Helping Patients With Cancer Prepare for Hospice

Kelly K. Hill, MSN, RN, OCN®, and Eileen D. Hacker, PhD, APN, AOCN®

People with life-limiting cancer will make decisions about their end-of-life (EOL) care at some point during their illness. Hospice is an option of care aimed at providing optimal quality of life at EOL. Nursing plays a major role in helping people transition from curative treatments or treatments that control the disease to EOL care. Choosing hospice is difficult for many patients with cancer. In addition, healthcare providers also face challenges in discussing EOL care. This article explores issues pertaining to EOL care conversations between nurses and patients and offers strategies that can be implemented by nurses to aid patients’ transition to hospice care.

Hospice Care

Hospice care is defined as an interdisciplinary approach to provide medical and nursing care, pain management, and emotional and spiritual support directed at fulfilling patients’ needs and wishes at EOL (National Hospice and Palliative Care Organization [NHPCO], 2008). Hospice care is one option for people with life-limiting cancer when curative therapy or control of the disease is no longer realistic. Hospice programs provide holistic care at EOL, with an emphasis on meeting the patient’s goals of comfort and quality of life. The hospice model of care uses an interdisciplinary approach to provide nursing, medical, social, spiritual, nutrition, volunteer, and bereavement services (Carlson, Morrison, Holford, & Bradley, 2007).

The benefits of hospice care have been documented extensively and include relief of pain (Miller, Mor, Wu, Gozalo, & Lapane, 2002; NHPCO, 2008; Owens, Simmons, Gibson, & Weeks, 2001), enhanced quality of life (McMillan & Mahon, 1994), longer survival (Connor, Pyenson, Fitch, Spence, & Iwaski, 2007), improved bereavement (Christakis & Iwashyna, 2003),

At a Glance

- Many issues exist in discussing end-of-life care and hospice referral for people with life-limiting cancer.
- Nurses can have a greater role in transitioning people with life-limiting cancer to hospice.
- Using an algorithm, nurses can become more comfortable and adept at transitioning patients to hospice care.

Cancer is the second-leading cause of death in the United States (Jemal et al., 2008). Since the early 2000s, researchers, educators, and clinicians have directed tremendous efforts toward improving the quality of end-of-life (EOL) care (Aulino & Foley, 2001; EPEC Project, 2009; Ferrell, Virani, & Malloy, 2006). Nursing plays a major role in helping patients at EOL prepare for hospice. Many nurses, however, may not be comfortable engaging patients with life-limiting illnesses, such as advanced cancer, in discussions regarding EOL treatment options. Reasons for this include a lack of comfort with the topic, reluctance to discuss EOL care with the patient or family if the physician is uncertain of the prognosis, patient’s or family’s rejection of a terminal prognosis, sudden change in patient status, and/or a desire to maintain hope (Schulman-Green, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2005). The purpose of this article is to discuss issues associated with engaging patients in conversations regarding EOL care and to offer strategies that can be implemented by nurses to help patients with cancer prepare for hospice care. Topics to be addressed include uncertainty of prognosis, initiating EOL discussions, timing discussions, determining eligibility, multiple cancer treatment options, possible patient reactions, and the role of the family and caregivers. Strategies for nursing begin with examining personal beliefs and developing a thorough understanding of hospice and EOL care. Nurses can then identify appropriate patients, observe for opportunities to engage, assess patient needs, and provide information to patients or caregivers. Through the use of communication techniques and developing an interdisciplinary team approach, patients will be better prepared to transition to hospice care.

Kelly K. Hill, MSN, RN, OCN®, is a nurse practitioner for Cancer Care Associates at the Community Cancer Center in Normal, IL, and Eileen D. Hacker, PhD, APN, AOCN®, is a clinical associate professor in the Department of Biobehavioral Health Science at the University of Illinois in Chicago. (First submission June 2009. Revision submitted July 2009. Accepted for publication July 12, 2009.)

