Mapping the Progress and Impacts of Community Engagement and Health Promoting Palliative Care in End of Life Care: a scoping review protocol

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| Complete List of Authors: | Archibald, Daryll; University of Edinburgh, Centre for Population Health Sciences  
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Title: Mapping the Progress and Impacts of Community Engagement and Health Promoting Palliative Care in End of Life Care: a scoping review protocol

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ABSTRACT

Introduction: Community engagement in end-of-life care is an umbrella term encompassing a variety of approaches, which involve working with communities to improve people’s experience of death, dying and bereavement. Recently, approaches to community engagement in end-of-life care, and specifically the development of “health promoting palliative care” have gained momentum within UK health policy and palliative care services. There is general consensus that community engagement in end-of-life care can complement and go beyond the scope of formal service models of palliative care. However, there is no clarity about how these approaches can be undertaken in practice or how evidence can be gathered relating to the effectiveness of these approaches. Here we outline a scoping review protocol that will systematically map and categorise the variety of activities and programmes that could be classified under the umbrella term ‘community engagement in end-of-life care’ and highlight the impact of these activities where measured.

Methods and analysis: This review will be guided by Arksey and O’Malley’s (2005) scoping review methodology and incorporate insights from more recent innovations in scoping review methodology, specifically from Levac et al. (2010) and the Joanna Briggs Institute (2015). Sensitive searches of 9 electronic databases from 1999 to 2016 will supplemented by grey literature searches. Eligible studies will be screened independently by two reviewers using a data charting tool developed for this scoping review.

Ethics and dissemination: This scoping review will undertake a secondary analysis of data already collected and does not require ethical approval. The results will facilitate better understanding of the practical application of community engagement in end-of-life care, the impacts these activities can have and how to build the evidence base for this work in future. The results will be disseminated through both traditional academic routes such as conferences and journals and also policy and third sector seminars.

STRENGTHS AND LIMITATIONS OF THIS STUDY

• No previous work has been done to systematically map and categorise the wide variety of activities and programmes that could be classified under the umbrella term ‘community engagement in end-of-life care’.
• This work will shed much needed light on the potentially wide-ranging impact of community engagement in end of life care activities and explore ways in which impact has been or might be measured.
• A scoping review can help to understand whether the palliative care community instigate this type of engagement activity, or whether other organisations (for example local charities, community groups and arts organisations) are involved in activities which constitute community engagement in end-of-life care but which they haven’t labelled as such.
• No formal quality assessment of included studies is performed. This is because scoping reviews provide a map of what evidence has been produced as opposed to seeking only the best available evidence to answer a particular policy and practice-related question.
INTRODUCTION

A social model of health recognises that influences on people’s health are far broader than disease and injury and that they include social, cultural, environmental and economic factors, looking further than lifestyles and behaviour, and recognising that social change can be a prerequisite for health. In recent decades there has been growing recognition that a social model of health is helpful in understanding how to improve people’s experiences of death, dying and bereavement. Allan Kellehear has been a key influence in academic and practical work this area, developing the Health Promoting Palliative Care (HPPC) model in the late 1990s. As its name suggests, HPPC brings together two perspectives — health promotion and palliative care — to focus on improving experiences of death, dying and bereavement.

Kellehear’s work illustrates how the principals of the World Health Promotion Guidelines contained in the Ottawa Charter can be applied to palliative and end of life care, widening the traditional service-oriented palliative care model by building policies, creating supportive environments, strengthening community actions, developing personal skills and re-orienting health services to support the experiences of dying, death and loss. The linkage of palliative care and health promotion is a good example of the ‘new public health’ that became prominent in the 1980s which emphasised the importance of the social determinants of health and the active role of individuals in securing their own health.

