■ CNE Article/Journal Club

End-of-Life Decision Making in Hematopoietic Cell Transplantation Recipients

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Discussions about futile treatment options for patients undergoing hematopoietic cell transplantation (HCT) can be difficult for healthcare providers. These discussions often are not initiated before transplantation, but only after a patient's healthcare status deteriorates. Nurses are in a key position to provide support and advocate for patients and their families in end-of-life (EOL) decisions. A need exists for increased autonomy for nurses as patient advocates. Implementation of multidisciplinary nursing education, both in schools and in the workplace, will support these new responsibilities. This article will provide a review of the literature related to the nurse role in the transition from active treatment (aggressive care) to EOL care in the HCT population.

Decision making in health care often involves balancing the risks and benefits among multiple options (Tariman, Berry, Cochrane, Doorenbos, & Schepp, 2012). In oncology practice, patients undergoing hematopoietic cell transplantation (HCT) often are faced with the difficult task of balancing the risks and benefits of treatment. The authors of this article sought to examine the literature regarding factors that affect decision making and treatment decisions for patients undergoing HCT, and to examine nurse roles in the treatment and care of that population.

HCT has become standard care for many cancer diagnoses, and nursing care is critical for the success of these complex transplantation treatment modalities. Nurses administer the treatment medications, assess and monitor patient responses to treatment, and manage psychological needs and treatment effects before, during, and following HCT. Unfortunately, HCT becomes a final treatment option for some patients who need to be informed of the possibility of an unfavorable response to treatment. Literature and clinical observations suggest that discussions about futile treatment options can be difficult for some healthcare providers and often are not initiated before transplantation but, rather, only after a patient's healthcare sta-

tus deteriorates (Adams, Bailey, Anderson, & Docherty, 2011). Futile treatment is commonly referred to as "treatment that is unable to reverse the course of the disease and that offers no hope of benefit" (Coveney, 2007, p. 68). End-of-life (EOL) care is an area in which nurses are well-positioned to take the lead in developing patient- and family-centered interventions targeted at improving care during this significant part of their patients' lives.

National guidelines recommend advanced care planning (ACP) for patients with terminal illness who have a life expectancy of less than one year (National Comprehensive Cancer Network [NCCN], 2010). However, despite the relatively high transplantation-related mortality of patients undergoing HCT, EOL care is a poorly understood issue, and the problems of providing palliative care to patients undergoing transplantation may be underestimated. According to Keating et al. (2010), some physicians who are aware of the ACP guidelines for terminally ill patients may delay EOL discussions because they fear discussing death early in a patient's terminal course may be associated with less hope and poorer outcomes. Research also suggests that physicians delay discussing EOL options while patients still feel well and may, instead, wait for the onset of

symptoms or until no further non-palliative options are available (Keating et al., 2010). Unfortunately, most patients do not have ACP and continue to receive chemotherapy during the last month of life, with only a minority (20%–40%) using hospice care (Zhou, Stoltzfus, Houldin, Parks, & Swan, 2010).

Methods

The authors of the current article searched the CINAHL®, MEDLINE® (PubMed), and SCOPUS electronic databases for all available dates to identify literature published using a combination of keywords and subject headings. Subject headings included *palliative care, decision making, advanced care planning, stem cell transplantation, bone marrow transplantation, withholding treatment, treatment failure*, and *oncologic nursing*. Keywords included *cancer nurs** and *transplant** and *ventilat**. These searches resulted in 409 articles that matched the question, "What is the nurse's role in the transition from active treatment (aggressive care) to EOL care in HCT patients?"

Because of the limited research conducted on this question specifically related to the HCT population, the authors expanded the search to include the adult cancer population. Inclusion criteria for the review were English-language studies, occurring in patients with cancer (any type), that addressed families making critical decisions regarding the psychological, social, legal, physical, and ethical aspects of improving EOL care. The authors did not limit the selection to articles that only addressed the nurse role in the transition to EOL care because of the lack of research conducted on only the nurse role. The authors excluded articles that reported research on pediatric cancer populations. Of the 409 articles, 90 articles were selected that addressed a facet of the research question. These were evaluated by study design, setting, and significant findings. An additional five articles were selected for inclusion after reference lists from previously collected articles were reviewed.

