Primary bereavement care across health care settings and contexts:
a systematic review protocol of qualitative evidence

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Review question/objective

The objective of this review is to identify the appropriateness of primary bereavement care interventions from the perspectives of health care providers and recipients in a variety of health care settings (e.g., acute care (emergency department, labor and delivery, geriatrics, pediatrics), community care, long term care etc.) and contexts (e.g. perinatal infant death, SIDS, child death, accidental/traumatic death, palliative care, etc.).

The review will be guided by the following review question:

What are health care providers’ and recipients’ experiences of primary bereavement care interventions in a variety of health care settings and contexts?
Background

Losing a loved one is often described as one of the most challenging life experiences. Experiences of loss, grief and bereavement are unique, dynamic and wide-ranging in spite of the ubiquitous presence, commonality and universality of death in our lives.\(^1\)\(^-\)\(^3\) Although death - both expected and unexpected - is a certainty, family members’ responses are not. This is because “no two of us experience bereavement in identical ways”\(^4\)\(^,\)\(^p.56\) Nevertheless, grief is present in recognizable patterns around which guiding principles for the care of the bereaved may be recommended but not prescribed. Grief and bereavement have been explored and studied through the ages. Bereavement research “has already passed through a number of identifiable generations, each being characterized by attention to a distinct set of important issues, theoretical advancements and unique implications for society”.\(^5\)\(^,\)\(^p(3)\)

Freud’s Mourning and Melancholia, published in 1917, is touted as one of the earliest scholarly reports on grief in which he described mourning as a process of “detaching oneself from the deceased”,\(^6\)\(^,\)\(^p(833)\) that grief “is a job of psychological work that we neglect at our peril”,\(^7\)\(^,\)\(^p(26)\) and that bereavement may be a cause of depression. Explorations of grief and bereavement since that time have ranged from conceptualizations of grief as ‘normal’, with deviations from normal,\(^8\) to grief as a cause of psychiatric problems,\(^9\) to the development of several theories involving anticipated or expected stages, tasks or processes of mourning.\(^10\)\(^-\)\(^13\)

Although the research evidence indicates that the bereaved can suffer from a range of physical, emotional, social, and financial concerns (i.e. elevated risks of depression, increased somatic complaints, increased medication and substance abuse, increased absenteeism and disability days, etc.),\(^5\)\(^,\)\(^15\)\(^-\)\(^16\) bereavement care delivered by health care providers is generally not valued, well done, or remunerated. For example, palliative care services focus on the care of the dying and generally do not extend to include bereavement care after the death of a patient. Yet, family members and significant others often grieve throughout the phase of palliative care as well as following the death of their loved one. Although it is still unclear which groups of bereaved individuals are most vulnerable, there is agreement that the death of a loved one affects the health and well-being of all who are bereaved.\(^5\)\(^,\)\(^15\)

Care providers can often intensify grief when they fail to recognize how their reactions impact on the experiences of these vulnerable individuals and families.\(^17\) Words and actions from staff at the critical time of loss are not forgotten, regardless of the type of loss, “heartfelt comforting words or touches can become sustaining memories that promote healing, just as callous indifference can make painful scars.”\(^18\)\(^(para51)\)

Caring for the bereaved is crucial to support and promote the health of individuals, families, and communities. To date, the focus of bereavement care ‘interventions’ has been centered on those who present with complications, rather than on primary prevention interventions.\(^19\)\(^-\)\(^20\) The focus is usually on pathology or the difficulty experienced by the bereaved and is frequently provided by bereavement care specialists (e.g., psychologists, psychiatrists, social workers, etc.). However, the human and financial costs of providing support for bereaved across the board should be set against the potential long-term personal and societal costs of not providing preventative or primary bereavement support. Primary bereavement care is defined as health care professionals capturing and creating opportunities to be with and support individuals/families in their experiences of grief and mourning surrounding the death of a loved one.\(^17\) These supportive practices are needed for all bereaved individuals/family members to differing extents,\(^20\) whether it is five minutes in an emergency room or five months in palliative care.
Thus, the emphasis of primary bereavement care is on the prevention of negative sequelae and on health promotion for the bereaved.

The Joanna Briggs Institute Library of Systematic Reviews, Medline, CINAHL and the ProQuest Nursing and Allied Health databases were searched and no systematic reviews on primary bereavement care interventions were found. Given the absence of current evidence syntheses to inform primary care interventions, the purpose of this systematic review is to synthesize the best available qualitative evidence on primary bereavement care interventions. This review will provide research evidence to inform the care provided by all health care professionals who work with bereaved individuals and families, in a variety of settings and contexts.

**Definition of terms**

It is recognized that the expression and experience of grief and bereavement can vary across cultures and societies and various terms may be used to describe these experiences. For the purpose of this review, definitions of the following terms are intentionally broad in scope:

Bereavement is “the entire experience of family members and friends in the anticipation, death and subsequent adjustment to life surrounding the death of a loved one.”

Grief is “a primarily emotional (affective) reaction to the loss of a loved one through death.”

Mourning is “the social expression or acts expressive of grief that are shaped by the practices of a given society or cultural group.”

Primary bereavement care occurs as health care professionals capture and create opportunities to be with and support individuals/families in their experiences of grief and mourning surrounding the death of a loved one.