As the field has developed over recent years, several terms have emerged to describe approaches that are related to or similar to HPPC. In 2014 Sallnow & Paul attempted to develop some conceptual clarity around use of these terms:

“a range of terms have now entered the discourse, including ‘public health approaches to palliative care’ (Conway, 2008), ‘compassionate cities’ (Kellehear, 2005), ‘compassionate communities’ (Abel, Bowra, Walter, & Howarth, 2011) and ‘health promoting palliative care’ (Kellehear, 1999). Such initiatives serve to: improve the relevance of the services offered; develop skills, knowledge and capacity in communities; support coping and resilience in the face of death, dying and loss.” P.232

In the absence of established summary definitions for each of these terms, Sallnow & Paul provide an umbrella term that is useful for the purposes of this scoping review, which is mainly concerned with activity and impact rather terminology:

“Community engagement in end-of-life care is an umbrella term for a process which enables communities and services to work together to understand, build capacity and address issues to improve their experience of end-of-life and bereavement and their related well-being. It exists, depending on a range of factors such as the degree of participation from the local community and the intention of the work. Community engagement activities by end-of-life..."
In recent years, approaches to community engagement in end-of-life care have attracted interest and gradually gained momentum within UK health practice and policy, and among those who are part of and responsible for palliative care services. There is general consensus that community engagement in end-of-life care can complement and go beyond the scope of formal service models of palliative care. However, there is not widespread clarity about how these approaches can be undertaken in practice or how evidence can be gathered relating to the effectiveness of these approaches.

No previous work has been done to systematically map and categorise the wide variety of activities and programmes that could be classified under the umbrella term ‘community engagement in end-of-life care’, to understand the potentially wide-ranging impact of these activities, or to explore ways in which impact has been or might be measured.

Despite the rapid international growth of interest in approaches to community engagement in end-of-life care, few overviews of literature on these issues are available to date. Rosenberg and Yates (2010) conducted a critical review of literature relevant to the conceptual foundations of health promoting palliative care that explored the early considerations regarding the convergence of palliative care and health promotion. Sallnow et al. (2015) undertook a systematic review of the evidence relating to the impact of a new public health approach to end-of-life care, specifically as this applies to efforts to strengthen community action.

This paper outlines the protocol for a scoping review which aims to:

1. Systematically map and categorise the wide variety of activities and programmes that could be classified under the umbrella term ‘community engagement in end-of-life care’.

2. Document the impact of these activities where impact has been measured.

A review of this kind has the potential to shed light on whether the palliative care community are the main instigators of this type of engagement activity, or whether other organisations (for example local charities, community groups and arts organisations) are involved in activities which constitute community engagement in end-of-life care but which they haven’t labelled as such. It can increase awareness of the different understandings, interpretations and approaches which could fall under the umbrella of community engagement in end-of-life care. It can also provide valuable information about how the theory of community engagement in end-of-life care can be applied in practice in various settings. There is also the potential for future work which more fully explores how the
impact of activities can be evaluated and what barriers and enablers exist regarding building the evidence base for this field of work.

METHODS

Various approaches are available for reviewing and synthesising literature, however given the aims listed above, a scoping review is the most suitable review method to deploy in this case. This can be said as the intention of this review is to produce an overall map of what evidence has been produced as opposed to the approach associated with systematic reviewing where the best evidence available is sought to answer a tightly defined question related to policy and/or practice. 

Scoping reviews are thus broader in nature than systematic reviews in that they provide an overview of existing evidence regardless of quality. Scoping reviews therefore allow researchers to examine the extent, range and nature of research activity in their chosen area. Despite no formal quality assessment being undertaken, scoping reviews nevertheless apply a comprehensive and systematic approach to mapping the literature, key concepts, theories, evidence and research gaps in a field using broadly framed questions.

This scoping review will conform to the 5-stage framework laid out by Arksey and O’ Malley (2005), however in setting out the plan of the review in this way we will also draw upon more recent refinements to Arksey and O’ Malley’s framework by Levac et al. (2010) and Joanna Briggs Institute (2015).

