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THE EMOTIONAL AND ECONOMIC COSTS OF BEREAVEMENT IN HEALTH CARE SETTINGS

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Research to date on grief and bereavement in health care providers has focused on those experiences from the perspective of the individual. We propose, however, that the emotional costs of bereavement in the health care setting are also health care systems issues. This paper focuses on the emotional costs of grief and bereavement in health care providers, and on the economic costs of bereavement and bereavement care in health care settings. Evidence regarding the costs and cost-effectiveness of bereavement interventions is limited. We summarise existing relevant research and offer an overview of the types of costs and cost information that would optimally be collected in research on bereavement in health care settings. We also propose an analytic framework that could be used to systematically consider the larger picture of bereavement in health care settings, how available evidence fits into this picture, and what evidence is needed to improve care. This approach is derived from health services research. It is hoped that the proposed framework will prove useful in stimulating new research questions, and in guiding research that not only advances our understanding of the emotional and economic costs of bereavement but also improves bereavement care.

Introduction

Although circumstances vary from country to country, a reality of death in the developed world is that most people die in a hospital or other health care setting (Last Acts, 2002; Wilson, Truman, Thomas, Fainsinger, Kovacs-Burns, Frogatt et al., 2009). This presents individual health care providers and health care systems with the challenge of determining how to offer care that makes

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it possible "… to expect and achieve a good or decent death – one that is free from avoidable distress and suffering for patients, families, and caregivers" (Institute of Medicine, 2003, p. 3). We believe that understanding the emotional and economic costs of bereavement in health care settings is one essential step in working toward compassionate, high-quality end-of-life care.

In this article, we briefly summarise the empirical literature related to the emotional and economic costs of bereavement in health care settings and propose an analytic framework as one possibility for generating future systematic research to improve bereavement-related care.

The existing empirical work in this area is in the earliest stages of development, and as has been true of other fields at this stage, research on bereavement in health care settings comprises a patchwork of individual studies rather than a cohesive body of evidence. In addition, the generalizability of the findings of many of the studies is limited by the samples or methods utilised and by differences in health care organisation and financing across countries. However, we believe that it is important to summarise what has been demonstrated with some consistency, both to encourage the use of this information to improve current care and to set the stage for additional, systematic research to guide care improvements in the future.

Our focus with respect to the emotional costs of bereavement is on findings regarding the emotional responses of health care providers to loss; the mental and physical health consequences of grief and bereavement in family members and others have been well described elsewhere (e.g., Genevro, Marshall, & Miller, 2004; Joanna Briggs Institute, 2006; Stroebe, Schut, & Stroebe, 2007).

In examining economic costs associated with bereavement in health care settings, we expand our focus to include all bereaved persons. Knowledge about the cost of bereavement (in terms of usage of medical care and other types of services, for example) and the cost-effectiveness of bereavement interventions (for whom and under what conditions) is likely to be valuable for health care policy makers and others who wish to improve the quality of end-of-life care and must make decisions about how limited health care resources are allocated. We summarise the relevant empirical literature, which consists of only a few studies, and then describe the types of information that would be needed to produce reliable estimates of the economic costs of bereavement for use by health care decision makers.

In keeping with the recommendations of the National Institutes of Health (NIH) State-of-the Science Conference Statement on Improving End-of-Life Care (NIH, 2005), we then propose a conceptual framework based on a health care systems perspective that could be used to guide future research related to the emotional and economic costs of bereavement in health care settings. The use of a conceptual framework is proposed as one pathway to the development of a systematic body of evidence that ultimately could result in improvements in the quality and accessibility of appropriate end-of-life care, and in improvements in the work lives of health care providers.

This article is based on a review of literature pertaining to the emotional and economic costs of bereavement in health care providers. The empirical research literature that was considered for review was limited to English-language reports published subsequent to 2000; studies were identified through two targeted search processes, the first covering the years 2000-2005 and the second covering 2005-2008. The searches built on previous work by the authors (Genevro et al., 2004). Searches were conducted using key word and MeSH terms in Medline and other relevant health and social sciences data bases. Searches also were conducted using Google Scholar to identify publications in which the primary articles had been cited. Additional searches were conducted using citations in peer-reviewed reports of empirical research published subsequent to 2000 as a starting point. Other potential sources of background or contextual information (e.g., program reports, white papers, reports in the popular media) were identified primarily through Google searches and from citations in articles.

For the purposes of this article, we have focused on studies of the highest quality available. For quantitative studies, quality has been defined as "…the extent to which a study's design, conduct, and analysis have minimized bias in selecting subjects and measuring both outcomes and differences in the study groups" (Lohr, 2004, p. 12; West, King, Carey et al., 2002). Three core criteria for judging the quality of evidence are internal validity (does a study generate valid information about the populations and settings in which it was carried out?), external validity (can the findings of a study be generalised to broader populations of interest?), and coherence or consistency (does the body of evidence make sense in the context of a larger conceptual model?) (Lohr, 2004, p. 12).

Based on these considerations, we have not included quantitative studies that relied on extremely small samples of convenience, studies that were designed to test the effects of an educational intervention but did not include a control or comparison group, or studies that had other serious design flaws. We have included well-designed and conducted qualitative studies. We caution that this targeted presentation does not represent a systematic review of the evidence.

