cancer.

Research literature shows that community palliative care may improve quality of life, decrease symptoms, increase survival, reduce healthcare costs, and increase the person’s satisfaction with their health care. Older persons, however, also need to contend with the physical, psychosocial and spiritual changes occurring with normal aging which may affect their palliative care needs, experiences and satisfaction with palliative care differently than with persons receiving palliative care in other adult age groups.

However, there is paucity of research on palliative care for older persons in general, and on the experiences and perceptions of older persons receiving community palliative care in particular. Following a review of databases, as outlined in our search strategy, no systematic reviews on this topic were identified. Therefore it is important to systematically review the research available on older persons’ experiences and perceptions of community palliative care to inform providers of palliative care and policy makers, and enhance their understanding of older persons’ unique needs, perceptions and experiences of community palliative care, as well as illuminating how research and practice may be enhanced so as to best provide high quality community palliative care for older persons.

Inclusion criteria
Types of participants
This review will consider studies that include participants aged 65 years and over who have experiences of community palliative care services.

Phenomena of interest
The synthesis will consider studies that include a focus on the experiences and perceptions of older persons who have experienced community palliative care. Studies focusing on older persons’ experiences and perceptions of non-community palliative care will be excluded.

Context
The review will consider studies that investigate older persons’ experiences and perceptions of palliative care provided in community-based settings, such as the older person’s home, a community living environment and a retirement village, but excluding residential aged care facilities.

Types of studies
The study will review qualitative studies, including (but not limited to), phenomenological, grounded theory, ethnographic and thematic analysis studies of older persons’ experiences and perceptions of community palliative care. It may also include qualitative aspects of mixed method studies that focus on the older person’s experiences and perceptions of community palliative care. Only studies published in the English language will be reviewed. Quantitative studies will be excluded.

Search strategy
This qualitative systematic review will utilize a three-step search strategy. The first step will entail a limited search of MEDLINE and CINAHL to identify primary key words used in the title, abstract and index words of an article that will be applied in these search engines. The second step of the search will involve using all identified keywords and index terms to search across all included databases. In the third and final step, the reference list of all identified reports and articles will be searched for additional studies. Given the recent emergence of palliative care as specialist practice, searches will be limited to 2000 to 2015. Only studies published in English will be considered for inclusion in this review.
The databases to be searched for published studies will include:
- CINAHL
- EMBASE
- PubMed
- SCOPUS
- Web of Science.

The search for unpublished studies will include:
- MedNar
- Networked Digital Library of Theses and Dissertations
- ProQuest Dissertations and Theses
- CareSearch Grey Literature.

Initial keywords to be used will be: older (i.e. aged, elderly) persons (i.e. people, adults), experience, perception, community palliative care

Assessment of methodological quality
Papers selected for retrieval will be assessed by two independent reviewers for methodological quality prior to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute Meta-Analysis of Statistics Assessment and Review Instrument (JBI-QARI) (Appendix I). Any disagreements that arise between the reviewers will be resolved through discussion or consultation with a third reviewer.

Data extraction
Data will be extracted from the papers in the review using the JBI-QARI standardized data extraction tool (Appendix II). The data extracted will include specific details about the phenomenon of interests, populations, study methods and outcomes of significance to the review question and objectives.

Data synthesis
Qualitative research findings will, where possible, be pooled using JBI-QARI. This will involve synthesis or aggregation of findings to enable generation of a set of statements that represent that aggregation (Level 1 findings), rated according to their quality, and categorized according to their similarity of meaning (Level 2 findings). A meta-aggregation of categories will be undertaken to enable production of a single comprehensive set of aggregated findings (Level 3 findings) that may be used as a basis for evidence-based practice. Where textual pooling cannot be undertaken, the findings will be presented in narrative form.

References
3. Centers for Disease Control and Prevention. Healthy aging: Helping people to live long and productive lives and enjoy a good quality of life. At a glance 2011. Atlanta, GA: CDC National Center for Chronic Disease Prevention and Health Promotion, Division of Adult and Community Health; 2011
# Appendix I: Appraisal instruments

QARI appraisal instrument

## JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

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<tr>
<th>Question</th>
<th>Yes</th>
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<th>Unclear</th>
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<td>1. Is there congruity between the stated philosophical perspective and the research methodology?</td>
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<td>6. Is there a statement locating the researcher culturally or theoretically?</td>
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<td>7. Is the influence of the researcher on the research, and vice versa, addressed?</td>
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<td>8. Are participants, and their voices, adequately represented?</td>
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<td>9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?</td>
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<td>10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?</td>
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Overall appraisal: □ Include □ Exclude □ Seek further info. □

Comments (including reason for exclusion)
Appendix II: Data extraction instruments

QARI data extraction instrument

**JBI QARI Data Extraction Form for Interpretive & Critical Research**

Reviewer ___________________________ Date ___________________________

Author ___________________________ Year ___________________________

Journal ___________________________ Record Number ___________________________

**Study Description**

Methodology

Method

Phenomena of interest

Setting

Geographical

Cultural

Participants

Data analysis

Authors Conclusions

Comments

Complete Yes □ No □
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<th>Findings</th>
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Extraction of findings complete: Yes □ No □