Stage 1: Identifying the research questions

The first stage in the process of conducting a scoping review is to identify the research question(s) for the study and to link the question with purpose of the study. With that in mind, we developed a series of research questions related to the aims of the study. However, as the process of conducting a scoping review is often iterative, requiring a reflexive approach to each stage as the researcher becomes increasingly familiar with the literature, there is a possibility that revisions may be made to the research questions. Six research questions were identified to guide the scoping review. These questions were developed via a series of research team meetings:

1. What programmes have been carried out and are presented in the social science and medical literature around community engagement in end-of-life care?
2. What barriers and facilitators to implementing programmes are identified in the social science and medical literature around community engagement in end-of-life care?
3. What programmes have been evaluated in the social science and medical literature around community engagement in end-of-life care and how have they been evaluated?
4. What impacts are reported in the social science and medical literature around community engagement in end-of-life-care?
5. What are the key gaps in the social science and medical literature around community engagement in end-of-life care?

6. What are the target populations being addressed in the social science and medical literature around community engagement in end-of-life care?

Stage 2: Identifying relevant studies

Sallnow & Paul (2014) provide a useful conceptualisation of the type of activity that constitutes ‘community engagement in end-of-life care’ which acts as a useful basis for identifying relevant work:

“Such initiatives serve to: improve the relevance of the services offered; develop skills, knowledge and capacity in communities; support coping and resilience in the face of death, dying and loss.” (p.232)

In consultation with a senior medical librarian at the University of Edinburgh, we developed a working framework for a search strategy (see Appendix 1). The design of the search strategy was underpinned by key inclusion criteria (see Table 1). These criteria were categorised according to the broad Population - Concept – Context (PCC) mnemonic recommended by The Joanna Briggs Institute for scoping reviews as a less restrictive alternative to the PICO (Population, Intervention, Comparator, and Outcome) mnemonic recommended for systematic reviews.

Table 1: Inclusion criteria

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
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<tr>
<td>Population</td>
<td>Human subjects</td>
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<tr>
<td></td>
<td>Any age</td>
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<td></td>
<td>Any sex</td>
</tr>
<tr>
<td>Concept</td>
<td>Any initiative promoting community engagement in end of life care carried out between 1999 and 2016</td>
</tr>
<tr>
<td>Context</td>
<td>Research articles are limited to developed countries (and regions) including UK, Canada, USA, Continental Europe, Australia and New Zealand where contemporary societal attitudes to death and dying may be comparable.</td>
</tr>
<tr>
<td></td>
<td>All settings considered</td>
</tr>
<tr>
<td></td>
<td>Original research articles (any methods) and review articles including: systematic reviews, meta analyses, meta-syntheses, narrative</td>
</tr>
</tbody>
</table>
Search strategy

The search strategy will follow the three-step process recommended by Joanna Briggs Institute (2015). The first of these steps has been undertaken and involved a limited preliminary search of one online database relevant to the topic (Ovid Medline). This search resulted in 6787 studies.

The second step will contain an analysis of the text words contained in the title and abstract of retrieved papers, and of index terms used to describe the articles. A second search using all identified keywords and index terms will then be undertaken across all included databases. These databases will include Ovid EMBASE, EBSCO CINAHL, EBSCO PsycINFO, Proquest Applied Social Sciences Index and Abstracts, Proquest Education, Resources Information Center, OCLC Anthropology Plus, Ovid British Nursing Index, Social Sciences Citation Index, and Conference Proceedings Citation Index – Social Science & Humanities.

The third and final step will check the reference lists of all identified reports and articles for additional studies. Grey literature searches will also be undertaken to identify any non-indexed literature of relevance to this review. The final included studies will be held stored using a reference management software package and duplicates will be removed.

Stage 3: study selection

The study selection process will be implemented over two stages. The first stage will involve the review of titles by one reviewer (DA) to determine study eligibility based on the above stated inclusion and exclusion criteria. For example, foreign language titles or titles that indicate a study was carried out in an ineligible country will be removed. Titles will be screened as ‘included’, ‘excluded’ or ‘uncertain’. Should uncertainty arise with a title in the first stage, the citation will be considered in the second stage.

The second stage of the selection process will see two reviewers (DA and EH) apply the inclusion criteria to all abstracts. Should differences arise, the reviewers will consult with a third reviewer to reach consensus. When consensus is not reached, those articles will be included in the review.