Digital Object Identifier: 10.1188/10.CJON.180-188
and the option for death at home (NHPCO, 2008). Patient and family satisfaction with hospice care is high (NHPCO, 2008); however, patients and their families may not realize the full benefit of hospice services if enrollment occurs later in the disease trajectory. Shorter lengths of enrollment are associated with decreases in satisfaction among family members of patients in a hospice setting (Rickerson, Harrold, Kapo, Carroll, & Casarett, 2005). Family caregivers who perceive that they are referred to hospice programs “too late” report more unmet needs, greater concerns, and lower satisfaction (Teno et al., 2007). In patients with life-limiting cancer, lack of knowledge about hospice programs has delayed enrollment (Casarett, Crowley, & Hirschman, 2004). Improved communication regarding the availability and purpose of hospice programs provides a gateway for people with life-limiting cancer to make informed decisions about their EOL care.

Issues Associated With End-of-Life Discussions

Uncertainty of Prognosis

Uncertainty of prognosis, from a healthcare provider or patient and family point of view, impacts the ability to initiate or engage in discussions regarding EOL. Difficulty in determining prognosis has been cited by physicians as a reason for failing to refer patients to hospice (Brickner, Scannell, Marquet, & Acker-son, 2004). Understandably, nurses may feel apprehensive about discussing EOL care, such as hospice care, when the patient’s prognosis remains uncertain. Nurses are less likely to engage in EOL discussions if they perceive the physician as reluctant to give a terminal prognosis (Schluman-Green et al., 2005). Difficulty also arises when the patient and family are not willing to accept the physician’s terminal prognosis. An uncertain prognosis or inability to accept a terminal diagnosis may delay hospice enrollment.

Initiating End-of-Life Discussions

Determining who should initiate the EOL discussion is another difficult issue because it often is unclear which member of the healthcare team should approach the patient and family regarding the potential transition from curative therapy to hospice care. Physicians are responsible for curing the patient, and it is within their scope of practice to determine the patient’s prognosis and whether continuing therapy would be beneficial. Nurses do not determine prognosis but are capable of discussing the implications of a prognosis and supporting what the physician has said to the patient and family. Given the physician’s role in determining treatment options and prognosis, it seems logical that physicians would initiate the EOL discussion. Research supports this, as physicians and hospice staff most frequently initiate hospice discussions, followed by nurses (Casarett et al., 2004; Csikai, 2006). Nurses may wait for the physician to initiate the discussion because they may not feel it is within their scope of practice to do so, specifically if a determination in prognosis has not been made, or they may encourage the physician to have that discussion. A team approach for initiating EOL discussions may be highly beneficial. Although physicians most often initi-
When it comes to helping patients with cancer prepare for hospice, several issues exist with the Medicare reimbursement for hospice. The requirement that treatment for cancer must end is distressful for some patients and may be why hospice is not discussed as an option. This situation is particularly problematic when the patient has previously expressed his or her desire to pursue all available cancer treatment options. Unfortunately, even treatments thought to extend life or control the disease and/or symptoms but not cure the underlying malignancy, such as blood transfusions, palliative radiation, and chemotherapy, are not available to patients under Medicare’s current hospice reimbursement guidelines. Patients may desire the supportive services of hospice, but they also may require relief from dyspnea provided by palliative blood transfusions. If a patient chooses to receive one of these therapies, even if palliative in nature, they may become ineligible for hospice depending on their insurance benefits. Private insurances vary in what services are covered by benefits (Wright & Katz, 2007). This variation may further complicate the decision-making processes.

