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Palliative or Hospice Care? Understanding the Similarities and Differences

Nancy Henne Batchelor, MSN RN CNS

With advances in health care and medical technology, the focus of medical care has been on curing. As people live longer, the possibility of experiencing chronic and life-limiting disease not only increases but also spurs the ethical question "Is length of life or quality of life most important?" Palliative care may be confused with hospice care, as both focus on symptom management and improved quality of life for those with chronic life-limiting disease. A better understanding of each healthcare option is needed for appropriate and timely patient referral. The purpose of this article is to identify the similarities and differences between these two options, clarify when referral is appropriate for hospice or palliative care services, and discuss the nurse's role in caring for patients with chronic disease.

The projected life expectancy in 2050 for men and women, respectively, is 81 and 87 years, according to the 2000 census (He, Sengupta, Velkoff, & DeBarros, 2005). Statistics of significant health characteristics reveal that 80% of those 65 years of age and older have at least one chronic condition and 50% have at least two chronic conditions (He et al.). As the number of people with life-limiting disease continues to rise, there is a need to identify the trajectories of illness and healthcare alternatives that can provide viable choices when health status declines.

Nurses care for patients with multiple comorbidities who are being referred more frequently for rehabilitation. Not only is rehabilitation ordered after surgery; it also is offered after acute illness or as a general strengthening measure to prevent increasing frailty secondary to chronic disease. When caring for patients in a rehabilitation setting, nurses may face questions regarding patient outcomes and the possibility of ceasing aggressive treatment. With knowledge of end-of-life issues and palliative and hospice care, nurses working in rehabilitation and any other healthcare settings can help patients and families understand the basic principles of these modalities and make informed decisions regarding their care.

Trajectories of Decline and End-of-Life Issues

Three trajectories of decline have been identified for people experiencing chronic illness: 20% experience long-term maintenance of good function despite a known fatal illness, with a few weeks or months of rapid decline as the illness progresses and leads to death (Trajectory 1); 25% experience slow decline in physical capacities and periods of exacerbations

ending in a rather sudden death (Trajectory 2); and 40% experience long-term dwindling of function, requiring years of personal care (Trajectory 3; Lynn, 2005). The remaining 15% of the population dies of sudden illness or accidents.

Chronic conditions limit activity for more than 40 million people (Lorenz et al., 2004). Consequently, it is safe to assume the majority of people with serious chronic illness will live a long time with that illness, and they will require supportive medical and nursing care along the spectrum. The goal of healthcare providers and, in particular, the rehabilitation team is to maximize and extend stable periods while adapting to and managing chronic illness. Consider a patient with progressive heart disease, for example. Management requires an interdisciplinary approach using multimodal strategies. During an acute event, a patient may experience a change in functional ability and physical symptoms, as well as depression, anxiety, or fear related to the diagnosis. Pharmacological management may be necessary, as well as nonpharmacological modalities to reduce risk factors and compensate for damage that already has occurred. In addition, cardiac rehabilitation may help to promote maximum function through strategies to increase endurance and quality of life. The Institute of Medicine's 1997 report "Approaching Death: Improving Care at the End of Life" identified care issues prevalent at the end of life including failure to provide palliative and other types of care known to be effective; provision of care that is known to be ineffective or harmful; legal, organizational, and economic obstacles detrimental to optimal care at the end of life; failure to provide training that reflects attitudes, knowledge, and skills regarding good care for dying patients; and the inability to discuss end-of-life

issues realistically and comfortably (Institute of Medicine, 1997).

More than 1 in 10 hospice families believe their family member was referred “too late” to hospice; in fact, one-third of hospice patients received care for less than 1 week (National Hospice and Palliative Care Organization [NHPCO], 2008b; Teno et al., 2007). Almost 70% of those who die each year could benefit from palliative or hospice care (NHPCO, 2008d). NHPCO research consistently shows that most people prefer to die at home, yet most die in hospitals (National Hospice Foundation, 2007).

When cure is not possible, it is difficult to determine the right time to discuss palliative and end-of-life care. When the subject is broached, the automatic interpretation is death, the end, and one size fits all. Healthcare professionals, patients, and families may equate palliative care with hospice care. When hospice and palliative care referrals finally are made, it often is late in the illness or when a person is close to dying. A better understanding of each healthcare option is needed for appropriate and timely referral.

Historically, medical care has focused on cure. As people live longer, the possibility of experiencing chronic and life-limiting disease increases and raises the ethical question, “Is length of life or quality of life most important?” For people facing incurable or life-limiting diseases, palliative care can be instituted as early as at the time of diagnosis. This type of care is coordinated by an interdisciplinary team of professionals focused on providing symptom management with the goal of enhancing quality of life.

Palliative Care

Palliative care is “an approach that improves the quality of life of patients and their families facing the problem 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” (WHO, 2002b, p. 3).

