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Palliative and End-of-Life Care: Precepts and Ethics for the Orthopaedic Population

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Abstract

Since the emergence of reports such as the National Consensus Project for Quality Palliative Care (2013) and the National Association of Orthopaedic Nurses Palliative Care Consensus Document (2005), there continues to be a growing recognition of the multiple adverse effects of serious illness and chronic conditions, as well as the potential benefits of receiving palliative or end-of-life care. As modern technology expands its ability to support life, ethical dilemmas may be encountered in the provision of palliative or end-of-life care. Through integration of the precepts of palliative care and consideration of the relevant ethical principles, orthopaedic nurses may best meet their patients' comprehensive needs at an exceedingly difficult time.

Orthopaedic nurses care for individuals with many serious illnesses and chronic conditions. Advanced osteoporosis, arthritis, Parkinson's

disease, malignancies, and muscular dystrophy all impact an individual's functional status and quality of life (Watters, Harvey, Meehan, & Schoenly, 2005). Hip fractures from any number of underlying conditions, with a 1-year mortality rate of up to 35%, exact a significant toll on functional capacity, quality of life, and costs (National Association of Orthopaedic Nurses [NAON], 2005). Since the emergence of reports such as the National Consensus Project for Quality Palliative Care (2013) and the NAON Palliative Care Consensus Document (2005), there continues to be a growing recognition of the multiple adverse effects of serious illness and chronic conditions, as well as the potential benefits of receiving palliative care. The purpose of this study was to review the tenets and ethical principles guiding palliative and end-of-life care and examine their relevance in the care of orthopaedic patients facing the diagnosis of a chronic, life-threatening, or life-limiting condition.

Palliative Care

Palliative care is a philosophy, as well as a clearly identified system for delivering patient care that prioritizes quality of life for the patient and family, optimal level of function, assistance with the decision-making process, and opportunities for individual growth throughout the illness trajectory (National Consensus Project for Quality Palliative Care, 2013). This care is provided at any time point in the disease trajectory; optimally, palliative care should be initiated when an individual is diagnosed with a serious, life-threatening, or life-altering disease. Primary palliative care, which employs skills and competencies expected of all healthcare providers, is an approach to care that involves the integration of palliative care principles into relevant aspects of any patient's care. Secondary palliative care is specialized care and consultation by specialist clinicians who provide consultation and specialty care, while tertiary palliative care involves care provided at tertiary medical centers where specialists' knowledge of the most complex cases is researched, taught, and practiced (Weissman & Meier, 2011). Definitive improvements in the quality of care and healthcare cost savings have been associated with the provision of palliative care (Center to Advance Palliative Care, 2010).

Palliative care is both the science and the art of preventing, managing, and relieving physical, psychosocial, emotional, and

spiritual suffering through impeccable assessment and treatment, while focusing on cure, prolonging quality life, or easing the pain of bereavement (National Hospice and Palliative Care Organization, 2001; World Health Organization, 2013). Goals include enhancing the quality of life, increasing the effectiveness of communication with the patient and family, restoring function, and maximizing respect for an individual's cultural and spiritual values and beliefs (NAON, 2005). The patient and the family are viewed as one entity at the center of care, and palliative care is considered appropriate even when cure remains a distinct possibility (Himmelstein, Hilden, Boldt, & Weissman, 2004). Together, the interdisciplinary team, made up of occupational therapists, physical therapists, psychologists, social workers, nurses, and chaplains, strives to provide care to best address the patient's and family's needs, values, and preferences (Zahradnik, 2013). Composition of this interdisciplinary team may vary with time, depending on the patient's and family's needs. The team, working in collaboration with the patient and family, facilitates the achievement of redefined goals as either the illness progresses or the patient finds a cure (Waldman & Wolfe, 2013).

Hope is integral to the practice of palliative care, regardless of the patient's prognosis. Words must be carefully chosen to instill hope, allowing for comfort and better quality of life for patients and their families, while still being realistic and acknowledging the typical trajectory of the illness at hand (O'Shea & Bennett-Kanarek, 2013). While patients and families express their wishes to receive honest information, hope provides an essential way of coping with tragedy and allows them to look forward to realistic, redefined goals even as a disease progresses (Bergstraesser, 2013). Effective communication is a key aspect of palliative care to form a true partnership between the patient, family, and healthcare team. In addition to providing hope, providers must assess patients' and families' knowledge and understanding of the illness, anticipated efficacy of treatment, and the plan for management of symptoms. Effective communication between the healthcare team and the patient allows the patient's values, beliefs, and wishes to be identified and respected, for these may vary greatly from one individual to another (Cozier & Hancock, 2012). An important aspect of communication is listening, the most important gift that a palliative healthcare provider can give to a patient, for it fosters an environment conducive to trust and the sharing of

thoughts, fears, and feelings (O'Shea & Bennett-Kanarek, 2013). In addition, the critical attributes of quality of life from the perspective of the individual are important to consider in the provision of palliative care. These attributes include an individual's subjective evaluation of the nature of their lives, satisfaction with the physical, psychological, social, and spiritual domains, and objective measures of a successful life. The physical domain includes health and physical functioning, with the psychological domain focused on emotional and spiritual well-being, satisfaction with life, and a sense of fulfillment. Relationships with others, a sense of belonging, and social roles are included in the social domain. Individuals' assessments of objective measures, such as housing, finances, and level of education, also play a part in evaluation of the overall quality of one's life (Mandzuk & McMillan, 2005). Through the collaborative work of an interdisciplinary palliative care team, each of these areas should be addressed in the provision of comprehensive palliative care to ensure that needs are met and quality of life is maximized throughout the duration of the illness.