To recap, a formal assessment of the quality of included studies will not be undertaken as scoping reviews aim to provide a map of what evidence has been produced rather than seeking only the best available evidence to answer a particular question related to policy and practice.
Stage 4: Charting the data

The process of data extraction in scoping reviews is termed ‘charting’ the results. The charting process aims to generate a descriptive summary of the results that corresponds to the aims and research questions of the scoping review. A draft charting form (see Table 2) has been developed at the protocol stage to aid the collection and sorting of key pieces of information from the selected articles.

Data to be extracted from the included studies will include standard information (such as author, year of publication, study objectives). In addition, further information pertaining to the key features of programmes and activities that promote ‘community engagement in end-of-life care’ will be searched for in the included studies. This additional information takes the form of a priori categories that incorporate Kellehear’s ‘Big 7’ checklist, which is a seven-point checklist to assess how well a programme/initiative matches the criteria of Health Promoting Palliative Care (HPPC). However, additional categories may emerge during the data collection and the data extraction form will include a category for reviewers to record emergent themes that will be discussed and refined during research team meetings. This may be further refined at the review stage and the charting form updated accordingly.

Table 2 Draft Data Charting Form

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<tr>
<td>Type of publication (journal article, book chapter, grey literature)</td>
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<th>2. RESEARCHER DETAILS</th>
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<td>Authors and affiliations (list as presented on paper)</td>
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<th>3. AIMS &amp; METHODS</th>
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<td>Methodology</td>
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Stage 5: collating, summarising and reporting the results

The central challenges to undertaking a scoping review centre on determining a framework for presenting a narrative account.\textsuperscript{11} With that said, the strategy of reporting results from this review will draw on recent innovations in reporting scoping review results, such as from Halas et al. (2015)\textsuperscript{12} and Nelson et al. (2015).\textsuperscript{13} Both of the aforementioned studies advocate using a modified version of the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA)\textsuperscript{14} to present results from the search process. We will also modify the PRISMA checklist, specifically by
incorporating the elements of the checklist that are congruent with the underpinnings of scoping review methodology whilst removing points that are not, such as those points that relate to bias. Drawing further on the work of Levac et al. (2010) and Nelson et al. (2015) we will also present a numerical overview of the amount, type and distribution of the included studies. The central section of the review will comprise a thematic summary of the findings that relates the a priori and emergent categories extracted from the included studies to the research questions stated above.

CONCLUSION

Scoping reviews can be complex to undertake, however an a priori protocol will help in the process of preparing for such a review in order to provide an approach that offers clarity, strength and transparency to avoid problems occurring during the undertaking of the review. The review will have relevance to a variety of audiences including researchers, clinicians and policy makers interested in better understanding the practical application of community engagement in end-of-life care, the impacts these activities can have and how to build the evidence base for this work in future. The study research team includes experts in community engagement in end-of-life care from academia, NHS Scotland and the third sector.

Table 3 Timeline for protocol and scoping review

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ACKNOWLEDGMENTS

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AUTHOR CONTRIBUTORSHIP STATEMENT

All authors have contributed to the development of the research questions and study design. Daryll Archibald led the preparation of the manuscript and led the writing of the methods and discussion sections. Rebecca Patterson led the writing of the introduction section and contributed to the study design and development of research questions and provided detailed comments on earlier drafts. Erna Haraldsdottir, Mark Hazelwood and Shirley Fife jointly conceived the idea for the project, contributed to the study design and development of research questions and provided detailed comments on earlier drafts. Scott A Murray led the supervision of the manuscript preparation, jointly conceived the idea for the project, contributed to the study design and development of research questions and provided detailed comments on earlier drafts.

COMPETING INTERESTS

There are no competing interests to declare.