The emotional costs of bereavement in health care settings

Research to date on grief and bereavement in health care providers has focused on those experiences from the perspective of the individual. Findings from the growing body of research on grief in health care providers converge with the content of the personal observations of physicians, nurses, and other health care providers who have written eloquently, and often in profoundly moving ways, about their experiences of grief and bereavement in response to the deaths of patients (e.g., Bereiter, 2008; Chen, 2007; Katz & Johnson, 2006; Shanafelt, Adjei, & Meyskens, 2003). Although we do not address them here, these personal reflections offer another window into emotional reactions to death in the health care setting for the interested reader.

We propose that the emotional costs of bereavement in the health care setting are also health care systems issues. Examining the systems-level factors that may contribute to, exacerbate, or ameliorate the responses of health care providers to loss is, we believe, an important avenue for research in the future that could inform improvements in the quality of end-of-life care and in the work lives of providers of care.

Existing quantitative and qualitative research on the emotional costs of bereavement in health care providers is summarised briefly here, highlighting themes that are consistent across the empirical literature of good quality and the personal observations of providers, starting from the individual perspective. We then move to the level of the health care system. Finally, an organising framework for future research from a systems-level perspective is proposed.

Health care professionals' emotional responses to loss and death in their work

Papadatou (e.g., 2009) has proposed a model of grief in health care providers that emphasises the role that relationships play in the provision of compassionate health care. This model suggests that health care providers, as other people, are likely to experience grief to the extent that they feel emotionally attached to the patients and families for whom they care. Rather than viewing health care providers as remote technicians and patients as simply bodies needing to be fixed, proponents of relationship-centred and patient-centred care suggest that the human interaction between providers and patients is not only beneficial to the patient, but a source of meaning to the provider. This perspective suggests that health care providers who invest themselves in the care they provide, and in the people for whom they care, are likely to experience grief when those patients die.

Studies of medical students and trainees, physicians, nurses, and long-term care staff indicate that many providers – often half or more – report at least one grief-related symptom in response to the death of a patient (e.g., Redinbaugh, Sullivan, Lock, Gadmer, Lakoma, Mitchell et al., 2003; Rickerson, Somers, Allen, Lewis, Strumpf, & Casarett, 2005). Common symptoms included sadness, feeling upset when thinking about the patient, and feeling numb. A smaller number of health care staff, up to about 10 per cent, reported that they experienced more intense emotional and physical responses (e.g., Redinbaugh et al., 2003).

These responses are consistent with a model of health professionals' grieving processes proposed by Papadatou (2000; 2009). This model suggests that health professionals fluctuate between two types of responses to the deaths of patients – experiencing grief reactions (by focusing on the experience of loss) and avoiding grief reactions. Papadatou (2000, p. 64) suggests that this fluctuation is "necessary, adaptive, and healthy". This model is similar in many ways to the Dual Process Model proposed by Stroebe and Schut (1999).

Factors that have been found to influence providers' emotional reactions to the death of patients include the provider's sense of closeness or relationship with the patient. For example, duration of the relationship with the patient and closeness with the patient were two factors associated with the number of grief-related symptoms reported by staff in a long-term care facility (Rickerson et al., 2005). In another study of in-hospital physicians, the length of time the staff person had cared for the patient was associated with the number of symptoms of grief, and with the extent to which the provider found the death disturbing, but also was associated with greater feelings of closeness with the patient and having had a positive experience in caring for them (Redinbaugh et al., 2003).

The possible consequences of providers' repeated exposures to loss and the deaths of patients also include burnout and occupational distress (e.g., Redinbaugh, Schuerger, Weiss, Brufsky, & Arnold, 2001). For example, a survey of the reactions of obstetricians to stillbirth or neonatal death found that 10 per cent of respondents indicated that the emotional toll of caring for a mother with a stillbirth led them to consider giving up their obstetric practice entirely (Gold, Kuznia, & Hayward, 2008).

Preliminary evidence indicates that the same complex set of emotions that health care providers may experience in response to the deaths of patients may also contribute to the provision of perceived or actual suboptimal care. For example, a study of family practice and internal medicine physicians indicates that clinicians who perceive themselves as stressed, dissatisfied, and burned out also report that they feel less capable of providing optimal care (Williams, Manwell, Konrad, & Linzer, 2007). In addition, depression is associated with self-reported medical errors in medical trainees (Fahrenkopf, Sectish, Barger, Sharek, Lewin, Chiang et al., 2008),

One reaction to the death of a patient can be to question the quality of the care that was provided (e.g., Reynolds, 2006; Ruopp, Good, Lakoma, Gadmer, Arnold, & Block, 2005). Physicians and medical students have reported feeling guilty in response to the death of a patient (Ruopp et al., 2005;

Serwint, Rutherford, & Hutton, 2006). Providers also may experience guilt because of perceived pressure to provide highly technological and aggressive care (Ruopp et al., 2005) that may be at odds with what they believe to be best for the patient, potentially at odds with other care providers, or at odds with the needs and wishes of the patient and family (e.g., Chiu, Hilliard, Azzie, & Fecteau, 2008). This perceived pressure may lead to ethical dilemmas regarding the provision of care and the health care provider's role in determining and providing the highest-quality, most appropriate end-of-life care. These ethical dilemmas can themselves cause stress, which has been characterised as 'moral distress' (Kälvemark, Höglund, Hansson, Westerholm, & Arnetz, 2004, p. 1075). Moral distress has been called "… an endemic problem among critical care nurses and a common reason for nurses to leave the field" (Byock, 2006, S419-S420).

