

Clinically Differentiating Palliative Care and Hospice

Dawn Bonebrake, RN, Cheryl Culver, RN, OCN®, Katherine Call, RN, OCN®, and Peggy Ward-Smith, RN, PhD

Knowing the differences and potential benefits of hospice and palliative care can help healthcare professionals advocate for their patients and make proactive decisions about patient care. Providing admission into the appropriate program can facilitate symptom management and impart the best quality of life possible for this vulnerable population. Case studies will be used to differentiate hospice from palliative care, and the history, philosophy, availability, requirements, and barriers to receiving care will be discussed.

Within the United States, hospice care is available for individuals with an anticipated life expectancy of six months or less. Once certified by a physician, hospice care can be provided in a variety of settings (i.e., inpatient, home, extended-care facility, or a freestanding hospice facility). Hospice care is designed to support individuals in the final stage of life when aggressive or curative treatments are no longer appropriate and when focus shifts to quality of life and relief from physical and psychological pain (American Cancer Society, 2009). Palliative care is sought out earlier in the disease trajectory; it should be integrated with treatments and therapies and uses a multidisciplinary focus to attain the best quality of life possible. Palliative care can be provided in conjunction with curative treatments or with interventions that aim to minimize the symptoms associated with the disease (Center to Advance Palliative Care, 2009). Palliative care is available within many hospitals, extended-care facilities, clinics, and homecare settings (Meier, 2006). Delineating the differences between the two care philosophies often is difficult, which is a result of the overlap between the two and the proven reluctance of healthcare professionals to initiate palliative care or hospice referrals (Egan & Labyak, 2006). The purpose of this article is to describe the similarities and differences of these two care philosophies and provide case studies that

demonstrate the appropriate use of each care model.

Hospice Care

Since the first hospice in the United States opened in New Haven, CT, in 1974, the availability of hospice within the U.S. has grown from a volunteer-led movement to a significant force within the healthcare system. According to the Hospice Foundation of America (2009), one of three people in the United States choose hospice care when they are dying. To date, more than 4,700 hospice programs in the United States provide care for about 1.4 million people (National Hospice and Palliative Care Organization, 2009a, 2009b).

The biggest barrier toward initiating hospice services surrounds the ability of the physician to initiate an end-of-life conversation and the patient's willingness to comprehend the notion that no curative treatments exist (Steinhauser, Christakis, et al., 2000). Accepting one's mortality is a difficult concept to grasp,

even when a life-threatening or life-limiting healthcare condition is present. When the hospice medical directors and the attending physician certify that the patient's prognosis is six months or less given normal progression of the disease, the timing of the conversation and a caring attitude can prevent the perception of "giving up" and minimize the use of ineffective, futile, and often painful treatments (Steinhauser, Clipp, et al., 2000).

Palliative Care

The Institute of Medicine ([IOM], 2003) defined palliative care as the total active care of the body, mind, and spirit. The aim "of palliative care is to prevent or lessen the severity of pain and other symptoms, and to achieve the best quality of life" (IOM, 2003, p. 2) throughout the course of any life-threatening or life-limiting healthcare condition. In the United States, the availability of inpatient and outpatient palliative care programs has grown exponentially since 1980. At that time, palliative care programs were

Dawn Bonebrake, RN, is a weekend charge nurse at NorthCare Hospice and Palliative Care in North Kansas City, MO; Cheryl Culver, RN, OCN®, is a compliance review nurse at NorthCare Hospice and Palliative Care and serves as a liaison for NorthCare's affiliated hospital, North Kansas City Hospital; Katherine Call, RN, OCN®, is an oncology nurse team leader at Midwest Cancer Care at Menorah Medical Center in Overland Park, KS; and Peggy Ward-Smith, RN, PhD, is an associate professor in the School of Nursing at the University of Missouri in Kansas City.

Digital Object Identifier: 10.1188/10.CJON.273-275

available in only 13 states (Last Acts, 2002). In 2008, however, 53% of adult hospitals with 50 or more beds reported providing palliative care (Goldsmith, Dietrich, Qingling, & Morrison, 2008).

Referral to a palliative care program is indicated when quality of life begins to diminish and treatments are accompanied by severe adverse effects, which may be more devastating than the disease itself. Using a multidisciplinary approach, all aspects of care are addressed, which may include physical, psychological, and spiritual needs. Insurance reimbursement for palliative care programs vary and may not necessarily provide coverage for these services.

Palliative care may be appropriate for anyone with a chronic progressive disease when symptom management becomes a challenge. Implementing a palliative care philosophy provides healthcare professionals with a forum for holistic care, which may include complementary and alternative medicine interventions. Palliative care is the only care program that provides holistic care, using an array of treatments or interventions desired by the patients and focused on quality of life and pain management regardless of prognosis (Center to Advance Palliative Care, 2009). For a quick comparison, see Table 1.