REFERENCES


APPENDIX 1: Search Strategy for Ovid Medline

1. Health promoting palliative care.mp.
2. public health approaches to palliative care.mp.
3. (public health approach* adj3 (palliative or end of life)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
4. end of life care.mp.
5. compassionate cities.mp.
6. compassionate communities.mp.
7. compassionate commun*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
8. palliative care/ or terminal care/ or hospice care/
9. health promotion/ and (end of life or hospice or terminal or palliative).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
10. or/1-9
11. Attitude to Death/
12. bereavement/ or grief/ or loneliness/
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14. community engagement.mp.
15. social support.mp. or Social Support/
16. (program* or intervention* or campaign* or strateg*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
17. death education.mp.
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19. 10 and 18
20. limit 19 to english language
21. limit 20 to yr="1999 -Current"
22. limit 21 to journal article
23. 11 or 12 or 13 or 14 or 15 or 17
24. 10 and 23
25. limit 24 to journal article
# Mapping the Progress and Impacts of Public Health approaches to Palliative Care: a scoping review protocol

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ABSTRACT

Introduction: Public health palliative care is a term which can be used to encompass a variety of approaches that involve working with communities to improve people’s experience of death, dying and bereavement. Recently, public health palliative care approaches have gained recognition and momentum within UK health policy and palliative care services. There is general consensus that public health palliative care approaches can complement and go beyond the scope of formal service models of palliative care. However, there is no clarity about how these approaches can be undertaken in practice or how evidence can be gathered relating to their effectiveness. Here we outline a scoping review protocol that will systematically map and categorise the variety of activities and programmes that could be classified under the umbrella term ‘public health palliative care’ and highlight the impact of these activities where measured.

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“a range of terms have now entered the discourse, including ‘public health approaches to palliative care’ (Conway, 2008), ‘compassionate cities’ (Kellehear, 2005), ‘compassionate communities’ (Abel, Bowra, Walter, & Howarth, 2011) and ‘health promoting palliative care’ (Kellehear, 1999). Such initiatives serve to: improve the relevance of the services offered; develop skills, knowledge and capacity in communities; support coping and resilience in the face of death, dying and loss.” P.232

In this relatively new and rapidly developing field, there remains a lack of clarity regarding definitions and use of terminology, and it is outside the remit of this review to address this issue in detail. With the establishment of two new organisations, Public Health Palliative Care International and Public Health Palliative Care UK in 2015, ‘public health palliative care’ is a relatively recently devised term which is growing in popularity. Recognising that no single term is perfect, within this paper we use the term ‘public health palliative care’ as an umbrella term to encompass the range of
approaches and initiatives relevant to this review, drawing on the conceptualisation by Sallnow & Paul referenced above.

In recent years, approaches to public health palliative care have attracted interest and gradually gained momentum within UK health practice and policy, and among those who are part of and responsible for palliative care services. There is general consensus that public health palliative care approaches can complement and go beyond the scope of formal service models of palliative care. However, there is not widespread clarity about how these approaches can be undertaken in practice or how evidence can be gathered relating to the effectiveness of these approaches.

No previous work has been done to systematically map and categorise the wide variety of activities and programmes that could be classified under the umbrella term ‘public health palliative care’, to understand the potentially wide-ranging impact of these activities, or to explore ways in which impact has been or might be measured.

Despite the rapid international growth of interest in approaches to public health palliative care, few overviews of literature on these issues are available to date. Rosenberg and Yates (2010) conducted a critical review of literature relevant to the conceptual foundations of health promoting palliative care that explored the early considerations regarding the convergence of palliative care and health promotion. Sallnow et al. (2015) undertook a systematic review of the evidence relating to the impact of a new public health approach to end-of-life care, specifically as this applies to efforts to strengthen community action.

This paper outlines the protocol for a scoping review which aims to:

1. Systematically map and categorise the wide variety of activities and programmes that could be classified under the umbrella term ‘public health palliative care’.
2. Document the impact of these activities where impact has been measured.

A review of this kind has the potential to shed light on whether the palliative care community are the main instigators of this type of engagement activity, or whether other organisations (for example local charities, community groups and arts organisations) are involved in activities which constitute public health palliative care but which they haven’t labelled as such. It will set out some of the different understandings, interpretations and approaches which could fall under the umbrella of public health palliative care. It can also provide valuable information about the range of ways that the theory of public health palliative care has been applied in practice in various settings, to inform how the concept is understood in practice as well as informing future work in this area. There is also
the potential for future work which more fully explores how the impact of activities can be evaluated and what barriers and enablers exist regarding building the evidence base for this field of work.