Conclusion

Limited evidence indicates that some health care providers experience grief and other emotional reactions in response to the death of patients. The studies that are available indicate that factors such as closeness and duration of the relationship with the patient affect the responses of providers to patients' deaths. However, large, representative (and therefore generalisable) studies have not been conducted. It is therefore not possible to draw firm conclusions about the extent to which health care providers experience grief, or are at risk for complications of grief.

Health care system influences on providers' responses to death and loss

The culture of medicine and the training of health care providers have the potential to promote the provision of compassionate, high-quality care, and promote and sustain the well-being of individual providers. Research and the observations of individual providers would suggest, however, that this is a missed opportunity. Critiques of the prevailing culture of medicine in the United States suggest that an emphasis on technology rather than on the psychosocial aspects of care, in combination with a focus on cure, leads to a perception of death as failure (e.g., Sullivan, Lakoma, & Block, 2003, p. 693).

Data from multiple studies indicate that many physicians and physicians-in-training do not feel that they have been adequately prepared to provide end-of-life care or manage their own emotional reactions to the deaths of patients. Concerns about the training of health care professionals are reflected in evaluations of textbook content as well as content of curricula. Although it is possible that the inclusion of content related to end-of-life care and bereavement care has improved in the past several years, content analysis of medical textbooks, pharmacy textbooks, and introductory psychology textbooks early in this decade indicate that substantial gaps exist in content related to grief and bereavement (e.g., Bookwalter, Rabow, & McPhee, 2003; Coppola & Strohmetz, 2002; Doe & Katz, 2006; Rabow, Hardie, Fair, & McPhee, 2000).

Health care providers also report feeling unsupported by their workplace and colleagues in their efforts to deal with their emotional reactions to the deaths of their patients, both in terms of formal support from their workplaces and more informal support from colleagues (Kaplan, 2000; Papadatou, 2000). Stage of career is related to reported levels of desired support from colleagues, with physicians in their first year after medical school (known as interns in the United States) reporting needing more support than more experienced faculty (Redinbaugh et al., 2003). Available evidence indicates that mentoring and support from colleagues may be particularly effective strategies to help providers develop ways of responding to patients' deaths that are healthy for them personally and help them provide good care (e.g., Rushton, Reder, Hall, Comello, Sellers, & Hutton, 2006; Spickard, Gabbe, & Christensen, 2002).

In addition to feeling that they have not received adequate training and are unsupported in providing optimal psychosocial care at the end-of-life, health care providers have observed that the characteristics of the systems in which they work, including demands of time, make it difficult to allow themselves to experience the complex emotions associated with losing a patient (Shanafelt et al., 2003).

Moss and Moss (2002, p. 206) found that nursing home staff "carefully monitor their own feelings and expressions in an attempt to reach an appropriate balance between the loss and the expectations of the world of work". Nursing home staff, who may develop very close relationships with those for whom they care over extended periods of interaction, also may experience "disenfranchised grief" (e.g., Doka, 2002) when they feel their relationships with the person who died does not give them the right to feel or express grief, or that their loss is not considered legitimate by the families of their patients, their institutions, or others. Moss and Moss (2002) suggested that disenfranchised grief may have direct costs to caregivers (in terms of staff well-being) and indirect costs to others, including other staff and residents. It may also have benefits, however, in that disenfranchised grief may make it possible for staff to do their jobs through the emotional distance it provides.

Conclusion

To conclude, we believe that as part of their commitment to the provision of high-quality end-of-life care, health systems must attend to the grief and other emotional responses that may be experienced by health care providers. Doing so has the potential to improve the care of patients and families and reduce occupational distress in health care providers.

Additional research, especially epidemiological and descriptive research with representative samples and psychometrically sound measures, is needed to provide a firm foundation of evidence regarding health care professionals' emotional responses to loss and death in their work. What is the prevalence of symptoms of grief in the general population of health care providers? In what ways does the experience of grief vary by years in practice, by specialty, by setting? Do the attitudes of clinicians toward death and loss differ from those of the general population, and if so, in what ways? How do most health care providers cope with the loss of patients? Specific areas that merit further investigation include the identification of factors that may predispose health care providers to complicated grief reactions, including organisational or professional attitudes toward the experience or expression of grief, "chronic" bereavement that may be experienced when working in certain specialties or in certain settings, and the loss of meaning in one's work. As noted here, preliminary evidence has been gathered that addresses some of these questions, but a great deal of additional research is needed.

The economic costs of bereavement in health care settings

Although our examination of the literature related to the emotional costs of bereavement in health care settings was limited to health care providers, in this section on economic costs we expand the focus to include health care-related costs for all bereaved persons. Information about the effects of bereavement on health care utilisation and related costs, and about the cost-effectiveness of bereavement interventions, is likely to be of value to health care policy makers and others who wish to improve the quality of end-of-life care and must make decisions about how limited health care resources are allocated.

Unfortunately, evidence regarding the costs and cost-effectiveness of bereavement interventions is limited (e.g., Onrust, Smit, Willemse, van den Bout, & Cuijpers, 2008). Therefore, we provide an overview of the types of costs and cost information that would optimally be collected in research on bereavement in health care settings, and then summarise relevant research findings.