The Medicare reimbursement guidelines for hospice care run counter to the thinking of at least some oncology healthcare professionals. A survey revealed that 67% of hospice staff and 91% of principal investigators of phase I trials felt that patients with cancer should be able to participate in clinical trials along with hospice care (Casarett, Karlawish, Henry, & Hirschman, 2002). Although life expectancy beyond six months is unlikely for many phase I trial participants, the fact that these patients may act as a deterrent to discussing EOL care with patients with advanced cancer, even when dying, report the ability to maintain hope (Elliott & Olver, 2007). In addition, no difference in hope level of patients with advanced cancer has failed, phase I clinical trials may still be an option (albeit not curative), further prolonging the referral to hospice. The important point is that patients and their families may find it difficult to choose between pursuing additional cancer treatments when the cancer is progressing or enrolling in a hospice program. Likewise, healthcare professionals must be careful that their personal belief systems or preferences do not cloud or unduly influence the preferences of patients and their families.

Patient Reaction to End-of-Life Discussions

Fear of negative patient reactions to the possibility of hospice may act as a deterrent to discussing EOL care with patients with life-limiting cancer. These reactions can be influenced by many factors, including the patient’s cultural background (Searight & Christakis, 2002; Woods, Craig, & Dereng, 2006). This, however, does not mean that oncologists are overly aggressive in their treatment of cancer. The availability of multiple treatment regimens gives the oncologist and the patient and family several treatment strategies to consider before deciding to discontinue treatment. Even when standard treatment options for patients with cancer have failed, phase I clinical trials may still be an option (albeit not curative), further prolonging the referral to hospice. The important point is that patients and their families may find it difficult to choose between pursuing additional cancer treatments when the cancer is progressing or enrolling in a hospice program. Likewise, healthcare professionals must be careful that their personal belief systems or preferences do not cloud or unduly influence the preferences of patients and their families.

Role of Family and Caregivers

Family and caregivers have an important role in EOL decision making and often will need to be included in these discussions. Family is known to have a significant influence over the patient’s decision to choose hospice (Casarett et al., 2004; Zhang & Simonoff, 2005). For example, a study of 173 patients in a hospice setting reported that the final decision to enter hospice was made by their families (42%), followed by the patients themselves.
(28%), and, lastly, by physicians (27%) (Chen, Haley, Robinson, & Schonwetter, 2003). This study clearly indicates the influence that family and caregivers have and how their opinions and preferences influence the course of action at EOL.

Reaching a consensus regarding EOL for patients and their families is not always possible, and conflicts have been documented (Siminoff, Rose, Zhang, & Zyzanski, 2006; Zhang & Siminoff, 2003). Conflict may result in behaviors such as hiding information from one another in an attempt to protect the other (Clayton et al., 2005b; Rose, 1999). Disagreement may exist over pursuing aggressive care versus care aimed at relieving symptoms (Zhang & Siminoff, 2003). Some patients with cancer may be trying to survive longer for the sake of a family member or to live long enough to reach a certain milestone. Although these motivations are not considered negative, they may cause patients to experience internal conflict over making EOL decisions. With a better understanding of the issues and conflicts that surround EOL planning for patients with cancer, nurses can implement strategies to improve the process of preparing for hospice.

**Strategies for Nurses**

Multiple strategies exist that nurses can use to help patients with cancer prepare for hospice, including examining personal beliefs, developing a thorough understanding of hospice and EOL care, helping to identify appropriate patients, identifying opportunities to discuss EOL and hospice care, assessing patient needs for EOL care, recognizing information needs, engaging using communication techniques, and developing an interdisciplinary team approach. The algorithm presented in Figure 2 provides a sequence for implementing these strategies. Strategies and the algorithm were developed for nurses new to oncology as well as experienced oncology nurses seeking guidance with patients who are transitioning to hospice.

**Examine Personal Beliefs**

A highly beneficial strategy for nurses to take when helping patients with cancer prepare for hospice is for nurses to examine their own personal beliefs about hospice. Biases about hospice can influence how the information is presented to the patient (Weiner & Cole, 2004). For example, a belief that hospice offers little benefit to the patient is likely to be conveyed either verbally or nonverbally during the discussion. Conversely, research indicates that nurses who are knowledgeable about hospice and perceive it to be beneficial are more likely to discuss hospice with patients and their families (Cramer, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2003). Therefore, examining
personal beliefs toward and experiences with hospice can influence EOL discussion patterns.