METHODS

Various approaches are available for reviewing and synthesising literature, however given the aims listed above, a scoping review is the most suitable review method to deploy in this case. This can be said as the intention of this review is to produce an overall map of what evidence has been produced as opposed to the approach associated with systematic reviewing where the best evidence available is sought to answer a tightly defined question related to policy and/or practice.  

Scoping reviews are thus broader in nature than systematic reviews in that they provide an overview of existing evidence regardless of quality. Scoping reviews therefore allow researchers to examine the extent, range and nature of research activity in their chosen area. Despite no formal quality assessment being undertaken, scoping reviews nevertheless apply a comprehensive and systematic approach to mapping the literature, key concepts, theories, evidence and research gaps in a field using broadly framed questions.  

This scoping review will conform to the 5-stage framework laid out by Arksey and O’ Malley (2005), however in setting out the plan of the review in this way we will also draw upon more recent refinements to Arksey and O’ Malley’s framework by Levac et al. (2010) and Joanna Briggs Institute (2015).  

Stage 1: Identifying the research questions

The first stage in the process of conducting a scoping review is to identify the research question(s) for the study and to link the question with purpose of the study. With that in mind, we developed a series of research questions related to the aims of the study. However, as the process of conducting a scoping review is often iterative, requiring a reflexive approach to each stage as the researcher becomes increasingly familiar with the literature, there is a possibility that revisions may be made to the research questions. Six research questions were identified to guide the scoping review. These questions were developed via a series of research team meetings:

1. What programmes have been carried out and are presented in the social science and medical literature around public health palliative care?
2. What barriers and facilitators to implementing programmes are identified in the social science and medical literature around public health palliative care?
3. What programmes have been evaluated in the social science and medical literature around public health palliative care and how have they been evaluated?
4. What impacts are reported in the social science and medical literature around public health palliative care?
5. What are the key gaps in the social science and medical literature around public health palliative care?

6. What are the target populations being addressed in the social science and medical literature around public health palliative care?

Stage 2: Identifying relevant studies

Sallnow & Paul (2014) provide a conceptualisation which acts as a useful basis for identifying relevant work for this scoping review:

“Such initiatives serve to: improve the relevance of the services offered; develop skills, knowledge and capacity in communities; support coping and resilience in the face of death, dying and loss.” (p.232)

In consultation with a senior medical librarian at the University of Edinburgh, we developed a working framework for a search strategy (see Appendix 1). The design of the search strategy was underpinned by key inclusion criteria (see Table 1). These criteria were categorised according to the broad Population - Concept – Context (PCC) mnemonic recommended by The Joanna Briggs Institute for scoping reviews as a less restrictive alternative to the PICO (Population, Intervention, Comparator, and Outcome) mnemonic recommended for systematic reviews.

Table 1: Inclusion criteria

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
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<tbody>
<tr>
<td><strong>Population</strong></td>
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<tr>
<td></td>
<td>Human subjects.</td>
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<tr>
<td></td>
<td>Any age.</td>
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<tr>
<td></td>
<td>Any sex.</td>
</tr>
<tr>
<td><strong>Concept</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Any initiative promoting community engagement in end of life care carried out between 1999 and 2016.</td>
</tr>
<tr>
<td><strong>Context</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Research articles are limited to developed countries (and regions) including UK, Canada, USA, Continental Europe, Australia and New Zealand where contemporary societal attitudes to death and dying may be comparable.</td>
</tr>
<tr>
<td></td>
<td>All settings considered.</td>
</tr>
<tr>
<td></td>
<td>Original research articles (any methods) and review articles including: systematic reviews, meta analyses, meta-syntheses, narrative reviews, mixed-methods reviews, qualitative reviews and rapid reviews.</td>
</tr>
</tbody>
</table>
Search strategy

The search strategy will follow the three-step process recommended by Joanna Briggs Institute (2015). The first of these steps has been undertaken and involved a limited preliminary search of one online database relevant to the topic (Ovid Medline). This search resulted in 6787 studies.