Analysing costs in health care is difficult for many reasons, including challenges in measuring costs, challenges in acquiring data, and challenges in defining what actual costs consist of (Lipscomb, Barnett, Brown, Lawrence, & Yabroff, 2009). Four types of costs have been identified as important in analysing the costs of preventive interventions such as bereavement programs (Foster, Porter, Ayers, Kaplan, & Sandler, 2007). These are medical, nonmedical, productivity, and intangible costs. Direct medical costs include, for example, the costs of consultations with physicians, hospitalisation, and home care. Nonmedical costs include costs such as parking and travel, which may be direct costs to the patient or may be covered by some other entity. Categorisation of medical and nonmedical costs may vary from organisation to organisation. For example, depending on how services such as ethics consultations or chaplaincy services are provided and paid for, these services could be considered direct medical costs or nonmedical costs. Productivity costs are indirect, and include costs associated with work time lost due to incapacitation and/or time spent in medical visits. Estimates of productivity costs also may include the loss of capacity to perform tasks at home. Intangible costs are costs that are nonmonetary, such as stigma or loss of professional satisfaction, and are often extremely difficult to measure (e.g., Foster et al., 2007; Onrust et al., 2008).

In our search of the literature, we found four studies and one report from a large research initiative on end-of-life care that included information relevant to the economic costs of bereavement care in health care settings.

In the most directly applicable study, Onrust and colleagues (2008) conducted a cost-utility analysis of a community bereavement intervention comprising a visiting service for widowed individuals. The cost-utility analysis was conducted in conjunction with a randomized clinical trial of the visiting service intervention, which was carried out in 18 municipalities in The Netherlands. The researchers examined costs from a societal perspective, and included direct medical costs (costs of all types of health care services, not just services delivered by physicians), direct non-medical costs to patients (travel expenses, parking), and costs to patients attributable to inability to perform domestic tasks. The intervention consisted of 10-12 home visits by trained volunteers, offered to older individuals who had been widowed during the past year, had moderate or strong feelings of loneliness, no “full-blown mental disorder”, and the capability of participating in a 1-hour interview. Participants in the comparison intervention received a brochure on depressive symptoms that also included information to improve well-being. The primary outcome measure was a widely-used, generic measure of health status, quality-adjusted life years. The results of the study indicate individuals in the intervention group made less use of health care services. In the intervention group, costs separate from the cost of the intervention decreased. In the comparison group, costs increased. However, the cost savings in the intervention group were not large enough to compensate for the actual cost of the intervention (Onrust et al., 2008).

One other estimate of the cost of bereavement counselling is embedded in an actuarial assessment of the costs of hospice care commissioned by the National Hospice and Palliative Care Organization (NHPCO) in the United States. Using data from 1998-1999, it was estimated that the "per patient per day" (PPPD) cost of bereavement counselling (based on an estimated 1.5 visits per patient) is $5.46 (Cheung, Fitch, & Pyenson, 2001, p. 16). The NHPCO National Hospice Data Set (Connor, Tecca, LundPerson, & Teno, 2004) also includes cost data gathered in 2002 from hospices around the country, but costs for bereavement services were not reported.

Prigerson, Maciejewski, and Rosenheck (2000, p. 350) studied health, health services use, and health costs in widowed and married individuals using data gathered as part of the longitudinal Americans Changing Lives study, which surveyed a representative sample of adults over the age of 25 years who lived in the continental United States. After controlling for demographic characteristics, life satisfaction, a number of variables related to health status, follow-up health insurance coverage, health services utilisation at baseline, and sample selection bias, the authors found that the widowed group at follow-up had a significantly higher average number of physician visits and days spent in a nursing home than the married group. Analyses also revealed that mean total health care costs and adjusted mean outpatient costs were higher for the widowed group than for the group that did not become widowed between 2 assessments (conducted 3 years apart). However, the researchers found that estimated adjusted total health care costs and estimated adjusted outpatient costs were significantly higher for widowed individuals who reported high levels of marital harmony than for widowed individuals who described their marriages as discordant. The authors suggest that "prior work demonstrating the connection between positive marital quality and greater severity of traumatic grief symptoms suggest that the influence of marital harmony on health, health service utilisation, and health care costs may be mediated through symptoms of pathological, or complicated, grief" (Prigerson et al., 2000, p. 356). It was not possible to test this hypothesis directly, however, because the data did not include assessments of traumatic grief symptomatology.

The study examined many of the variables that should be considered in estimating health care costs related to bereavement (e.g., total health care costs, costs of outpatient care), but findings were based on a small sub-sample of 61 adults drawn from the larger study. Because of the limitations of the study (the small sample size and the self-report nature of the health services utilisation data), these findings can contribute only modestly to a larger understanding of the economic costs of bereavement in health care settings.

In another study conducted in the United States, Prigerson and colleagues (Zhang, Wright, Huskamp, Nilsson, Maciejewski, Earle et al., 2009) investigated associations between end-of-life conversations between patients with advanced cancer and their physicians, and health care costs in the last week of life; bereavement care was not directly addressed in this study. As part of this study, formal (e.g., physicians and nurses) and informal caregivers (e.g., spouses) were asked to rate the "overall quality of the patient's death/last week of life" on a Likert-type scale that ranged in value from 0 (worst possible) to 10 (best possible). The investigators found that end-of-life conversations between patients and physicians were associated with significantly lower health costs in the patient's last week of life. The researchers also found that higher health care costs at the end of life "were associated with poorer quality of death/last week of life, as reported by the patient's formal (e.g., physicians and nurses) and informal (e.g., spouse) caregivers" (Zhang et al., 2009, pp. 480-481).