Hospice Case Study

M.C., a 32-year-old Caucasian woman, was transferred to a tertiary care facility from a rural hospital for additional evaluation of her unrelenting headaches. Prior to her transfer, M.C. had undergone a computed tomography scan of her brain, which documented a 3 x 4 cm lesion within the right occipital lobe and a 2 x 4 cm lesion in the right parietal lobe. Her medical history included a new onset, three week history of severe headaches that were persistent and nonresponsive to analgesics. M.C. reported no seizure activity.

Physical examination was unremarkable; a 0.5 cm symmetrical mole was noted on her left flank, which the patient had not previously noted. Results of the diagnostic procedures revealed lesions in M.C.'s brain, lung, liver, peritoneum, and ovaries. Tissue results, obtained from a bronchoscopy, identified the tumor type as stage IV malignant melanoma. Initial treatment consisted of outpatient whole brain radiation and oral temozolomide,

Table 1. Comparison of Hospice and Palliative Care

VARIABLE	HOSPICE	PALLIATIVE CARE
Focus	On symptom management	On symptom management
Patient's condition	Terminal (usually less than six months)	Need not be terminal
Seeking aggressive therapy?	No	May still be continuing
Decision making	The healthcare team supports and helps with decision making.	The healthcare team supports and helps with decision making.

which were provided by a facility closer to home. M.C. tolerated these treatments without incident. Three months later, M.C. was readmitted for treatment of persistent ascites. Follow-up diagnostic scans demonstrated additional peritoneal lesions, which were treated with paracentesis, IV cisplatin, and dacarbazine. Given her overall prognosis, a family conference, coordinated by her oncologist, was held with all appropriate healthcare professionals and family members. Both M.C. and her husband understood that curative treatments were not feasible and stated that they desired to have her pain controlled and to remain at home. Additional admissions to the tertiary care facility were not desired because it was too far from home. Individuals from all healthcare disciplines (i.e., chaplaincy, rehabilitative services, social services, nursing, and dietary) provided education and care suggestions for M.C.

M.C. and her husband interviewed a representative from each available hospice organization. After selecting an agency, a representative came to the hospital to complete all paperwork, determine the durable medical equipment needs, coordinate medications, and meet the patient.

M.C. was dismissed home, where care was provided by a local hospice agency. Using dermal patches supplemented by liquid morphine, her pain was well controlled, even when oral intake became impossible. M.C. was able to remain home where family and friends could visit. Her mother best described M.C.'s death two months later as "peacefully slipping away." At her request, personnel from the local hospice agency assisted M.C. in planning her memorial and funeral services. Routine follow-up with M.C.'s family would occur for 13 months after her death.

Palliative Care Case Study

J.T., a 58-year-old Hispanic man, was diagnosed in April 2002 with prostate carcinoma, initially detected as a result of an elevated prostate-specific antigen (PSA) screening procedure. J.T. underwent a radical prostatectomy; however, subsequent PSA levels remained elevated. External beam radiation therapy was initiated and completed in July 2003, with subsequent PSA levels in the normal range. In 2007, J.T.'s PSA was elevated and luprolide was initiated. This controlled his disease for a few months. At that time, bicalutamide was initiated. When the bicalutamide was no longer effective, J.T. began docetaxel as a single chemotherapy agent. J.T. tolerated treatment with few minor allergic reactions, but his PSA remained in the 40 ng/ml range for the next eight months (a PSA above 10 ng/ml indicates very high risk). PSA results in July 2008 jumped to the 220s. Despite the administration of mitoxantrone, a subsequent PSA result was 750 ng/ml. J.T. developed metastatic disease to his lung and right iliac crest. In November 2008, J.T.'s oncologist recommended additional treatment with estramustine and steroids. At that time, J.T.'s quality of life was diminished by progressive generalized weakness and fatigue, cytopenias with bruising, and bone pain.

In January 2009, J.T.'s wife took him to the hospital because he "just wasn't acting right." She reported that he had been having increased pain and she did not think he had been taking his medication as prescribed. On admission to the oncology unit, two units of packed red blood cells were transfused in response to a critical hemoglobin level of 6.8 g/dl. J.T. slowly recovered, but his pain continued and he appeared depressed.

His wife and adult sons expressed their frustration to the oncology nurse at not knowing what to do or how to help. After a discussion focusing on J.T.'s healthcare options, the nurse contacted the oncologist and obtained an order for a palliative care consult.

The purpose of the palliative care consult was to provide and coordinate support and symptom management. In this instance, the palliative care social worker arranged for a family meeting to develop a plan that would manage J.T.'s care needs. At the meeting, the palliative care physician stated that J.T.'s symptoms and pain could effectively be managed. A discussion occurred regarding the goals and wishes of the family; these were kept appropriate by the palliative care physician and linked with J.T.'s expected disease trajectory. J.T. did not have an advanced directive and the palliative care team social worker offered assistance by explaining all options, including the meaning of a do-not-resuscitate order, and provided the necessary paperwork.