A second search looked for published guidelines and established definitions for palliative care and EOL care. Guidelines included in this review were from the NCCN and the National Guideline Clearinghouse. The authors organized results into five categories for palliative care and EOL care: ethical principles, decision making, implications for nursing practice, implications for nursing education, and implications for nursing research. The following sections provide discussions related to each category.

Results and Discussion

Palliative Care and End-of-Life Care Definitions

The terms palliative care, EOL care, hospice care, and supportive care need to be more clearly defined to avoid confusion among healthcare providers, patients, and caregivers. The World Health Organization (2002) has defined palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness. This approach includes prevention and relief of suffering by means of early identification and assessment as well as treatment of pain, and physical, psychosocial, and spiritual problems. Such care must be regarded as integral and essential elements of a national cancer control program, regardless of the possibilities of cure (World Health Organization, 2002). The NCCN (2010) palliative care guidelines identified the goal of palliative care, which is to prevent and relieve suffering and to support the best possible quality of life for patients and their families (see Table 1), regardless of the stage of the disease or the need for other therapies.

The term EOL care often is used interchangeably with hospice care and was originally associated with a time-defined aspect of care provided to terminally ill patients and their families (Kuebler, Lynn, & Von Rohen, 2005). Berger, Portenoy, and Weissman (1998) defined supportive care in oncology as those aspects of medical care concerned with the physical, psychological, and spiritual issues faced by patients with cancer, their families, their communities, and their healthcare providers. In this context, supportive oncology describes both those interventions used to support patients who experience adverse effects caused by antineoplastic therapies and those interventions now considered under the broad rubric of palliative care.

Ethical Principles

Ethics is an integral part of the foundation of nursing (American Nurses Association [ANA], 2001). The ANA code of ethics is composed of nine provisions related to the care of patients and

TABLE 1. Steps for Supporting the Journey of Families Through the Dying Process

Concept	Strategies
Organize, define, and take steps for providing information to families.	• Evaluate the perception of the family regarding what is happening with their family member. • Communicate a trustworthy outlook of the patient's status and prognosis. • Organize end-of-life care that respects the patient's and family's wishes. • Define and give the meaning of medical information in a language that is easy to understand. • Present information in increments to assist understanding. • Serve as an advocate for the patient and family in a way that is compatible with the needs and values of the family.
Create trusting relationships with families.	• Make time to find out the story of the patient and family through active listening. • Become involved in a straightforward and direct discussion with the family to learn the values, preferences, and goals of care of the patient and family.
Impact of culture on end-of-life care	• Keep in mind the culture of the unit when giving end-of-life care. • Recommend privacy and space for the patient and family. • Manage the environment in a way that is conforming to federal and healthcare regulations, but is cognizant to the needs of the patient and family at end of life. • Build a culture of educated and experienced nurses in palliative and end-of-life care through engagement in education and certification.

Note. Based on information from Liaschenko et al., 2009.

provides a framework for use in ethical analysis and decision making (Hook & White, 2001). These provisions or statements speak to the nurse as an advocate for the patient. Therefore, ethical principles such as autonomy, beneficence, nonmaleficence, and justice should serve as a framework to assist in the delivery of health care (Simon, 2008). Autonomy pertains to the patient's ability to make his or her own decisions (Wainright & Gallagher, 2007) and to accept appropriate medical interventions. Healthcare professionals are obligated to provide full information in a way that a patient completely understands his or her treatments. If a patient lacks the capacity to decide for him or herself, a designated surrogate or proxy (usually a family member) will act on behalf of the patient to ensure that outcomes are with the patient's values or wishes (Gavrin, 2007).