A final report demonstrates additional challenges in gathering cost data that can be used to develop a general understanding of the economic costs of bereavement in health care settings. Twenty-two demonstration projects for delivering improved palliative care were funded by the Promoting Excellence in End-of-Life Care, a national program of The Robert Wood Johnson Foundation in the United States. These demonstration projects were designed to address "documented deficiencies in the care of patients and families facing the final stage of life" (Byock, Twohig, Merriman, & Collins, 2006, p. 137). Financial outcomes and effects on costs were assessed in some projects, but because of variations in research design and methods across projects, there are no aggregate findings available. For example, in some of the evaluations of individual projects, resource use (measured in visits, hospitalisations, and hospice days) was used as a proxy for cost data. In other projects, financial outcomes were assessed directly; key informant interviews were also used in some projects to gather information on costs to participating health care systems (Byock et al., 2006, p. 139). In addition, "[c]omplexities of health care billing and pricing make it difficult to account for actual costs" (Byock et al., 2006, p. 142). Taking these limitations into consideration, data were reported by several of the projects that indicate that providing palliative care (concurrent with life-prolonging treatment) "was financially neutral or associated with measurable savings" (Byock et al., 2006, p. 142). No cost data were reported related to provision of bereavement services.

Conclusion

The evidence available indicates how difficult it is to collect and analyse reliable cost data at the individual, provider, and systems level, all of which are required to accurately estimate the total economic costs of bereavement in health care settings. Because of the limited research in this area, it is not possible at present to draw conclusions about the costs of bereavement, or the cost-effectiveness of bereavement services, in health care settings even in one country. In addition, although the types of costs and principles of cost analysis might be the same, differences in health care financing in different countries dictate that conclusions cannot be generalised across financing systems. However, findings from the most directly relevant studies suggest that additional well-designed, larger-scale studies of the economic costs of bereavement and bereavement care in targeted populations (e.g., older widowed adults) would be likely to provide information that could be used in a variety of circumstances to guide the design and provision of effective care.

A framework for studying the emotional and economic costs of bereavement in health care providers and health care systems

Research on the emotional and economic costs of bereavement in health care settings is in the early stages of development and there is much to be learned. A recent systematic review of evidence on improving the quality of palliative care at the end of life did not include bereavement research, but suggests that future reviews address this topic (Lorenz, Lynn, Dy, Shugarman, Wilkinson, Mularski et al., 2008). A tremendous opportunity exists, therefore, to systematically consider what evidence is needed by policy- and decision-makers to improve the quality of bereavement care in health care settings, identify gaps in current knowledge, and formulate research questions that should be asked to advance knowledge. The challenge is to build a systematic body of evidence to guide improvements in the quality of end-of-life care, in access to appropriate end-of-life care, and in the work lives of health care providers.

In Figure 1, we propose a conceptual framework that could be used to guide research on the emotional and economic costs of bereavement in health care settings. It is based on similar frameworks developed by the U.S. Preventive Services Task Force in the systematic review of evidence related to the harms and benefits of clinical preventive services (Harris, Helfand, Woolf, Lohr, Mulrow, Teutsch et al., 2001). The value of this type of framework is that it facilitates the systematic identification of key research questions and the types of evidence that could be used – or should be generated – to answer those questions. The proposed analytic framework identifies the chain of evidence that would be necessary to establish the effectiveness of screening for and treatment of complications of grief or other bereavement-related concerns on outcomes such as health, productivity, and quality of life. The framework could apply to a family member, informal caregiver or health care professional who has experienced a loss.

The analytic framework as depicted also builds on a suggested process

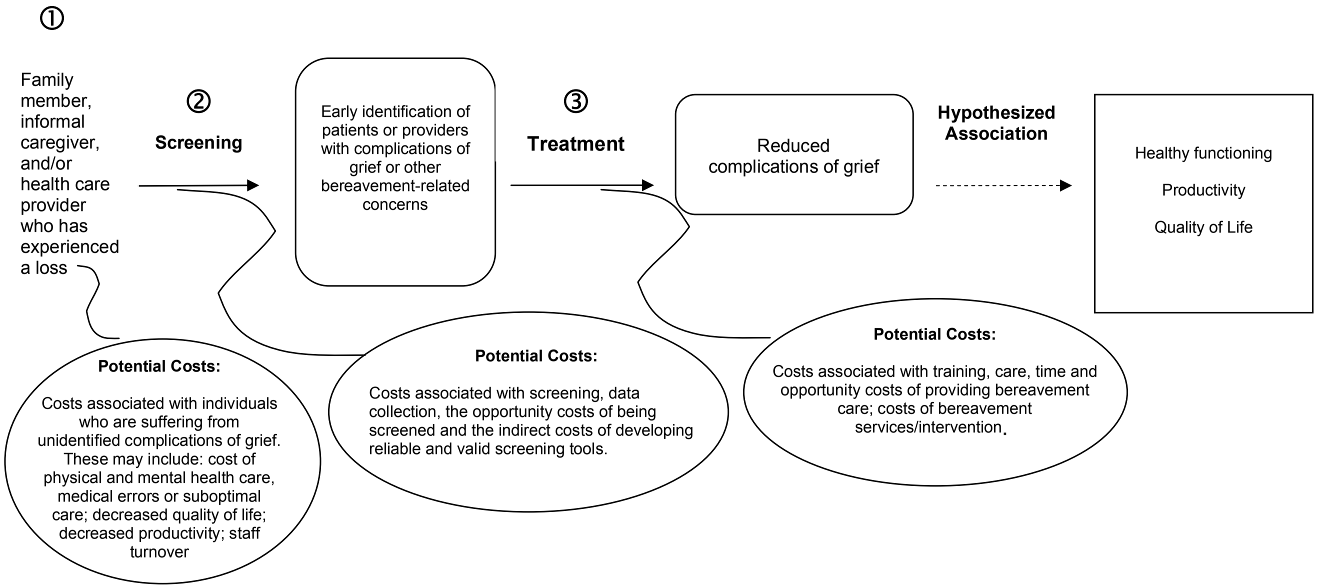

Figure 1
Understanding the effects of bereavement on costs: a proposed analytic framework from a health systems perspective

