

Discourse

Directions in Palliative Care Nursing Research: Impeccable Care, Timing, and Complexity

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Notable advances have been made in the past three decades in palliative care nursing. The features that distinguish palliative care — attention to the whole person and to all aspects of a patient's suffering as well as a multidisciplinary approach to care — have resulted in marked improvements in the standard of care for those with advanced and incurable cancer (Woodruff, 2004). Palliative care research has resulted in better knowledge of symptom assessment and treatment, improved psychosocial care, and a more refined approach to managing family care needs. The need for palliative care is enormous and will continue to increase, placing tremendous pressures on existing services. Until recently, palliative care tended to concentrate on the needs of cancer patients and their families, focusing on the terminal stages of a person's life. However, the field is being challenged to provide high-quality care to a wider range of patients, receiving care in a variety of settings, with more complex symptoms and co-morbidities, at earlier stages of their illness. These challenges are captured well in the most recent World Health Organization (2002) definition of palliative care:

An approach that improves the quality of life of individuals and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (p. 1)

This definition improves on previous ones, which were cancer-centric, too narrow, and too time-specific. It presents palliative care nursing research with three specific challenges:

- to produce empirical evidence that will inform impeccable nursing assessment and treatment of pain and other problems — physical, psychosocial, and spiritual

- to conduct research that will guide decisions about when to offer a palliative approach to patients who may have very different life-threatening disease trajectories
- to investigate the palliative care needs of individuals with non-malignant life-threatening conditions, prompting us to consider a broader and more complex range of palliative conditions

These three research challenges are examined below, with a focus on how palliative care nursing research ought to respond.

Impeccable Assessment and Treatment

When a person is facing a life-threatening progressive illness, the close attention of those whose role it is to provide care is critical. In fact, the attention given to the patient's comfort, complex symptoms, and confusing feelings, as well as difficult family dynamics, is what makes palliative care effective. It is impossible to be an expert palliative care nurse and skim over the patient's concerns, minimize distress, or ignore minor difficulties. Indeed, it is the nurse's detailed attention to the small aspects of a patient's physical, emotional, and spiritual state that makes a difference. As one family member stated to me when referring to the palliative care provided to her mother, "Nothing was too much trouble for the nurses." If palliative care nurses are to truly pay impeccable attention to the needs of our patients and their families, they must systematically and vigorously address the need for sound research to inform our practice. However, research efforts to improve assessment and resolution of the problems faced by patients and their families will be more refined and tailored if researchers are able to distinguish among a *palliative approach*, *specialized palliative services*, and *end-of-life or terminal care* (Kristjanson, Toye, & Dawson, 2003). These different types of palliative care responses provide a context for different types of research questions and variations in assessment and treatment.

A Palliative Approach

A palliative approach is one in which the person's condition is not amenable to cure and the symptoms of the disease require effective symptom management. Active treatment of the disease may still be required and may be provided concurrently with a palliative approach. However, the primary goal of a palliative approach is to ensure that the patient is comfortable and maintains a level of functioning.

Specialized Palliative Services

This form of palliative care involves referral to a specialist palliative care team or health professional. It does not replace a palliative approach but,

rather, augments it with focused, specific input as required, usually in one of two ways: assessment and treatment of complex symptoms, or provision of information and advice to staff about complex issues (e.g., ethical dilemmas, family issues, or psychological or existential distress).

End-of-Life or Terminal Care

This form of palliative care is appropriate when the individual is in the final days or weeks of life, and care decisions and goals are focused on his or her physical, emotional, and spiritual comfort and on support for the family.

The ability to differentiate among these three types of palliative care is important in formulating research questions about who receives palliative care, how to structure services, when to offer palliative care, and how to resource palliative care. This distinction provides direction for palliative care nursing research to ensure that studies undertaken address the range of palliative services/interventions that may be needed.

When to Move to a Palliative Approach

It is important to first dismiss the idea that one can easily and clearly distinguish curative from palliative care, or that patients move neatly from one modality to another. Introcaso and Lynn (2002) report that the best way to identify those patients who need a palliative approach is to ask the following question: "Which of your patients is sick enough that death within a few months would not be surprising?" This question is a useful one clinically because it identifies patients with eventually fatal illnesses at a time when they will need comprehensive services and support for the rest of their lives.