Develop a Thorough Understanding of Hospice and End-of-Life Care

Nurses that increase their understanding and knowledge of hospice and EOL care may be more comfortable discussing these options with patients. Unfortunately, many nurses feel that their training related to EOL care is inadequate (Cramer et al., 2003; White, Coyne, & Patel, 2001). Multiple training programs related to hospice and EOL care have been developed that provide nurses with the necessary knowledge to become comfortable discussing EOL care. Training by the End-of-Life Nursing Education Consortium (ELNEC) is just one example of a standardized training program about EOL care that nurses can access through a variety of sources, including the Oncology Nursing Society or the ELNEC Web sites (see Figure 3). An oncology ELNEC version is available and has been shown to increase user-rated effectiveness in EOL care (Coyne et al., 2007). Nurses who have completed ELNEC training are encouraged to share this information with colleagues, further disseminating knowledge gained from the program. In addition to the ELNEC and other standardized training programs, becoming familiar with the resources available within a geographic area may be highly beneficial. In locations where hospice services are abundant, hospice use has increased (Earle et al., 2008); therefore, knowledge of and access to local hospice programs may increase hospice use.

Helping Identify Appropriate Patients

Another beneficial strategy for nurses is to become familiar with and understand the admission criteria of hospice. Nurses who are knowledgeable about the admission criteria may be more comfortable identifying potential patients during interdisciplinary patient care rounds, thus facilitating discussion of appropriate EOL treatment options. In a collaborative practice setting, the nurse may have more firsthand knowledge because of frequent interactions with the patient’s struggles with curative therapy or therapy aimed at controlling the disease. However, not all patients struggling with the effects of anticancer therapy are ready to transition to hospice (Matsuyama, Reddy, & Smith, 2006). Knowing the criteria can help these patients avoid early admission and reevaluation of hospice if they choose to pursue aggressive care at a later time. Use of the Palliative Performance Scale has been shown to be an accurate predictor of prognosis and could help identify patients who are approaching EOL (Lau, Dowing, Lesperance, Shaw, & Kuziemsky, 2006). The scale measures patient performance status by evaluating domains such as ambulation, activity level, self-care ability, nutrition intake, and level of consciousness. Version 2 of the scale is available on the Victoria Hospice Web site (www.victoriahospice.org/health-care-professionals/clinical-tools/palliative-performance-scale).

Identify Opportunities to Discuss End-of-Life Care or Hospice

Knowing when to discuss EOL care with patients and families is an important strategy for preparing patients with cancer for hospice. Patients have identified treatment changes as being a milestone associated with the transition toward hospice (Reinke et al., 2008). Although treatment changes may not necessarily indicate cancer progression, multiple treatment failures are indicative of a poorer prognosis. Helping patients understand the goal of the current treatment is vitally important, particularly when the goal of treatment changes from curative to control to palliation. Patients receiving therapy aimed at controlling the underlying malignancy or palliating symptoms (i.e., palliative radiation therapy) may be more amenable to EOL discussions even if they are not currently ready to make significant treatment changes. For example, when a patient’s cancer progresses while on therapy that is meant to control but not cure the disease, this progression may serve as an opportunity to assess the patient’s thoughts about the desire for additional medical therapies. Nurses should be aware that, when treatment stops, an opportunity to discuss hospice may exist.

Individual cues from a patient or family also may help identify when patients are ready to discuss EOL care (Clayton et al., 2005b). Statements, such as “I can’t take these treatment side effects anymore,” or “I don’t think that I want to spend my remaining time here feeling sick and tired from chemo[therapy],” may serve as cues for nurses to initiate discussion about quality of life and care preferences.

