Deaths from cancer will continue to rise with an increasing and aging population. Family caregivers of patients with cancer will face loss, grief, and bereavement as a result. As mandated by cancer and palliative care clinical practice guidelines, support for family caregivers continues through the processes of grief and bereavement to facilitate a positive transition through loss. To provide evidence-based nursing with this population, an analysis of their context of care was undertaken. Key health policies, characteristics of the healthcare delivery system, and the results of research with bereaved palliative caregivers are described. A model of effectiveness, efficiency, and equity is used to examine the situation of bereaved caregivers and to suggest research questions to fill the gaps in what is known about their needs and experience. Bereaved caregivers are at high risk for many distressing symptoms, including depression and sleeplessness, related to a range of complex variables, such as age, gender, social support, resources, and their experiences during caregiving. Current systems of support have not been adequate to meet the needs of this population and very little is known about the caregivers’ quality of life, well-being, and health outcomes or how best to provide compassionate and effective nursing care.

Cancer will be the leading cause of death sometime in the 21st century (Proctor, 1995). More than 1,500 Americans die of cancer each day, currently accounting for 1 of every 4 deaths in the United States (American Cancer Society, 2008). The number of cancer deaths will continue to rise each year because of an increasing and aging population (Canadian Cancer Society, National Cancer Institute of Canada, Statistics Canada, Provincial/Territorial Cancer Registries, Public Health Agency of Canada, 2008). As a result, many family caregivers will face bereavement because of cancer deaths. Family caregivers, defined as family members who have assumed a caregiving role that often involves making critical medical decisions, assisting with activities of daily living, and providing treatments in the home (Hauser & Kramer, 2004), play key roles in providing care for patients with cancer. Over time, they have taken on added responsibilities for providing increasingly complex care in the home (Canadian Hospice Palliative Care Association, 2004). Experiences during caregiving have consequences affecting physical and mental health in bereavement (Brazil, Bedard, & Willison, 2003; Grande, Farquhar, & Barclay, 2004).

The National Comprehensive Cancer Network ([NCCN], 2008) guidelines for palliative care include death as an expected outcome and care for families after the death of a relative as essential parts of a continuum of cancer care. Palliative care addresses issues of quality of life of patients and their families by providing symptom relief and spiritual and psychosocial support extending from diagnosis to the end of life and bereavement (World Health Organization [WHO], 2002). However, very little is known about the experience of bereavement for family caregivers, or how best to provide effective, evidence-based nursing care and support after the death of a family member from cancer.

Bereaved caregivers have been mostly neglected in the delivery of palliative care services and in research to examine their needs. Most hospices and palliative care programs regard bereavement support as integral to their services, yet it remains

At a Glance

- After the death of patients from cancer, family caregivers require active and ongoing support through the processes of grief and bereavement.
- Nurses have a key role in supporting bereaved caregivers, who may be at risk for depression, distressing symptoms, and even death.
- An analysis of the context of care included relevant health policy, the results of research, and an examination of current bereavement services, with the goal of effective, efficient, equitable, evidence-based care for bereaved family caregivers.

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one of the most marginalized areas of hospice development (Payne, 2004). Although more and more clients are accessing hospice services, bereavement care remains a low priority when limited resources are being allocated (Demmer, 2003). The loss and grief of bereaved palliative caregivers can become a public health issue if caregivers experience ongoing difficulty recovering from caregiving and moving forward through the challenging journey of grief and bereavement.

Nurses have a significant role in supporting and guiding bereaved caregivers as they recover from the difficulties of providing care, face their loss, and endeavor to rebuild their lives. This population’s context of care was analyzed by reviewing key health policies, synthesizing the relevant research literature, and examining bereavement services to reflect on effective, efficient, equitable, evidence-based practice for bereaved family caregivers. A model of effectiveness, efficiency, and equity (Aday, Begley, Lairson, & Slater, 1993) was applied to address the determinants of health and the health services needed by palliative caregivers during bereavement. Suggestions for research to address the gaps in what is known in this area of nursing practice are presented in Figure 1. According to Aday et al., examining the health policy that affects the population at risk is a starting point to improve a system of care. The outline of Aday et al.’s framework involves structure, process, and outcomes: The structure of care includes health policy, characteristics of the delivery system, and characteristics of the population at risk; the process is the delivery of care; and intermediate outcomes of equity, efficiency, and effectiveness and the ultimate outcome of the health services system is well-being or quality of life for the population being studied.