The second step will contain an analysis of the text words contained in the title and abstract of retrieved papers, and of index terms used to describe the articles. A second search using all identified keywords and index terms will then be undertaken across all included databases. These databases will include Ovid EMBASE, EBSCO CINAHL, EBSCO PsycINFO, Proquest, Applied Social Sciences Index and Abstracts, Proquest Education, Resources Information Center, OCLC Anthropology Plus, Ovid British Nursing Index, Social Sciences Citation Index, and Conference Proceedings Citation Index – Social Science & Humanities.

The third and final step will check the reference lists of all identified reports and articles for additional studies. Grey literature searches will also be undertaken to identify any non-indexed literature of relevance to this review. The final included studies will be held stored using a reference management software package and duplicates will be removed.

Stage 3: study selection

The study selection process will be implemented over two stages. The first stage will involve the review of titles by one reviewer (DA) to determine study eligibility based on the above stated inclusion and exclusion criteria. For example, foreign language titles or titles that indicate a study was carried out in an ineligible country will be removed. Titles will be screened as ‘included’, ‘excluded’ or ‘uncertain’. Should uncertainty arise with a title in the first stage, the citation will be considered in the second stage.

The second stage of the selection process will see two reviewers (DA and EH) apply the inclusion criteria to all abstracts. Should differences arise, the reviewers will consult with a third reviewer to reach consensus. When consensus is not reached, those articles will be included in the review.

To recap, a formal assessment of the quality of included studies will not be undertaken as scoping reviews aim to provide a map of what evidence has been produced rather than seeking only the best available evidence to answer a particular question related to policy and practice.
Stage 4: Charting the data

The process of data extraction in scoping reviews is termed ‘charting’ the results. The charting process aims to generate a descriptive summary of the results that corresponds to the aims and research questions of the scoping review. A draft charting form (see Table 2) has been developed at the protocol stage to aid the collection and sorting of key pieces of information from the selected articles.

Data to be extracted from the included studies will include standard information (such as author, year of publication, study objectives). In addition, further information pertaining to the key features of programmes and activities that promote ‘public health palliative care’ will be searched for in the included studies. This additional information takes the form of a priori categories that incorporate Kellehear’s ‘Big 7’ checklist, which is a seven-point checklist to assess how well a programme/initiative matches the criteria of Health Promoting Palliative Care (HPPC). However, additional categories may emerge during the data collection and the data extraction form will include a category for reviewers to record emergent themes that will be discussed and refined during research team meetings. This may be further refined at the review stage and the charting form updated accordingly.

Table 2 Draft Data Charting Form

<table>
<thead>
<tr>
<th>1. BIBLIOGRAPHIC INFORMATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study ID</td>
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<tr>
<td>Article title</td>
</tr>
<tr>
<td>Extracted by</td>
</tr>
<tr>
<td>Checked by</td>
</tr>
<tr>
<td>Type of publication</td>
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<tr>
<td>Country</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>2. RESEARCHER DETAILS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Authors and affiliations</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. AIMS &amp; METHODS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study aims/objectives</td>
</tr>
<tr>
<td>Methodology</td>
</tr>
</tbody>
</table>
### Methods

#### 4. SCOPING REVIEW PCC

<table>
<thead>
<tr>
<th>Population</th>
<th></th>
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<tbody>
<tr>
<td>Concept (interventions/programmes and outcomes assessed)</td>
<td></td>
</tr>
<tr>
<td>Context</td>
<td></td>
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</table>

#### 5. A PRIORI THEMES (does the paper report data relating to the following?)

- a. Social difficulties around death, dying, loss or care
- b. Reducing harms associated with death, dying, loss or care (e.g. isolation/loneliness)
- c. Early interventions along the journey of death, dying, loss or care?
- d. Changes to settings/environments
- e. Participatory approaches
- f. Sustainable approaches
- g. Evaluability

#### 6. EMERGENT THEMES (does the paper report on any further issues not related to the above that might be of interest to this review?)