Assess Patient Needs for End-of-Life Care

Assessing patient needs that will be met with hospice care is another important strategy for helping patients with cancer prepare for hospice. Oncology nurses have excellent assessment abilities, and most often are very in tune with the patient’s and family’s needs from the frequent interaction over time. Common symptoms among patients with advanced cancer are weakness, pain, dyspnea, anxiety, constipation, anorexia, nausea, and depression (Chen et al., 2005). All of these symptoms have the potential to negatively impact quality of life. Assessing and communicating this information with the hospice team members is paramount for successful outcomes.
In addition to symptom assessment, functional ability in activities of daily living (ADL) should be assessed. Patients who had at least one ADL dependency were identified as also having greater need for hospice (Casarett et al., 2009). Among patients with lung or colon cancer, a majority did not have any ADL impairment until the last month of life (McCarthey et al., 2000). During the last month of life, these patients experienced a median of five ADL dependencies. Casarett and Quill (2007) suggested considering hospice for patients with a Karnofsky Performance Status lower than 50% or an Eastern Cooperative Oncology Group score of higher than 2. Those who have poor performance status may desire hospice at home; however, the patient’s care needs may exceed the caregiver’s capabilities. Assessing the capabilities of the potential caregiver is required to develop a comprehensive plan that meets both the needs of the patient and the caregiver. Patients with lower functional dependency are more likely to receive hospice services in the home (Tang, 2003). Conversely, other patients may not have adequate caregiver support at home, and providing hospice care in a skilled nursing setting may be more appropriate. Because the nurse will most likely work with the discharge planner, hospice team, and/or social worker to arrange home health services, determining the needs of the patient and caregiver up front will facilitate an appropriate discussion of needs as patients transition into hospice.

Once a patient’s needs have been assessed, the nurse should compare those needs with services that hospice can provide. More often than not, hospice care is able to adequately meet the EOL needs of the patient and family. Frequently, pain or symptom management needs precipitate the decision for hospice care (Casarett et al., 2004). Patients with poor social support and/or psychological distress demonstrate an even greater need for hospice (Casarett et al., 2009). Discussing how their symptoms may be treated through the multidisciplinary approach of hospice will help patients understand the benefits of hospice.

Recognize Information Needs

Comprehensively addressing patient and caregiver information needs will allow for more informed decision making for EOL care. Caregivers of clinic patients with cancer rated their information needs as “not so well satisfied” (Harrington, Lackey, & Gates, 1996). Addressing these information needs is a part of the role of the oncology nurse. Figure 4 summarizes questions commonly asked by caregivers and patients. These conversations may need to be repeated as patients and caregivers realize new questions or concerns. Patients may not want details about future symptoms; however, caregivers will desire such knowledge so they can be prepared (Clayton et al., 2005a). Before giving information, the nurse should inquire about how much detail the patient desires to know. The patient may only want to know that their needs will be met and that maximum attempts will be made to minimize or avoid suffering. If the patient does not want specific details about the dying process, the nurse can ask the patient’s permission to discuss these details with their caregiver. This separate conversation will enable meeting the information needs of the caregivers.

Engage Using Communication Techniques

Communication approaches aid in engaging patients and caregivers about EOL care. Patients often have reported wanting to know the truth in a compassionate manner (Royak-Schaler et al., 2006). Conveying compassion during EOL discussions communicates the nurse’s desire to help the patient. Many models for communicating about poor prognosis are geared toward a physician audience. However, these suggestions can be adapted for nursing.