Palliative care evolved from the hospice movement and has become a care-management strategy to care for patients who have chronic illnesses but are not yet eligible for hospice support. Palliative care is a resource for anyone who has a chronic disease that eventually will cause his or her death, or for elderly people who experience general disability and discomfort. Palliative interventions can be implemented in conjunction with curative interventions during all phases of an illness. Any chronic disease can be managed using palliative care principles, and treatment can be customized to meet the needs of each person. Not only are physical symptoms addressed, but support is also provided for the psychosocial and spiritual challenges that arise for both the patient and the family. The goal is to provide the best-possible quality of life for each person during the course of an illness and to improve quality of dying for people and families facing a life-threatening illness.

The WHO (2002a) identifies key characteristics of palliative care (**Table 1**). During the last 5 years, NHPCO further expanded the WHO definition of palliative care, explaining that “Palliative care extends the principles of hospice care to a broader population that could benefit from receiving this type of care earlier in their illness or disease process. No specific therapy is excluded from consideration. An individual’s needs must be continually assessed and treatment options should be explored and evaluated in the context of the individual’s values and symptoms. Palliative care, ideally, would segue into hospice care as the illness progresses” (NHPCO, 2003, p. 1). Moreover, palliative care can be provided in a variety of settings, including the home, assisted living facility, long-term care facility, or hospital. Care is provided

Table 1. World Health Organization Key Characteristics of Palliative Care (WHO, 2002a)

Provides relief from pain and other distressing symptoms
Affirms life and regards dying as a normal process
Intends neither to hasten nor postpone death
Integrates the psychological and spiritual aspects of patient care
Offers a support system to help patients live as actively as possible until death
Offers a support system to help the family cope during the patients’ illness and during their own bereavement
Uses a team approach to address the needs of patients and their families, including bereavement counseling if indicated
Will enhance quality of life, and also may positively influence the course of illness
Is applicable early in the course of illness in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

Key Practice Points

1. As the number of people suffering from life-limiting diseases continues to increase, there is a lack of information available to help patients make healthcare choices when health status declines.
2. People with serious chronic illness often live long lives and require effective supportive medical care throughout the healthcare continuum.
3. Early referral to palliative or hospice care can provide symptom management and increased quality of life for patients suffering progressive chronic disease.
4. Nurses can provide support and guidance for patients and families as they experience chronic illness, declining health, and face end-of-life issues.

by an interdisciplinary team including physicians, nurses, social workers, dietitians, pharmacists, and complementary therapists. Primary care physicians also work in conjunction with palliative care physicians to provide seamless care.

Palliative care is not reserved for adults. Pediatric palliative care can be initiated for children experiencing serious illness that may become fatal. Children may be symptom-free and live “normal” lives between periods of exacerbation. Families frequently sacrifice their life savings and employment to seek treatment, focusing their energies on the ill child while siblings are cared for by others during their absence, and leave support systems behind if treatment centers are located outside their geographic area.

For people experiencing progressive heart failure, pharmacological modalities enhance comfort while nonpharmacological interventions focus on adaptation and increased functioning. Energy-conservation strategies and education about early identification of symptoms signaling exacerbation are interventions that are considered palliative measures in the treatment of advanced cardiac disease. As the disease progresses and the heart’s pumping capacity diminishes, patients experience unrelieved physical symptoms such as breathlessness, fatigue, and difficulty walking and sleeping. These symptoms accentuate psychological, social, and spiritual symptoms. By taking a palliative approach, patients with heart failure who are at the end of life receive treatment that is intended to relieve or eliminate symptoms and provide individualized comfort care.

Open communication and respect for family roles are other crucial elements in optimal end-of-life care. Positive outcomes for patients and families can be

achieved through honest discussions that may cover available services, conflict resolution on withholding or withdrawing therapy, medical futility, and expectations about the final hours of life. With effective symptom management and use of palliative principles, quality of life can be enhanced for people experiencing end-stage disease.

Hospice Care

Hospice is a philosophy of care dating back to the early Middle Ages (Paradis, 1985; Stoddard, 1991) that became incorporated into modern-day health care in 1967 through the work of Dame Cicely Saunders in London, who specialized in humane and compassionate care of dying people during the last phases of incurable diseases (Kuebler, Davis, & Moore, 2005). Hospice is an interdisciplinary approach to providing comprehensive care for those approaching the end of life. To qualify for hospice services (Table 2), a patient must be in the terminal phase of an illness with a life expectancy of 6 or fewer months as certified by two physicians (U.S. Department of Health and Human Services, 2001). Hospice care focuses on symptom management, which enables patients to maintain dignity and quality of life. Hospice treats the person and family rather than the disease and affirms life, neither hastening nor prolonging death (NHPCO, 2008a). NHPCO states “hospice recognizes that the dying process is a part of the normal process of living and focuses on enhancing the quality of remaining life” (NHPCO, 2008a, p. 2). Support and comfort-care measures are employed so patients can live as fully and comfortably as possible.