J.T. chose to continue estramustine and steroids for the treatment of his prostate cancer. The palliative care physician added new medication orders to treat his pain. He was placed on 40 mg of extended release oxycodone every 12 hours with an as needed dose of immediate release oxycodone 10–20 mg every six hours for breakthrough pain. He was set on a scheduled time for a bowel regimen, which included senna and docusate. Within 72 hours after the medication changes, J.T. expressed a decrease in pain. Although the antidepressant had not begun to take effect, J.T. reported an overall sense of well-being and a feeling that he and his family were better prepared for the events to come and more open to discussion about admission into an appropriate hospice program.

Implications for Nursing

One of the principle roles of nursing is to advocate for patients and families. Nowhere is this more important than among those that have received a life-threatening or life-limiting illness. Differentiating palliative care and hospice care is confusing to healthcare professionals and lay people, providing an excellent opportunity for nurses to provide education (Curtis, Patrick, Caldwell, & Collier, 2000). Nurses

who interact with patients and families routinely are in an excellent position to provide education with respect to the goals and philosophy of hospice and palliative care. Nurses should be knowledgeable about care choices available, the differences between palliative care and hospice, and when each are appropriate.

Knowledge of the disease process and side effects of medications provide clinical indicators when hospice and palliative care may be appropriate. Combining oncology knowledge and a therapeutic relationship allows palliative care to be incorporated whenever needed for aggressive symptom management and for hospice to be initiated toward the end of life when treatments are no longer considered curative.

Oncology nurses provide care against seemingly insurmountable odds. The same is true for patients and their families. Although understanding and supporting treatments is important, just as important is the realization when additional treatment is not appropriate. Initiating end-of-life conversations may be personally and professionally difficult. The End-of-Life Nursing Education Consortium (2002) concluded that encouraging appropriate hope and maintaining quality of life should be expected outcomes of care. Patients place their trust in nurses. Anticipating their needs, guiding them toward appropriate care, and supporting their decisions should be a personal and professional goal for all oncology nurses. Although providing cancer care is rewarding to nurses, initiating or providing appropriate and valued palliative and hospice care will be rewarding to nurses, patients, and their family members.

The authors take full responsibility for the content of the article. The authors did not receive honoraria for this work. No financial relationships relevant to the content of this article have been disclosed by the authors or editorial staff.

Author Contact: Cheryl Culver, RN, OCN®, can be reached at cculver@northcarehospice.org, with copy to editor at CJONEditor@ons.org.

References

American Cancer Society. (2009). What is hospice care? Retrieved from http://www.cancer.org/docroot/ETO/content/ETO_2_5x_What_Is_Hospice_Care.asp

- Center to Advance Palliative Care. (2009). Palliative care vs. hospice care. Retrieved from <http://www.getpalliativecare.org/whatis>
- Curtis, J.R., Patrick, D.L., Caldwell, E.S., & Collier, A.C. (2000). Why don't patients and physicians talk about end-of-life care? *Archives of Internal Medicine*, *160*, 1690–1696. doi: 10.1001/archinte.160.11.1690
- Egan, K.A., & Labyak, M.J. (2006). Hospice and palliative care: A model for quality end-of-life care. In B.R. Ferrell and N. Coyle (Eds.), *Textbook of palliative nursing* (2nd ed., pp. 13–47). New York, NY: Oxford Press.
- End-of-Life Nursing Education Consortium. (2002). *Training manual*. Washington, DC: American Association of Colleges of Nursing.
- Goldsmith, B., Dietrich, J., Qingling, D., & Morrison, S. (2008). Variability in access to hospital palliative care in the United States. *Journal of Palliative Medicine*, *11*, 1094–1102. doi: 10.1089/jpm.2008.0053
- Hospice Foundation of America. (2009). Choosing hospice. Retrieved from <http://www.hospicefoundation.org>
- Institute of Medicine. (2003). *Improving palliative care: We can take better care of people with cancer*. Washington, DC: National Academies Press.
- Last Acts. (2002). Means to a better end: A report on dying in America today. Retrieved from <http://www.rwjf.org/pr/product.jsp?id=15788>
- Meier, D.E. (2006). Palliative care in hospitals. *Journal of Hospital Medicine*, *1*, 21–28. doi: 10.1002/jhm.3
- National Hospice and Palliative Care Organization. (2009a). About NHPCO. Retrieved from <http://www.nhpco.org/i4a/pages/index.cfm?pageid=3253&openpage=3253>
- National Hospice and Palliative Care Organization. (2009b). History of hospice care. Retrieved from <http://www.nhpco.org/i4a/pages/index.cfm?pageid=3285>
- Steinhauser, K.E., Christakis, N.A., Clipp, E.C., McNeilly, M., McIntyre, L., & Tulsky, J. (2000). Factors considered important at the end of life by patients, family, physicians, and other health care providers. *JAMA*, *284*, 2476–2482.
- Steinhauser, K.E., Clipp, E.C., McNeilly, M., Christakis, N.A., McIntyre, L.M., & Tulsky, J.A. (2000). In search of a good death: Observations of patients, families and providers. *Annals of Internal Medicine*, *132*, 825–832.