The Structure of Care

Health Policy

Bereavement care for families of patients with cancer is a core element of cancer and palliative care services according to national and international guidelines. Effective palliative care, as mandated by WHO international guidelines, requires a multidisciplinary team approach that includes patients and families and also offers bereavement support and counselling as needed. The NCCN (2008) guidelines for palliative cancer care integrate comprehensive care for patients’ families and caregivers, including bereavement support. Bereavement support, based on a clinical assessment of needs, is made available for at least 12 months, or as long as needed after the death of patients (National Consensus Project for Quality Palliative Care, 2004). The ultimate goal of palliative bereavement services is to facilitate a successful transition and reintegration into society after the caregiving experience or the loss of a family member (Ferris et al., 2002).

Characteristics of the Healthcare System

Although bereavement services are considered to be integral to a palliative care program, bereavement support remains limited by a scarcity of resources, a lack of time, and too few qualified personnel (Demmer, 2003). In Demmer’s national survey of 450 members of the National Hospice Palliative Care Organization (NHPCO), the main thrust of bereavement services was mailings of condolence letters and literature on grief. A study of hospice bereavement programs in the United Kingdom recommended that a program of bereavement support be integrated into palliative services and include volunteer counselors, bereavement befriending services, social bereavement groups, and ongoing telephone support (Reid, Field, Payne, & Relf, 2006). Bereavement services usually are tailored to the characteristics of the population being served and differ by geographic regions, based on available community resources and the unique approach of each area (Reid et al.).

Characteristics of Bereaved Family Caregivers

The themes that emerged from a review of research with bereaved family caregivers of patients with cancer included painful emotions and a lack of follow-up support (Gribich, Parker, & Maddocks, 2001; Hudson, 2006; Kristjanson, Cousins, Smith, & Lewin, 2005; McLaughlin, Sullivan, & Hasson, 2007), high rates of depression (Wyatt, Friedman, Given, & Given, 1999), loss of appetite (Brazel et al., 2003), severe sleep problems (Carter, 2005), distressing grief over an unpredictable length of time (Chentsova-Dutton et al., 2002), and even death during bereavement (Christakis & Iwashyna, 2003). In a retrospective cohort study of more than 195,000 older adult couples in the United States, mortality rates for hospice users were 4.9% for women and 13.2% for men at 18 months after the death of a loved one, compared to 5.4% for women and 13.2% for men who had not

Effectiveness research: examines the specific benefits from the healthcare system for the improvement of health

- What health services currently are being used by bereaved family caregivers?
- What is the quality of bereavement services offered?
- What are the quality of life, level of depression, grief, and morbidity and mortality rates for bereaved family caregivers?
- What are the unique determinants of health, such as secondary losses, change in employment, and life reorganization?

Efficiency research: examines the resources required by the healthcare system as they relate to health improvements

- What is the need for services? Do the services available relate to the specific needs of bereaved family caregivers?
- Can healthcare providers prevent more difficult problems by providing grief education and support during caregiving or in the initial phases of grief?
- Which provider is the best suited and most cost effective? Are the services offered based on theory derived from research into bereaved family caregivers’ unique experiences?

Equity research: examines whether the benefits of the healthcare system are equally distributed

- Are services needed equally accessible regardless of income or location?
- What about palliative care bereavement services for bereaved family caregivers who cared for a patient with a noncancer diagnosis?
- Are accessible services and materials available for caregivers who do not speak English?
- What are the needs of a diversity of cultural and ethnic groups; do they receive equitable care and services?

Figure 1. Suggestions for Research With Bereaved Family Caregivers
used hospice. The support from hospice predicted a slightly lower rate of mortality for women but not for men (Christakis & Iwashyna). A study of 150 bereaved family members in a home-based palliative service revealed significantly poorer health scores at three and six months after patients’ death compared to normative data (Kristianson et al.). The vast majority of the participants were not receiving follow-up bereavement support from any source other than the home hospice program.