The rapidity and stages of decline vary considerably with the type of illness. For example, the course of lung cancer may be very brief, the illness trajectory associated with dementia can be relatively long, and the debilitating effects of amyotrophic lateral sclerosis may be endured for months only or for several years. Individuals with organ failure such as renal disease may experience a more predictable terminal phase of illness, while those with chronic obstructive airway disease could well suffer many exacerbations followed by periods of recovery.

We cannot depend on prognosis as the basis for accessing palliative services or for determining what constitutes a palliative care research question or topic. Prognostication is frequently uncertain, may be riddled with error, and may not be the best marker of palliative care need (Christakis, 1999). Rather, in end-of-life care we must ask how we can provide comprehensive, reliable palliative nursing because the person is very sick and death may be an outcome of his or her progressive illness.

This framework shapes the type of nursing research questions we ask and the focus of our inquiries.

Who Is Likely to Need Palliative Care in the Future?

The number of cancer patients requiring palliative care will not diminish, and cancer is likely to remain the most common cause of premature death (death before age 65) and the second most common cause of death overall (Clinical Oncology Society of Australia, Cancer Council Australia, and National Cancer Control Initiative, 2003). However, we must also consider palliative services for those with other progressive degenerative illnesses, for children, and for segments of the aged population.

Neurodegenerative Illnesses

People living with neurological diseases such as amyotrophic lateral sclerosis, multiple sclerosis, Huntington's disease, and Parkinson's disease face long-term physical and psychological challenges. Neurodegenerative diseases have the capacity to evoke the most negative and despondent attitudes on the part of many health-care professionals. These attitudes can be readily transmitted to patients and their families. The fact that we cannot significantly alter disease progression is sometimes interpreted to mean that there is nothing more to be done. This is inaccurate and regrettable. It is precisely because we cannot reverse or even retard the disease process that we must do everything possible to alleviate symptoms and offer appropriate psychological and spiritual support. The illness trajectory for people with neurodegenerative diseases may be years or decades and entail lengthy periods of dependency. A range of technologies and health-care options may be used to ensure adequate nutrition, communication, cardiac and respiratory functioning, bowel motility, and skin integrity. All such interventions require learning and adjustment on the part of the patient and family. This is where a *palliative approach* has much to offer. The psychological and social factors associated with neurodegenerative diseases are as important as physical care, and the healthy recovery of family members after their eventual bereavement is also essential. These needs all fall within the practice domain of palliative care nurses.

Development and testing of a hybrid "package" of care with the correct mixture of rehabilitative care, respite, and palliative support appears necessary. As well, tailoring this package to a range of settings, perhaps "following" the patient as a supportive framework, may be helpful. This approach to care might then provide a useful template for planning supportive palliative care for individuals with other non-

malignant conditions. Palliative care nurses should play an active role in undertaking research aimed at addressing the needs of these populations.

A Palliative Approach for Children

The development of palliative services for adults has not been paralleled in pediatrics. It is not that death is less common amongst children than amongst adults. The dying child has been avoided in the literature and in practice, perhaps for emotionally charged reasons. The provision of pediatric palliative care is patchy and inconsistent. One of the reasons for this may be that many of the fatal diseases that afflict children are rare and the children suffering from them are distributed over a broad geographic area.

Most child deaths are due to uncontrollable malignant disease following unsuccessful attempts at curative treatment, and although cure rates for cancer have increased markedly in recent years, nearly one third of childhood malignancies result in death. However, pediatric palliative care needs extend beyond cancer diagnoses and may be appropriate for a range of progressive, life-threatening illnesses (e.g., neurodegenerative and metabolic disorders, organ failure).

To date, a sound model for pediatric palliative care has not been reported in the empirical literature. As well, research to document the needs of various subgroups of pediatric patients and their families has been lacking. Models of palliative care for children may be quite different from those for adults and likely would feature a greater emphasis on respite services, long-term support, family interventions focused on siblings, and community home support. Nurses can play an active role in addressing this gap in knowledge by providing the evidence needed to help guide care decisions and service developments for pediatric populations.