Table 1

Examples of key research questions related to a proposed framework for the investigation of the emotional and economic costs of bereavement in health care settings, presented in Figure 1

Steps in the Proposed Analytic Framework	Examples of Key Research Questions Related to Emotional Costs of Bereavement in Health Care Settings	Examples of Key Research Questions related to Potential Economic Costs of Bereavement in Health Care Settings	Purpose of the Analysis	Target Audience for the Analysis
1. Describe the population. **Example:** General population: Bereaved individuals (this could include family members, informal caregivers, and health care providers who have experienced a loss).				
Subpopulation of interest: Health care providers	What is the incidence and prevalence of grief-related symptoms in representative samples of health care providers? Do symptoms vary by professional role, health care setting, demographic characteristics, and other factors, such as the provision of patient-centred or relationship-centred care?	What are the direct costs to health care systems and individuals for physical and mental health care for bereaved health care providers? What are the indirect health care costs associated with bereavement in health care providers? These may include: opportunity costs to individuals for medical visits for physical or mental health problems; costs associated with medical errors and suboptimal care resulting from staff bereavement (or related depression); costs of staff turnover related to chronic bereavement (e.g., recruitment and training costs), decreased productivity, and diminished quality of life.	Describe the epidemiology of grief in health care providers; describe associated direct and indirect health care costs.	Researchers; health care policy- and decision-makers

Steps in the Proposed Analytic Framework	Examples of Key Research Questions Related to Emotional Costs of Bereavement in Health Care Settings	Examples of Key Research Questions related to Potential Economic Costs of Bereavement in Health Care Settings	Purpose of the Analysis	Target Audience for the Analysis
2. Identify the population(s) and sub-population(s) to which interventions could (should) be targeted. **Example:** General population: Bereaved individuals who are experiencing complications of grief or other bereavement- related problems.				
Subpopulation of interest: Health care providers who are experiencing complications of grief or other bereavement related problems.	Are there reliable and valid screening tools that accurately identify health care providers who are experiencing complications of grief? Are there reliable and valid screening tools that can be used to identify bereaved health care providers who are likely to benefit from bereavement care? What is the most effective method of screening health care providers for complications of grief (what benefits, if any, does screening offer; who should do it; where should it be done; what are the potential harms, if any, associated with screening)?	What are the direct costs to health care systems for screening and data collection? What are the indirect costs of screening? These might include the development and testing of reliable and valid screening tools.	Determine whether screening for complications of grief in health care providers is needed, feasible, reliable, and effective.	Researchers; health care policy- and decision- makers; health care providers

Steps in the Proposed Analytic Framework	Examples of Key Research Questions Related to Emotional Costs of Bereavement in Health Care Settings	Examples of Key Research Questions related to Potential Economic Costs of Bereavement in Health Care Settings	Purpose of the Analysis	Target Audience for the Analysis
3. Provide bereavement care. **Example:** Design, implement, and evaluate an on-site bereavement intervention for health care providers in nursing home settings.	What types of bereavement care (if any) lead to improved outcomes in health, quality of life, and productivity for health care providers in specific settings? Are there potential harms associated with bereavement care?	What are the **direct** costs associated with the intervention? These may include: staff salaries related to the provision of the intervention and associated administrative services; costs to the participants. What are the **indirect** costs associated with the intervention? These may include: the costs of training staff and/or volunteers to provide appropriate, high-quality bereavement care; overhead related to the provision of bereavement-related services. What are the **indirect** costs that apply in the absence of the intervention? These may include employee assistance services; costs associated with medical errors and suboptimal care resulting from staff bereavement (or related depression); and costs of staff burnout/turnover (e.g., recruitment). What is the effect of the intervention on total direct and non-direct costs?	Evaluate the effects of a bereavement intervention on physical and mental health outcomes in a specific sub-population of health care providers; determine the costs and cost-effectiveness of the intervention	Health care policy- and decision-makers; program planners; health care providers; researchers

for health cost analysis. Lipscomb and colleagues (2009, p. S120) recently identified “the elements of a research agenda for improving the scientific soundness and relevance of health cost analyses for decision making”. These elements comprise a series of steps in health cost analysis that the authors recommend be adapted to the specific area or intervention of interest. The two steps in the series that are most relevant here are: 1) to define the purpose of the analysis, the types of costs included, and the target audience for the analysis; and 2) to identify the resources used and their economic costs (Lipscomb et al., 2009, p. S120).

In Table 1, we combine the proposed analytic framework (Fig. 1) with the first two steps in health cost analysis proposed by Lipscomb and colleagues (2009). We link key research questions with steps in the analytic framework, define the purposes of and target audiences for the suggested analyses, and identify possible types of costs that could be included. The examples in Table 1 offer an idea of the types of studies that could be conducted to provide policy- and decision-makers with evidence about the emotional and economic costs of bereavement in health care settings, and that could be used to guide improvements in the quality of bereavement care.