Research with bereaved caregivers of patients with dementia highlights the distinctiveness of different illness trajectories that may impact bereavement. In a study of 217 bereaved caregivers of patients with dementia, 72% reported feelings of relief following the death of patients, and symptoms of depression were lessened during the bereavement period (Schulz et al., 2003). In dementia caregiving, grief and loss usually begin before the death of patients (Sanders & Corley, 2003), and other issues, such as nursing home placement and multiple losses, add to the mixed feelings of relief and intensified grief (Meuser & Marwit, 2001). The loss of a caregiver role may have long-lasting, negative effects on the caregiver (Boerner, Schulz, & Horowitz, 2004; Grant et al., 2002; Robinson-Whelen, Tada, MacCallum, McGuire, & Kiecolt-Glaser, 2001). The experience of bereaved caregivers of patients with cancer is different than the trajectory of caregiving for patients with dementia. Patients with cancer frequently experience a uniquely intense, challenging trajectory during end-of-life care, characterized by difficult symptoms and a sharp decline in functioning (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003), which may impact the bereavement process for the caregiver.

Bereaved family caregivers are at high risk for many distressing symptoms related to complex variables, such as age and gender (Brazil, Bedard, & Willison, 2002), social support (Brazil et al., 2003), available resources (Ingleton et al., 2004), and the experience of caregiving (Kris et al., 2006). A difficult caregiving trajectory was associated with poorer recovery in bereavement (Brazil et al., 2003; Gilbar & Ben-Zur, 2002; Kris et al.). Emotional distress and caregiving issues correlated with bereavement maladjustment issues (Rossi-Ferrario, Cardillo, Vicario, Balzarini, & Zotti, 2004). Patients’ high symptom severity and inadequate support were associated with worse caregiver bereavement outcomes (Grande et al., 2004). The type of care patients who were terminally ill received had a positive impact on the bereaved spouses’ psychological distress; a specialized oncology homecare nursing service was associated with significantly lower levels of depression and paranoidal ideation during bereavement compared to standard care (McCorkle, Robinson, Nuamah, Lev, & Benoliel, 1998). In some studies, home deaths correlated to worse bereavement outcomes (Addington-Hall & Karlsen, 2000; Gilbar & Ben-Zur). In contrast, in a study comparing adult daughters to male spousal caregivers of patients with breast cancer in the United States, home deaths correlated with more positive outcomes (Bernard & Guarnaccia, 2003).

### Process: The Delivery of Care

Bereavement services are the programs, policies, and supports provided by the healthcare system after the death of a terminally ill patient. Evaluation of bereavement services for their effectiveness, efficiency, and equity is needed because how these programs are implemented in practice is diverse (Bromberg & Higginson, 1996; Field, Reid, Payne, & Relf, 2004). In a survey of 29,292 bereaved family members who had received palliative services through the NHPCO, 18% noted a need for an improvement in the support they were offered, including an increased need for communication with families and overall coordination of care (Connor, Teno, Spence, & Smith, 2005). A survey conducted in the United Kingdom with 407 bereaved family caregivers found that only 20% had the opportunity to talk to someone from health and social services after the death of their loved ones (Ingleton et al., 2004). Organizational case studies of five English hospice bereavement services in the United Kingdom revealed that all offered information, follow-up phone calls, or letters, but none used a formal risk assessment to identify who might benefit from formal bereavement support (Reid et al., 2006). Bereavement programs worked best when they were integrated within a continuum of care for family members beginning with prebereavement discussions and continuing to offer support throughout the bereavement process (Reid et al.).

### Outcomes of the System of Care

Research from the perspective of the family caregivers’ experience of bereavement reveals a population at high risk for negative health outcomes; however, a systematic review of 74 studies of bereavement interventions did not reveal any rigorous nonpharmacologic, evidence-based recommendations regarding the treatment of bereaved caregivers (Forte, Hill, Pazder, & Feudtner, 2004). Figure 1 contains suggestions for research from the perspectives of effectiveness, efficiency, and equity needed to provide the evidence to address the gaps in health services and meet the needs of this neglected population.