A Palliative Approach in the Care of the Aged

Unique and challenging issues emerge in the provision of palliative care for the elderly. The illness trajectory may be prolonged and is likely to involve co-morbidity and cognitive and communication impairment. Institutional care may be required because of the often severe and long-term nature of functional incapacity and the frailty of elderly family caregivers. In the year 2000 the overall prevalence of dementia worldwide was approximately 25 million persons; about 6.5% of the population 65 years of age and older suffered from dementia and the number of new cases that year was estimated to be 4.6 million. Forecasts indicate a considerable increase in the number of demented elderly, to 63 million in 2030 and 114 million in 2050 (Wima, Winblad, Aguero-Torres, & von Strauss, 2003). Alzheimer disease averages about 7.5 years from onset to

death, but might last anywhere from 3 to 25 years (Kemp, 1995); each stage brings with it unique difficulties, further deterioration for the patient, and anguish for the family. A palliative approach to care for these individuals and their families is extremely relevant, providing attentive physical care, symptom relief, psychological support related to loss and grief, and sensitive discussions related to advance care directives.

Traditional models of palliative care have tended to focus on the care of patients with cancer. Although cancer is for the most part a disease of the elderly, these models do not necessarily meet the palliative care needs of the wider population of elders. The question is, therefore, how to provide the best possible palliative care for this population?

Recently, the Australian Department of Health and Aged Care funded the Australian Palliative Residential Aged Care project (www.apracproject.org) to examine how a palliative approach to care might be incorporated into residential aged care. This project involved the identification of evidence-based guidelines for a palliative approach in residential aged-care facilities, development of competencies for all aged-care staff, and educational programs to meet these competencies. Funding has now been provided to implement the guidelines and educational programs, with more than 10,000 copies of the guidelines produced for the aged-care sector. This project has fostered broad-reaching public expectations about the importance of a palliative approach at end of life and has stimulated new research into how to apply a palliative approach in aged care.

Palliative care nurses and their nursing research colleagues in gerontology are coming together to generate the empirical evidence required to address the end-of-life care needs of the older population. End-of-life care for this burgeoning sub-population will become our greatest health-care challenge, and palliative care nurses have an important proactive role to play in informing health-policy decisions about how to best meet this challenge.

Conclusion and Future Directions

Although notable progress has been made in recent decades in the area of palliative care nursing research, some of the symptoms (e.g., fatigue) and concerns of our patients and their families are not being well addressed. In addition, a number of patient groups are being undertreated. The following questions illustrate several research areas that warrant further work:

- What are the most effective ways to assess and manage fatigue?
- What are the most appropriate models of palliative care for children and their families?

- What are the most valid and reliable and clinically sensitive ways to assess pain and other symptoms of distress in individuals who are cognitively impaired?
- What is the most effective way of responding to the grief of surviving family members?
- How do we address the grief and loss of individuals with cognitive dementia?
- How can we best integrate advance care planning into care in such a way that families and patients feel supported and comfortable with the decisions they have made?
- How should we manage questions about nutrition and fluid support for people in the advanced stages of a terminal illness?
- How might we best address the needs of individuals from minority cultural groups?
- What approaches to palliative care are most helpful to individuals with non-malignant diseases (e.g., amyotrophic lateral sclerosis, multiple sclerosis, Huntington's disease, Parkinson's disease)?
- What are the most effective ways to provide palliative care to individuals who live alone and do not have the support of friends, family, or neighbours?
- What health-policy research must be undertaken to prepare for the aging population and shifting demographics that will require more caregivers for those who need support and a palliative approach in the end stages of their lives?
- How do we construct economically viable models of care that do not water down the palliative approach that promises impeccable attention to the concerns of patients and families?

There is a pressing need for palliative care nursing research that informs practice, allowing palliative care nurses to use the best possible empirical evidence so they can attend impeccably and tirelessly to the relief of distress. This knowledge development must be accelerated in order to respond to the challenges of delivering palliative care to populations who are currently not being well served by a palliative approach. We cannot assume that the models of palliative care developed to date will be appropriate for the future broad range of patients who will be receiving care in a variety of settings. The extension of palliative care to other populations will require innovative research approaches, to ensure that the models of palliative nursing care being used are responsive to the unique needs of the growing numbers and types of patients and families requiring care.

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