We understand that it is unlikely that any single study could address the entire analytic framework. However, it does offer a way to think systematically about a program of research that could be developed to provide evidence that answers questions at each step, with the goal of developing a chain of evidence across the entire framework.

Conclusions

Researchers have taken beginning steps to understand the grief reactions of health care providers and the economic costs of bereavement and bereavement care, but a great deal of work remains to be done to generate a comprehensive understanding of the emotional and economic costs of bereavement in health care settings. We propose that one way to maximise the intellectual contribution of research in this area would be to use an analytic framework to consider the larger picture of bereavement in health care settings, how available evidence fits into the larger picture, and what evidence is needed. This approach, which is derived from health services research, may be unfamiliar to social sciences researchers. We hope, however, that it will be useful in stimulating thinking about how best to investigate questions related to the emotional and economic costs of bereavement in health settings, and in guiding the design and implementation of multi-method, interdisciplinary research that both advances our understanding and improves bereavement care.

References

Bereiter, J. (2008). Crying for my grandmother. *Journal of the American Medical Association, 299*, 2129-2130.

Bookwalter, T.C., Rabow, M.W., & McPhee, S.J. (2003). Content on end-of-life care in major pharmacy textbooks. *American Journal of Health-System Pharmacists, 60*, 1246-1250.

Byock, I. (2006). Where do we go from here? A palliative care perspective. *Critical Care Medicine, 34*, S416-S420.

Byock, I., Twohig, J.S., Merriman, M., & Collins, K. (2006). Promoting excellence in end-of-life care: A report on innovative models of palliative care. *Journal of Palliative Medicine, 9*, 137-151.

Chen, P.W. (2007). *Final exam: A surgeon's reflections on mortality.* New York: Vintage Books.

Cheung, L., Fitch, K., & Pyenson, B. (2001). *The costs of hospice care: An actuarial evaluation of the Medicare hospice benefit.* New York: Milliman USA, Inc.

Chiu, P.P.L., Hilliard, R.I., Azzie, G., & Fecteau, A. (2008). Experience of moral distress among pediatric surgery trainees. *Journal of Pediatric Surgery, 43*, 986-993.

Connor, S.R., Tecca, M., LundPerson, J., & Teno, J. (2004). Measuring hospice care: The National Hospice and Palliative Care Organization National Hospice Data Set. *Journal of Pain and Symptom Management, 28*, 316-328.

Coppola, K.M., & Strohmetz, D.B. (2002). How is death and dying addressed in introductory psychology textbooks? *Death Studies, 26*, 689-699.

Doe, J., & Katz, R.S. (2006). Professionalism and our humanity: Working with children at the end of life. In R.S. Katz & T.A. Johnson (Eds.), *When professionals weep: Emotional and countertransference responses in end-of-life care* (pp. 157-170). New York: Routledge.

Doka, K.J. (Ed.). (2002). *Disenfranchised grief: New directions, challenges, and strategies for practice*. Champaign, IL: Research Press.

Fahrenkopf, A.M., Sectish, T.C., Barger, L.K., Sharek, P.J., Lewin, D., Chiang, V.W. et al. (published online 7 Feb 2008). Rates of medication errors among depressed and burnt out residents: Prospective cohort study. *BMJ*. doi:10.1136/bmj.39469.763218.BE

Foster, E.M., Porter, M.M., Ayers, T.S., Kaplan, D.L., & Sandler, I. (2007). Estimating the costs of preventive interventions. *Evaluation Review, 31*, 261-286.

Genevro, J.L., Marshall, T., & Miller, T.L. (2004). Report on bereavement and grief research. *Death Studies, 28*, 491-575.

Gold, K.J., Kuznia, A.L., & Hayward, R.A. (2008). How physicians cope with stillbirth or neonatal death. *Obstetrics & Gynecology, 112*, 29-34.

Harris, R.P., Helfand, M., Woolf, S.H., Lohr, K.N., Mulrow, C.D., Teutsch, S.M., & Atkins, D., for the Methods Work Group, third U.S. Preventive Services Task Force. (2001). Current methods of the U.S. Preventive Services Task Force: A review of the process. *American Journal of Preventive Medicine, 20*, 21-35.

Institute of Medicine. (2003). Describing death in America: What we need to know. Washington, D.C: National Academy Press.

Joanna Briggs Institute. (2006). *Literature review on bereavement and bereavement* *care*. Joanna Briggs Collaborating Centre for Evidence-based Multi-professional Practice, Faculty of Health and Social Care, The Robert Gordon University, Aberdeen, Scotland.

Kälvemark, S., Höglund, A.T., Hansson, M.G., Westerholm, P., & Arnetz, B. (2004). Living with conflicts – Ethical dilemmas and moral distress in the health care system. *Social Science & Medicine, 58*, 1075-1084.

Kaplan, L.J. (2000). Toward a model of caregiver grief: nurses' experiences of treating dying children. *Omega, 41*, 187-206.

Katz, R.S., & Johnson, T.A. (Eds.). (2006). *When professionals weep*: *Emotional and countertransference responses in end-of-life care*. New York: Routledge.

Last Acts. (2002). *Means to a better end: A report on dying in America today.* Washington, DC: Last Acts.

Lipscomb, J., Barnett, P.G., Brown, M.L., Lawrence, W., & Yabroff, K.R. (2009). Advancing the science of health care costing. *Medical Care, 47*, S120-S126.