**Effectiveness research:** The effectiveness of the healthcare system could be addressed by examination of the quality of services offered during bereavement. Do the services offered increase quality of life and address the patterns of morbidity and mortality of bereaved caregivers? Previous research shows that caregivers who were spouses experienced difficulties during caregiving, and those who had an inadequate support system experienced poorer mental status than other groups of caregivers (Brazil et al., 2003). Tools are available to identify the most at-risk families to prevent pathologic grief, such as the Family Relationships Index, which classifies families as dysfunctional, intermediate, or well-functioning (Kissane et al., 2006). Ongoing research is needed to examine the use of health services and general well-being of caregivers during bereavement and to identify correlates to health, such as the secondary losses experienced by spouses in later life (Carr, Wortman, & Nesse, 2006).

**Efficiency research:** Efficiency research could include the type, timing, amount, and theoretical base of available supports. What are the unique needs of different populations, such as the differences between bereaved children and bereaved spouses (Bernard & Guarnaccia, 2003)? Currently, most bereavement services rely heavily on volunteers (Field, Payne, Relf, & Reid,
2007); is this the most efficient way to deliver services? Do volunteers receive adequate training and support in their role? Targeting specific groups, such as individuals with a very short hospice enrollment (Kris et al., 2006) or spouses who did not receive hospice support (Christakis & Iwashyna, 2003) or had a very difficult caregiving experience and a more difficult bereavement response (Grande et al., 2004), may lower risk for depression. Grief support in Spain involved mainly telephone contact and an informal assessment of the needs of the bereaved, basically because of a lack of human and economic resources to provide effective and efficient bereavement services (Yi et al., 2006). A more formal approach to bereavement risk assessment, intervention, and follow-up would improve the efficiency of the healthcare system in providing for the needs of bereaved family members.

**Equity research**: Very little research has been conducted with rural and remote populations or from the perspective of diverse ethnic and cultural groups. Equity research would address the accessibility of services, regardless of location, income, diagnosis, language spoken, and cultural group. Nursing research is needed to address the gaps in the current context of care for bereaved family caregivers.

**Nursing Role in Bereavement Care**

Nurses have key roles in providing an effective, efficient, and equitable system of care for family caregivers. The cancer caregiving trajectory is intense and challenging and can result in isolation and vulnerability during bereavement (Hauser & Kramer, 2004). Further development of programs of care for family caregivers that include bereavement is needed (Field et al., 2007). Kissane (2004) recommended the key components of a bereavement support program to be attendance at the funeral, expression of sympathy by cards or telephone calls, written information about grief, follow-up visits to the home, and commemorative services during the year. Also included is targeted preventive support for those at high risk and specific interventions for complicated grief. Bereavement risk includes a history of psychiatric illness, multiple losses, a lack of social support, and a difficult experience during the death (Hauser & Kramer).

**Formal Tools of Risk Assessment**
- Bereavement Risk Index (Kristjanson et al., 2005)
- Family Relationships Index (Kissane et al., 2006)

**Informal Assessment of Risk**
- History of psychiatric illness or multiple losses (Hauser & Kramer, 2004)
- Sleeping problems (Carter, 2005)
- Loss of a spouse (Brazil et al., 2003)
- A difficult caregiving experience (Rossi-Ferrario et al., 2004; Gilbar & Ben-Zur, 2002; Grande et al., 2004)
- Very short hospice enrollment (Kris et al., 2006)
- No hospice support (Christakis & Iwashyna, 2003)

**Conclusion**

The healthcare system is struggling to meet the needs of bereaved family caregivers, a neglected and marginalized group. Although mandated by policy at the international and national levels, services for bereaved palliative caregivers are very difficult to offer or evaluate because very little is known about their experience of bereavement. By examining the context of care for bereaved family caregivers through research and program evaluation, new insights are gained into the effectiveness, efficiency, and equity of healthcare services for this population. This also provides nurses with opportunities to improve well being, quality of life, and health outcomes for caregivers going through bereavement by ensuring care, services, and support.

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**Figure 2. Formal and Informal Assessment of Risk Factors for Bereaved Family Caregivers**
References


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