Beneficence is the prevention of patient exposure to any risk or extra suffering, unless the benefits outweigh the risks (Wainwright & Gallagher, 2007). Practitioners must "provide care that maintains or improves health, reduces disability, and alleviates physical and existential pain and suffering" (Gavrin, 2007, p. S87). Nonmaleficence means to avoid inflicting mental or physical harm to patients (Ebbesen & Pedersen, 2007). Finally, justice refers to equal treatment of patients with the same medical need (Gavrin, 2007).

Decision Making: Living Will and Advance Directives

Advance directives are legal documents that express a patient's wishes about what his or her medical care should be if the patient is unable to communicate. The healthcare team must be well informed about these documents and have access to them. Although providers at all healthcare facilities are required to present advance directive information to their patients, 85%–95% of the U.S. population does not have an advance directive in place when entering the healthcare setting (Alfonso, 2009). However, studies do suggest a higher prevalence of advance directives in patients with cancer than in any other group (Joffee, Mello, Cook, & Lee, 2007).

In a study of 155 patients undergoing HCT by Joffee et al. (2007), 69% had designated a healthcare proxy, 44% had completed a living will, 61% had an estate will, and 63% had discussed their wishes regarding life support with family and friends. However, only 16% had discussed their wishes regarding life support with their clinicians, and only 39% had actual written advance directives in their charts. In addition, documentation of a discussion between patients and clinicians regarding the elements of ACP was rare (Joffee et al., 2007). ACP is not a one-time conversation; rather, multiple parties may be included in the ongoing process throughout treatment. Healthcare providers should consider the cultural, familial, and religious beliefs that may affect patient and family willingness to discuss EOL care and to participate in decision making

Exploration on the Go

Hematopoietic Stem Cell Transplantation: A Manual for Nursing Practice is available in e-book format. To access, open a barcode scanner on your smartphone, take a photo of the code, and your phone will link automatically. Or, visit http://ons.metapress.com/content/U3733L.

Professional Responsibility

The nurse, as a patient advocate, helps the patient and family make important end-of-life (EOL) care decisions and serves as a liaison between them and the healthcare team. Patients and families turn to nurses for information, options, and resources. A study by Cramer, McKorkle, Cherlin, Johnson-Hurzeler, and Bradley (2003) found that 50% of all nurses did not discuss hospice with terminally ill patients. Those who did discuss it had satisfactory experience with hospice or worked as oncology nurses.

Efficacy of Hospice

In the United States, Medicare and insurance agencies limit hospice to the last six months of life, which is a barrier to efficacy because death cannot be predicted accurately (Ferrell & Coyle 2005). Other barriers include lack of education and reluctance to disclose, discuss, or acknowledge a patient's impending death, because doing so is considered giving up on a patient. The highest-rated barrier is knowledge deficit, noted by 90% of the hospice staff and physicians in a study by Johnson and Slaninka (1999). Nurses with hospice training reported greater perceived role responsibility and comfort levels in initiating discussions about EOL issues (Cramer et al., 2003).

Clinician-Patient Communication

Bradley et al. (2000) found that nurses frequently did not initiate discussions on critical EOL issues, preferring that the medical staff do so, which could result in delays of hospice referrals and depriving many terminally ill patients and families of the benefits of hospice services.

FIGURE 1. Concepts That Can Help to Measure Clinicians' Attitudes About End-of-Life Care to Inform, Evaluate, and Improve Care of the Dying

(Bloomer, Tan, & Lee, 2010). Joffee et al. (2007) reported that younger patients, particularly those younger than age 40, were much less likely than older adult patients to have engaged in ACP, and many patients considering HCT neither discussed nor planned to talk about EOL contingencies with their clinicians because "frank discussion of EOL contingencies threatened the hope of cure that many patients invest in HCT" (p. 70). Given that patients undergoing HCT often become incapacitated (with as many as 40% dying within a year of HCT), healthcare providers should routinely discuss the subject with patients and family members to meet their needs.

Family participation in care and decision making also may provide families with a feeling of purpose and closeness to the patient (Bloomer et al., 2010). In addition, the emotional cost and burden for family members is high. Family members would benefit from knowing that their loved one's exact wishes were carried out (Alfonso, 2009).