The hospice team includes an interdisciplinary team of professionals including physicians, nurses, home health aides, social workers, chaplains, counselors, and trained volunteers working together to provide physical, emotional, and spiritual care to patients and families. Table 3 lists major responsibilities of the team as identified by NHPCO (2008d).

Hospice care can be provided across settings. More than 90% of hospice services are provided in the home setting (American Cancer Society, 2008). Other setting options include hospital-based hospices, long-term-care facility-based hospices, and independent or free-standing hospice units. Admission to an inpatient acute-care unit is granted only for patients experiencing a crisis situation necessitating symptom management. Patients requiring inpatient admission must have uncontrolled pain or other uncontrolled physical symptoms, a caregiver or spiritual crisis, or safety issues. Regardless of the setting, comprehensive care is coordinated by the hospice team in conjunction with the facility healthcare team.

Table 2. Hospice Admission Criteria

The patient is certified as being terminal, with a life expectancy of 6 or fewer months if the illness runs its course.
The patient wants hospice care.
The patient has a physician who is willing to provide medical care and consultation.

Table 3. Major Responsibilities of the Hospice Team

Managing pain and symptoms
Providing needed medications, medical supplies, and equipment
Coaching and educating family caregivers
Delivering special services when needed
Making short-term inpatient care available for symptom management or respite
Providing grief/bereavement support for loved ones and friends

Table 4. Community and Support Resources

Organization	Web Address
National Hospice and Palliative Care Organization	www.nhpco.org
Caring Connections	www.caringinfo.org
Center to Advance Palliative Care	www.getpalliativecare.org

A special supplement to the Hastings Center Report “Access to Hospice Care: Expanding the Boundaries, Overcoming Barriers,” identified problems related to hospice care access: Some dying patients never are referred to hospice, some are referred only in the final days of life, and some aspects of hospice care are needed before the last 6 months of life (Jennings, Ryndes, D’Onodrio, & Baily, 2003). Jennings and colleagues also identified cultural differences and barriers as contributors to inequitable distribution and use of hospice services. Hospice services are not reserved only for people with cancer. Fewer than 25% of deaths in the United States are due to cancer, and only 41% of hospice patients have a cancer diagnosis (Heron, Hoyert, Xu, Scott, & Tejada-Vera, 2008). The majority of deaths are attributed to chronic conditions such as heart disease, unspecified debility, dementia, and lung disease (NHPCO, 2008b).

Financial Reimbursement

Unlike palliative care, for which eligibility is not restricted by federal guidelines, patients must meet hospice-admission criteria as defined by Medicare hospice benefit guidelines (Forman, Kitzes, Anderson, & Sheehan, 2003). Hospice services also can be reimbursed through Medicaid or private insurance plans. According to NHPCO (2008), more than 90% of hospices in the United States are certified by Medicare because the majority of patients using hospice services are older than age 65. Hospice services are available to anyone who meets eligibility criteria regardless of age.

Medicare Part B and Medicaid cover some treatments and medications used in palliative care. Private insurers also provide some coverage for palliative care through chronic care and long-term care benefits, but these benefits vary based on individual plans. Patients and families can contact their insurance providers for specific information about policies and available benefits.

Nursing Role

Nurses are positioned to integrate palliative and end-of-life care into their practice through education, support, and guidance for patients and families as they cope with the stresses of chronic illness and declining health. Nurses must have a sound knowledge base about death and dying and be able to provide competent and compassionate care for seriously ill or dying patients. End-of-life content included in undergraduate and graduate nursing curricula can strengthen a nurse’s knowledge and skills. Consultation and collaboration between nursing and medical schools and residency programs can provide needed educational and training experiences. Continuing education programs provide the theoretical component on pathophysiology, death, and dying, while consultation with palliative care nurse specialists and hospice-referral services can provide clinical support for nurses caring for seriously or chronically ill patients.

Compassionate and comprehensive conversations early in the disease process about patient care options, patient wishes, and care management can promote

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increased understanding of the illness and care choices and improve quality of life. Physical, social, and spiritual patient assessments provide nurses and the team with the necessary information to form individualized care options. Education about disease progression, symptom management, and available community resources (Table 4) is paramount in decision making for those who are considering a palliative care or hospice program. Discussing care options with patients and families is essential to developing an appropriate plan to promote quality health care and to initiate support for those coping with life-limiting diseases as they near the end of life.

About the Author

Nancy Henne Batchelor, MSN RN CNS, is an assistant professor of clinical nursing at the University of Cincinnati in Cincinnati, OH. Address correspondence to her at nancy.batchelor@uc.edu.

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