- a.  
- b.  
- c.  
- d.  

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**Stage 5: collating, summarising and reporting the results**

The central challenges to undertaking a scoping review centre on determining a framework for presenting a narrative account.\textsuperscript{13} With that said, the strategy of reporting results from this review will draw on recent innovations in reporting scoping review results, such as from Halas et al. (2015)\textsuperscript{13} and Nelson et al. (2015).\textsuperscript{14} Both of the aforementioned studies advocate using a modified version of the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA)\textsuperscript{15} to present results from the search process. We will also modify the PRISMA checklist, specifically by...
incorporating the elements of the checklist that are congruent with the underpinnings of scoping review methodology whilst removing points that are not, such as those points that relate to bias. Drawing further on the work of Levac et al. (2010) and Nelson et al. (2015) we will also present a numerical overview of the amount, type and distribution of the included studies. The central section of the review will comprise a thematic summary of the findings that relates the a priori and emergent categories extracted from the included studies to the research questions stated above.

CONCLUSION

Scoping reviews can be complex to undertake, however an a priori protocol will help in the process of preparing for such a review in order to provide an approach that offers clarity, strength and transparency to avoid problems occurring during the undertaking of the review. The review will have relevance to a variety of audiences including researchers, clinicians and policy makers interested in better understanding the practical application of public health palliative care, the impacts these activities can have and how to build the evidence base for this work in future. The study research team includes experts in public health palliative care from academia, NHS Scotland and the third sector. Table 3 below shows the timeline for study completion.

Table 3 Timeline for protocol and scoping review

<table>
<thead>
<tr>
<th>Month</th>
<th>Author Involvement</th>
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<tbody>
<tr>
<td>Feb 2016</td>
<td></td>
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<tr>
<td>Mar 2016</td>
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<tr>
<td>Apr 2016</td>
<td></td>
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<tr>
<td>May 2016</td>
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<tr>
<td>Jun 2016</td>
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<td>Jul 2016</td>
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<tr>
<td>Aug 2016</td>
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<tr>
<td>Sep 2016</td>
<td></td>
</tr>
<tr>
<td>Oct 2016</td>
<td></td>
</tr>
</tbody>
</table>

Writing protocol

Search

Screening

Analysis

Writing-up
ACKNOWLEDGMENTS

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AUTHOR CONTRIBUTORSHIP STATEMENT

All authors have contributed to the development of the research questions and study design. Daryll Archibald led the preparation of the manuscript and led the writing of the methods and discussion sections. Rebecca Patterson led the writing of the introduction section and contributed to the study design and development of research questions and provided detailed comments on earlier drafts. Erna Haraldsdottir, Mark Hazelwood and Shirley Fife jointly conceived the idea for the project, contributed to the study design and development of research questions and provided detailed comments on earlier drafts. Scott A Murray led the supervision of the manuscript preparation, jointly conceived the idea for the project, contributed to the study design and development of research questions and provided detailed comments on earlier drafts.

COMPETING INTERESTS

There are no competing interests to declare.

REFERENCES


APPENDIX 1: Search Strategy for Ovid Medline

1. Health promoting palliative care.mp.
2. public health approaches to palliative care.mp.
3. (public health approach* adj3 (palliative or end of life)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
4. Public health palliative care.mp.
5. end of life care.mp.
6. compassionate cities.mp.
7. compassionate communities.mp.
8. compassionate commun*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
9. palliative care/ or terminal care/ or hospice care/
10. health promotion/ and (end of life or hospice or terminal or palliative).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
11. or/1-9
12. Attitude to Death/
13. bereavement/ or grief/ or loneliness/
14. community development.mp. or Social Change/
15. community engagement.mp.
16. social support.mp. or Social Support/
17. (program* or intervention* or campaign* or strateg*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
18. death education.mp.
19. or/11-17
20. 10 and 18
21. limit 19 to english language
22. limit 20 to yr="1999 -Current"
23. limit 21 to journal article
24. 11 or 12 or 13 or 14 or 15 or 17
25. 10 and 23
26. limit 24 to journal article