Implications for Nursing Practice

Nurses are at the forefront in rendering optimal care in various stages of patient illness. When patients are given options about where to receive treatment, they often will seek their caregivers' or their medical practitioners' advice in EOL decision-making. Nurses, compared to other members of the healthcare team, have more interaction with patients who are facing death and are in a key position to provide support and to advocate for patients and their families in EOL decisions (Thacker, 2008). Trust that comes from truthful telling about

the patients' prognosis and treatment is an integral element of the nurse-patient relationship (Starzomski, 2009), and yet many nurses fail to advocate for their patients regarding EOL decisions because of fear that conflict may occur (Thacker, 2008). Healthcare personnel must be educated to help provide the needed patient support (Starzomski, 2009). A systematic review of 28 studies by Murray, Wilson, Kryworuchko, Stacey, and O'Conner (2009) indicated that nurses believe that supporting patients in their decision making is a vital component of patient-centered care, yet many nurses feel they lack the skills, confidence, and tools to help provide the needed support. Some studies also indicate that nurses believe that patients should be involved in making decisions about their care. However, nurses also indicated that they continue to be uncomfortable in discussing EOL care with patients, and the main learning need identified by oncology nurses is knowing how to talk with dying patients (Murray et al., 2009).

Although more patients die in a hospital than at home, many terminally ill patients and their families report dissatisfaction with EOL care (Moskowitz & Nelson, 1995). Rolland and Kalman (2007) found that a higher satisfaction with EOL care exists when healthcare efforts are focused on quality of life, which is the goal of hospice and palliative care. Unfortunately, few individuals benefit from this service because of delayed referrals (Rolland & Kalman, 2007). Rolland and Kalman (2007) showed that many patients were referred too late to use hospice services effectively because many patients died within one week of admission to hospice. Early referral to hospice or palliative care is imperative to improve dying patients' quality of life. Therefore, examining nurse attitudes about EOL care and their role in EOL care is imperative. Rolland and Kalman's (2007) research on measuring clinician attitudes about how EOL care can help inform patients of their situations, evaluate interventions, and improve care for the dying. This was based on three concepts: professional responsibility, efficacy of hospice, and clinician-patient communication (see Figure 1).

Nurse role in promoting self-care for patients: The nurse is the key healthcare professional to bring forth supported self-care. The issues described in clinical education, symptom-focused interventions, and preparation for death interventions could be addressed using minimal resources and time (Johnston et al., 2009). According to Johnston et al. (2009), self-care strategies for patients with advanced disease should be related to assisting patients with managing pain and other symptoms that impact their quality of life, such as adapting psychologically and emotionally to their illness and relieving distress associated with symptoms that cannot easily be altered. In addition, they suggested that future self-management programs should be planned for patients with advanced disease who are dealing with EOL care. Optimally, self-care in the future should be created from patient-initiated and patient- and family-centered evidence. Suggestions include adapting components of patient- and family-centered models of care to specific patient care populations through nurse and physician dyads, nursing council initiatives, and ethics and practice committees.

McCorkle et al.'s (2011) Chronic Care Model (CCM) characterizes the profile of effective communication between informed, motivated patients on the one hand and well-organized, dedicated healthcare provider teams on the other.

The CCM embodies the characteristics of a healthcare system that promotes high-quality care. These characteristics include six elements: assistance with self-management, planning of a delivery system, guidance with decision making, organization of clinical information, establishment of health care, and agencies of support from the community (Coleman, Austin, Brach, & Wagner, 2009; Wagner et al., 2001). Some oncology practices today include features of the early CCM, including a focus on more effective communication, organization of clinical information, guidance with decision making, and identifying support from the community to assist their patients and families with self-management skills.