Oncology nurses possess excellent communication skills. These skills become particularly helpful when discussing hospice. Developing a relationship with the patient and caregiver gives the patient more confidence that the nurse is concerned for his or her welfare and will take individual needs into consideration (Clayton et al., 2005b). Active listening helps the nurse understand the patient’s thoughts or reservations about hospice. Expressing empathy will communicate that the nurse is interested in knowing about and helping patients relieve their suffering. Simply being with the family, even in silence, will allow them to speak about their thoughts and feelings regarding EOL and hospice care. In addition, Harrington and Smith (2008) emphasized truthfulness and telling the patient that they will not be abandoned if they choose hospice. Additional education about communicating with oncology patients is available through the International Psycho-Oncology Society Web site (www.ipos-society.org/professionals/meetings-ed/core-curriculum/communication/en/player.html).
Question prompts also may be useful in assisting patients and their caregivers to discuss topics that they consider important. These prompts contain lists of questions that patients and caregivers may have regarding EOL decision making. They can be used to help the patient and caregiver ask the healthcare provider questions about EOL care. People with cancer who used a prompt list asked 2.3 times as many questions as controls and discussion time increased (Clayton et al., 2007). Patients who used the question list reported feeling more prepared for the future. In a separate study, 70%–75% of caregivers reported that question prompts made the discussion easier (Hebert, Schulz, Copeland, & Arnold, 2009). Prompt lists may be useful in a variety of settings, such as outpatient clinics and acute or chronic care facilities, to generate EOL discussions.

Develop an Interdisciplinary Team Approach

Nurses, physicians, social workers, and clergy, as well as other healthcare providers, play a role in helping the patient with cancer prepare for hospice. Physicians usually have one conversation about hospice with a patient (Casarett et al., 2004). Typically, the patient and family have additional questions or request clarification about prognosis. The nurse can collaborate with the medical staff to clarify issues and then communicate this information to the patient and family. Social work can assist in arranging services, help with financial issues, and provide psychosocial support. Clergy can provide spiritual guidance. Hospice staff also can provide additional detail for patients. In a survey of physicians, 74% preferred hospice staff to be present during discussions about hospice referral (Brickner et al., 2004). Medicare will reimburse for a one-time consultation with hospice staff; these consultations do not require the patient to choose hospice, but offer an opportunity to discuss details with hospice professionals (Centers for Medicare and Medicaid Services, 2008). It also will be important to convey confidence in the expertise of hospice staff, as patients may have concerns about their lack of familiarity about this new group of providers. Providing all of these services better prepares the patient with life-limiting cancer to make informed decisions about EOL care.

Conclusion

A great need exists to help prepare people with life-limiting diseases, such as cancer, for hospice. However, the process can be disjointed and abrupt, potentially resulting in increased suffering and a delay in receiving appropriate care. Nurses are uniquely positioned to help patients transition from curative therapy to hospice because of their frequent interactions with patients and families, as well as their intimate knowledge of the patients. Many issues, such as prognostic uncertainty and concerns about when to initiate EOL discussions, serve as barriers to engaging these discussions with patients. Identifying the issues that hamper the process in individual patients and families is important for rectifying the situation. In addition to navigating the issues involved with EOL discussions, nurses need strategies that can be implemented to facilitate EOL discussions. Unfortunately, no guide exists to help nurses ease the transition to hospice for patients. The algorithm presented in this article may serve as a resource for nursing strategies to help patients with cancer prepare for hospice.

The authors take full responsibility for the content of the article. The authors did not receive honoraria for this work. The content of this article has been reviewed by independent peer reviewers to ensure that it is balanced, objective, and free from commercial bias. No financial relationships relevant to the content of this article have been disclosed by the authors, planners, independent peer reviewers, or editorial staff.

Author Contact: Kelly K. Hill, MSN, RN, OCN®, can be reached at Kelly.k.hill@gmail.com, with copy to editor at CJONEditor@ons.org.

References


Receive free continuing nursing education credit for reading this article and taking a brief quiz online. To access the test for this and other articles, visit http://evaluationcenter.ons.org. After entering your Oncology Nursing Society profile username and password, select CNE Listing from the left-hand tabs. Scroll down to *Clinical Journal of Oncology Nursing* and choose the test(s) you would like to take.