**Keywords**

Bereavement, grief, mourning, bereavement care, primary bereavement care, bereavement support, bereavement intervention

**Inclusion criteria**

**Types of participants**

This systematic review will consider studies that include one or both of two types of participants, regardless of age, gender, or cultural identity. The first group will include family members and/or friends of individuals who were anticipating the death of a loved one, or were adjusting to life after the death of a loved one and who received primary bereavement care. The second group will include any health care provider, including but not limited to nurses, physicians, social workers, spiritual and religious care providers and psychologists, who have offered primary bereavement care to patients, family members and/or friends of persons who were dying, or who died.
**Phenomena of interest**

This review will consider studies that investigate primary bereavement care interventions, as reported by family members and friends who have lost a loved one in different health care settings and contexts. The phenomenon of interest also includes the perspectives of health care providers on primary bereavement care. Primary bereavement care may not be labeled as such in studies reviewed, but will be identified by descriptions of care surrounding the loss of a loved one.

**Context**

This systematic review can include any location where a death has occurred, such as urban, rural, remote, institutional and/or community health/home care settings, or contexts such as perinatal infant death, SIDS, child death, accidental/traumatic death, palliative care and so forth.

**Types of studies**

This review will consider studies that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research, case studies and feminist research.

In the absence of research studies, other texts such as opinion papers and reports will be considered.

**Search strategy**

The search strategy aims to find both published and unpublished studies. A three-step search strategy will be utilized in this review.

An initial limited search of MEDLINE and CINAHL will be undertaken, followed by analysis of the text words contained in the title and abstract and of the index terms used to describe the article. A second search using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference lists of all identified reports and articles will be searched for additional studies. Only studies published in English and French from 1982 onwards will be considered for inclusion in this review. However, all relevant studies published in any language will be identified and a log maintained. Data from studies in English and French will be extracted by the team, while citations in other languages will be tallied but not translated. The start date 1982 was selected because this was deemed as the relevant time frame for the emergence of the topic of primary bereavement care in the literature.

The databases to be searched include:

- Center for Reviews and Dissemination
- CINAHL
- Cochrane
- Embase
- Google Scholar
- Health Source: Nursing / Academic Edition
- Knowledge Network Scotland
The search for unpublished studies will include:

Google

New Zealand Nursing Research Database

OAIster (through WorldCat)

ProQuest Dissertations and Theses

science.gov

Scirus

Theses Portal Canada

Virginia Henderson International Nursing Library

Initial keywords to be used will be:

bereavement
grief (and its variants: grieving; grieves; anticipatory grieving; grief experience)
mourn (and its variants: mourning, mourns, mourn experience)
attitude to death
family (and its variants: extended family; nuclear family; spouse(s); husband; wife; significant other;
sibling(s); brother(s); sister(s); child; children; father(s); mother(s); son(s); daughter(s))
family attitude (and its variants: family attitudes; attitude(s) of the family)
family perspective (and its variants: family perspectives; perspective(s) of the family)
family centered care (and its variant: family centred care )
support (and its variant: supports)
health service (and its variants: health services; health care service; health care services; healthcare
service; healthcare services)
primary health care (and its variants: primary healthcare; primary care)
crisis intervention
hospice care
palliative care
community health care (and its variant: community healthcare)
resident care
long term care
nursing home care
home care (and its variant: home nursing)
extramural care
emergency room (and its variants: emergency room care; emergency department)

The search strategy will be adapted to the features and vocabulary of each database searched. It is intended that complicated grief, and its variants (for example, chronic sorrow, chronic grief, chronic compounded grief), will be excluded from the results by the search structure wherever possible. Interest is in health care providers’ perspectives on bereavement care and not on their personal experience of losing a patient. Therefore, it is intended that grief and bereavement literature related to health care professionals’ own stress and grief experiences over the death of a patient / client will be excluded via the search structure wherever possible.

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 Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix I). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

Data collection

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

Data synthesis

Qualitative research findings will, where possible be pooled using JBI-QARI. This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings rated according to their quality and categorizing these findings on the basis of similarity in meaning. These categories are then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice. Where textual pooling is not possible, the findings will be presented in narrative form.
Conflicts of interest

No conflict of interest.

Acknowledgements

We wish to gratefully acknowledge the Queen’s Joanna Briggs Collaboration for Patient Safety for their ongoing support and feedback.
References


Appendix I: Appraisal instruments

QARI appraisal instrument

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

<table>
<thead>
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<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Unclear</th>
<th>Not Applicable</th>
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<tr>
<td>1. Is there congruity between the stated philosophical perspective and the research methodology?</td>
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<td>2. Is there congruity between the research methodology and the research question or objectives?</td>
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<td>3. Is there congruity between the research methodology and the methods used to collect data?</td>
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<td>5. Is there congruity between the research methodology and the interpretation of results?</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)

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doi: 10.11124/jbisrir-2013-1051
Appendix II: Data extraction instruments

QARI data extraction instrument

<table>
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<tr>
<th>JBI QARI Data Extraction Form for Interpretive &amp; Critical Research</th>
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<td>Author: ___________ Year: ___________</td>
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<td>Journal: ___________ Record Number: ___________</td>
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**Study Description**

**Methodology**

**Method**

**Phenomena of interest**

**Setting**

**Geographical**

**Cultural**

**Participants**

**Data analysis**

**Authors Conclusions**

**Comments**

Complete: Yes [ ] No [ ]
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Extraction of findings complete  Yes ☐  No ☐