Progress has been made in developing ways to help patients deal with cancer symptoms during the therapy stage of the cancer care continuum. Initiatives for self-management of physical symptoms and psychological distress have been a factor in this advancement. An immediate necessity exists to translate these self-management interventions into clinical practice. Few studies have evaluated the usefulness and advantage of self-management interventions during the post-treatment and EOL stages of the continuum. The studies recommend that

TABLE 2. The Six-Step SPIKES Protocol

Step	Action
1	Set up the interview by arranging privacy, involving the family, making a connection with the patient, and managing time constraints and interruptions.
2	Assess the patient's perception with open-ended questions to determine the understanding of his or her medical condition.
3	Determine the patient's readiness to receive full disclosure of illness. If a patient refuses to know the details, the clinician should convey to the patient that he or she can talk to other family members or is available to sit with the patient whenever ready.
4	Use words such as "I'm sorry to tell you . . ." to warn a patient of upcoming news and to decrease his or her shock. It also is vital to use simple, nontechnical words such as "spread," instead of "metastasized"; avoid too much bluntness; provide information in small portions; and continue to monitor the patient's understanding of his or her situation.
5	Address the patient's emotions with empathic responses. This involves four steps: observing a patient's emotions after hearing the bad news, identifying the emotions by using open-ended questions to validate what the patient is thinking or feeling, recognizing the explanation for the emotions, and informing the patient that the clinician understands his or her feelings.
6	Inquire of a strategy and summary for the patient to feel that his or her wishes are important. The oncologist should ask the patient about future plans and be willing to listen to the treatment plan. The decision making should be a joint responsibility between the clinician and the patient, and the clinician should make sure the patient understands all discussions to minimize misinterpretation of the purpose of treatments.

SPIKES—Set up interview, assess patient Perception, obtain patient Invitation, provide Knowledge to patient, address patient Emotions, and inquire about patient Strategy

Note. Based on information from Baile et al., 2000.

Case Study 1

Carol was receiving her morning IV medications when she told the nurse that she wanted to ask her something important. The nurse sat beside her, held her hand, and gave her full attention. Carol asked the nurse what she thought of her condition. This was a delicate question that needed to be addressed by the medical team; however, the nurse asked Carol what she specifically wanted to know. Carol responded that she was tired of the treatments. If she was not going to be cured, she would rather go back home (she lived in another state) so she could spend more time with her family. The nurse encouraged Carol to let her husband know how she felt and then, together, they could speak with the medical team and ask for different options of care. That was just what they did when the husband came to visit.

After spending some time with Carol, the husband came out of her room teary-eyed. The nurse took him to a private conference room where he revealed that he and Carol had decided to go home. The nurse informed the team and, with the family, discussed the details of Carol's care and transition to another facility. Different interdisciplinary teams were involved.

The nurse learned later from the husband how peaceful Carol was with the decision. The husband continued to be in touch with the nursing staff and they continued to support him in his grieving process.

the stage of the cancer care continuum directs the overall framework for patient and family decisions on how to manage their own care. For example, McCorkle et al. (2011) proposed that by using the CCM, oncology practice teams can become "practice homes" for their patients. In these homes, "proactive oncology practice teams can use the self-management interventions to enable and empower patients and families to care for themselves across the cancer care continuum in the way they prefer" (pp. 58–59).

Implications for Nursing Education

Clearly, an enormous need exists for more dialogue about ethical issues across disciplines. Nurses, in particular, frequently report that additional education is in critical demand in this area (McLennon, Uhrich, Lasiter, Chamness, & Helft, 2013). In response to this need, the American Association of Colleges of Nurses and the City of Hope National Medical Center partnered together to create the End-of-Life Nursing Education Consortium (ELNEC) program to provide nurses with training, information, and resources about EOL care. Similarly, the Respectful Death Model established an EOL curriculum for family practice residents that describes how to discuss death with patients and posits that EOL care should begin when the professional determines that a patient could die within a year (Wasserman, 2008).

Research suggests that communication skills can be taught. Baile et al. (2000) collected information at a 1998 national oncology meeting on communication skills aimed at delivering bad news to patients. Based on their results, they devised a six-step protocol represented by the SPIKES acronym (Set up interview, assess patient Perception, obtain patient Invitation, provide Knowledge to patient, address patient Emotions, and inquire about patient Strategy) that has been noted to increase practitioner confidence in their ability to disclose unfavorable

medical information to patients (see Table 2). Overall data suggest that patients want the amount of information they receive to be tailored to their preferences (Baile et al., 2000).