Lohr, K.N. (2004). Rating the strength of scientific evidence: Relevance for quality improvement programs. *International Journal for Quality in Health Care, 16*, 9-18.

Lorenz, K.A., Lynn, J., Dy, S.M., Shugarman, L.R., Wilkinson, A., Mularski, R.A. et al. (2008). Evidence for improving palliative care at the end of life: A systematic review. *Annals of Internal Medicine, 148*, 147-159.

Moss, S., & Moss, M. (2002). Nursing home staff reactions to resident deaths. In K. Doka (Ed.), *Disenfranchised grief: New directions, challenges, and strategies for practice* (pp. 197-216). Champaign, IL: Research Press.

National Institutes of Health. (2005). National Institutes of Health State-of-the-Science Conference Statement: Improving End-of-Life Care, December 6-8, 2004.

Onrust, S., Smit, F., Willemse, G., van den Bout, J., & Cuijpers, P. (2008). Cost-utility of a visiting service for older widowed individuals: Randomised trial. *BMC Health Services Research, 8*, 128.

Papadatou, D. (2000). A proposed model of health professionals' grieving process. *Omega – Journal of Death & Dying, 41*, 59-77.

Papadatou, D. (2009). *In the face of death: Professionals who care for the dying and the bereaved*. New York: Springer Publishing Company, LLC.

Prigerson, H., Maciejewski, P., & Rosenheck, R. (2000). Preliminary explorations of the harmful interactive effects of widowhood and marital harmony on health, health service use, and health care costs. *The Gerontologist, 40*, 349-357.

Rabow, M.W., Hardie, G.E., Fair, J.M., & McPhee, S.J. (2000). End-of-life care content in 50 textbooks from multiple specialties. *Journal of the American Medical Association, 283*, 771-778.

Redinbaugh, E.M., Schuerger, J.M., Weiss, L.L., Brufsky, A., & Arnold, R. (2001). Health care professionals' grief: A model based on occupational style and coping. *Psycho-oncology, 10*, 187-198.

Redinbaugh, E., Sullivan, A., Lock, S., Gadmer, N., Lakoma, M., Mitchell, A., Seltzer, D., Woldford, J., & Arnold, R. (2003). Doctors' emotional reactions to recent death of a patient: Cross sectional study of hospital doctors. *British Medical Journal, 327*, 1-6.

Reynolds, F. (2006). How doctors cope with death. *Archives of Diseases in Childhood, 91*, 727.

Rickerson, E.M., Somers, C., Allen, C.M., Lewis, B., Strumpf, N., & Casarett, D.J. (2005). How well are we caring for caregivers? Prevalence of grief-related symptoms and need for bereavement support among long-term care staff. *Journal of Pain and Symptom Management, 30*, 227-233.

Ruopp, R., Good, M.D., Lakoma, M., Gadmer, N.M., Arnold, R.M., & Block, S.D. (2005). Questioning care at the end of life. *Journal of Palliative Medicine, 8*, 510-520.

Rushton, C.H., Reder, E., Hall, B., Comello, K., Sellers, D.E., & Hutton, N. (2006). Interdisciplinary interventions to improve pediatric palliative care and reduce health care professional suffering. *Journal of Palliative Medicine, 9*, 922-933.

Serwint, J.R., Rutherford, L.E., & Hutton, N. (2006). Personal and professional experiences of pediatric residents concerning death. *Journal of Palliative Medicine, 9*, 70-81.

Shanafelt, T., Adjei, A., & Meyskens, F.L. (2003). When your favorite patient relapses: Physician grief and well-being in the practice of oncology. *Journal of Clinical Oncology, 21*, 2616-2619.

Spickard, A., Jr., Gabbe, S.G., & Christensen, J.F. (2002). Mid-career burnout in generalist and specialist physicians. *Journal of the American Medical Association, 288*, 1147-1450.

Stroebe, M., & Schut, H. (1999). The dual process model of coping with bereavement: rationale and description. *Death Studies, 23*, 197-224.

Stroebe, M., Schut, H., & Stroebe, W. (2007). Health outcomes of bereavement. *The Lancet, 370*, 1960-1973.

Sullivan, A.M., Lakoma, M.D., & Block, S.D. (2003). The status of medical education in end-of-life care: A national report. *Journal of General Internal Medicine, 128*, 685-695.

West, S.L., King, V., & Carey, T.S. et al. (2002). *Systems to rate the strength of scientific evidence*, Structured Abstract. Agency for Healthcare Research and Quality, Rockville, MD. http://www.ahrq.gov/clinic/tp/strengthtp.htm

Williams, E.S., Manwell, L.B., Konrad, T.R., & Linzer, M. (2007). The relationship of organizational culture, stress, satisfaction, and burnout with physician-reported error and suboptimal patient care: Results from the MEMO study. *Health Care Management Review, 32*, 203-212.

Wilson, D.M., Truman, C.D., Thomas, R., Fainsinger, R., Kovacs-Burns, K., Frogatt, K. et al. (2009). The rapidly changing location of death in Canada, 1994-2004. *Social Science & Medicine, 68*, 1752-1758.

Zhang, B., Wright, A.A., Huskamp, H.A., Nilsson, M.W., Maciejewski, M.L., Earle, C.C. et al. (2009). Health care costs in the last week of life: Associations with end-of-life conversations. *Archives of Internal Medicine, 169*, 480-488.

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