Mahon and McAuley (2010) proposed a critical need to equip nurses with extensive education and clinical experience in palliative care, something not routinely included in nursing and medical curriculums at present. Because the subject is poorly addressed in healthcare institutions and schools, a need exists to bring education to the workplace. Although education by itself is not likely to alter practice, valuable clinical resources combined with education efforts will help achieve much needed changes in practice.

Implications for Nursing Research

More research is needed to discover how changes in practice affect and are affected by barriers across individuals, practices, professions, and institutions. Dudgeon et al. (2008) suggested that two methods exist where more research is needed for supportive palliative care within a continuous quality improvement model: improving standards in oncology and initiating palliative care triggers that promote palliative care consultations.

More research also is needed regarding how patients cope with their illness at the EOL. Johnston et al. (2009) conducted a systematic literature review that revealed three main themes: interventions for EOL care, self-care behaviors used by patients, and factors that prevent patients from self-care. These authors

Case Study 2

Amelia was in her late 50s and was in the last stage of her life. The day nurse reported that the husband was so distressed about this that he asked if euthanasia was an option for patients. The husband expressed the family's desire to be present when she passed. In addition to the husband, the couple's grown children and two young grandchildren were present.

The nurse discussed with them the goals for Amelia's care: her comfort and the opportunity for each member of the family to be with her. Each had a story to tell. At this point, Amelia had tachypnea and was gargling with breathing. Suctioning had made her breathing better and eliminated the disturbing gargling sounds. However, she was unresponsive to touch but still had sucking reflex with moistened mouth sponges.

Helping take care of Amelia was important to the family, so they assisted the nurses in repositioning her in bed, changing linen, moistening her mouth, and massaging her feet. They recalled different events and experiences with Amelia amidst tears and laughter. They also shared her wishes regarding her funeral services and a desire to donate her body to research. Knowing this, the nurse realized why it was important for them to grieve and find closure. Because they were comfortable with the nurse being there, they were able to sleep inside the room. They were assured that they would be woken up if her condition worsened and a discussion took place with her husband about the different measures that could help alleviate Amelia's breathing difficulty.

Her family repeatedly thanked the nurse for everything and for helping to ease the suffering. The nurse also thanked them for the honor and privilege of being part of their journey during Amelia's last stage, and what a gift it was for her as well. The family seemed more at peace and were accepting of the dying process. Amelia died early in the morning of the next shift, "when the sun rose," the husband later said. She loved the sunrises. It was very meaningful to them—a sign of hope and new life.

Implications for Practice

▶ Offer support and serve as advocates for patients and their families to make important decisions on palliative and hospice care.

▶ Receive education and training to enhance comfort levels while discussing end-of-life issues with patients and their family members.

▶ Introduce advanced care planning and end-of-life issues with patients with cancer when they initially present for evaluation.

recommend that intervention studies be designed based on in-depth, theoretic-driven patient experience research to support patients and their families in coping with advanced disease. More research on the effectiveness of ACP and informed decisions in quality EOL care is needed. Other implications for nursing research include the distinction of focusing on managing self-care at EOL rather than on self-care in chronic illness, which may largely focus on the activities of individuals and families with the intention of enhancing health, limiting illness, and restoring health (Johnston et al., 2009). In addition, minimal research exists on complementary and alternative medicine (CAM) therapies at the end of life. Based on the popular use of CAM therapies in palliative and EOL care, and cancer in general, more research is needed in this area.

Conclusions

Although the concept of palliative care for patients undergoing HCT remains controversial to some healthcare providers, evidence indicates a need for changes in the direction of palliative care within this patient population. In summary, the literature reviewed supports several main tenets: a need for interprofessional education, acknowledgment that nurses should have increased autonomy and responsibilities as patient advocates, and a need for more multidisciplinary discussions to determine what barriers exist to prevent the use of current guidelines. More rigorous research is needed to evaluate beliefs and trends in this area of practice, particularly since research has indicated a reluctance on the part of HCPs to initiate EOL discussions.

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