Nurses providing palliative care must serve as advocates to promote the best interest of patients, for many individuals and families may be vulnerable due to a lack of knowledge or capacity (Benner, 2003). To provide quality palliative care that holistically addresses patients' comprehensive needs, nurses require specialized skills, including the ability to listen, communicate, manage physical symptoms, provide expert care, and educate patients and families (Watters et al., 2005). Advocating for patients is a responsibility and a privilege of all nurses, and it is especially relevant in the field of pediatrics, where nurses may serve as the voice of their young patients to best express their needs, wishes, and intentions (Sanford, 2012). Despite the importance of advocacy, this nursing responsibility is not always fulfilled. Studies have found that many nurses have opinions regarding ethical issues at the end of life but may not become involved in these ethical issues for reasons including uncertainty about appropriate actions (Beckstrand, Callister, & Kirchoff, 2006; Erlen & Sereika, 1997). These studies indicate the importance of empowering nurses with knowledge of how to best manage ethical issues in patient care so they are prepared to advocate for their patients who are facing life-threatening or chronic illnesses.

End-of-Life Care

As modern technology expands its horizons and abilities to support life, the importance of balancing medical technology with humanistic care to enable individuals to experience a peaceful death becomes increasingly clear. In contrast to palliative care, which may be delivered alongside curative treatment, end-of-life care involves applying the concepts of palliative care to patients with advanced, chronic, life-threatening illness who may have 1–2 years or less left to live ([Ferrell & Coyle, 2010](#)). There are many dimensions that must be considered in the provision of end-of-life care, including individualizing the plan of care, focusing on individuality and dignity, and maximizing quality of life through effective pain and symptom management ([Hendrickson & McCorkle, 2008](#)). A focus on symptom control and quality of life serves to ease suffering, allowing the dying individual to address psychological and spiritual concerns. In a peaceful end-of-life experience, death occurs with dignity and minimal distress ([Yang & Lai, 2012](#)). Individuals are more likely to find peace at the end of life when their symptoms and suffering are controlled and they have found joy and meaning in their lives' accomplishments, relationships, and experiences. A peaceful end-of-life experience is a priority not only for the dying individual but also for the health of the family and loved ones, for the manner by which an individual dies will live with the family and loved ones forever ([Yang & Lai, 2012](#)). Care must continue for surviving family members through the offering of support, counseling, bereavement services, and acknowledgment of the value of their loved one's life through memorial services, anniversary cards, or phone calls.

Ethics in Palliative and End-of-Life Care

Ethical dilemmas encountered in the care of chronically or terminally ill patients are inevitable, complex, and challenging. Bioethics, or applied ethics that revolves around healthcare questions related to basic human rights, involves a process of identifying the best course of action from available options. Ethical decision-making may be complicated by patients' and families' lack of understanding about the diagnosis, prognosis, or treatment options or by healthcare professionals' lack of knowledge about palliative care options or patient's goals, values, and beliefs. Decision making in the face of

moral dilemmas is built around a guiding framework of four moral principles: justice, respect for persons, nonmaleficence, and beneficence (Rushton, 2009). Conscious use of basic ethical principles can assist nurses to make decisions that provide optimal treatment for every patient. Justice is the provision of comprehensive and equivalent care for every individual. This principle is violated when treatments are withheld or not administered solely on the basis of an individual's race, age, sex, or religion (Grace, 2009). There has been growth in recent years in the availability of palliative care, with 81% of hospitals with 300 or more beds and 70% of not-for-profit hospitals with 50 or more beds offering a palliative care program (Center to Advance Palliative Care, 2010). As these numbers continue to increase, the ethical principle of justice is supported, allowing more patients in need to have equivocal access to the comprehensive services offered by an interdisciplinary palliative care team. Respect for persons involves honoring an individual's goals, values, and inherent dignity. This ethical principle addresses an individual's autonomy or rights to self-determination. Autonomy involves identifying and honoring a patient, or in the case of a pediatric patient, a parent's preference for treatment, and this ethical principle is addressed in the first provision of the American Nurses Association (ANA) Code of Ethics (2001): each decisional individual or parent of a child under the age of 18 years has the right to determine what is to happen to their body or their child's body, as long as the decision is in their best interest. Each patient also has the right of informed consent to facilitate informed decision-making (ANA, 2001). Respect for persons also encompasses the right to privacy: individuals have a right to confidentiality, and nurses must protect this right (Grace, 2009). Veracity involves the duty of healthcare professionals to be truthful, for knowledge may relieve the fear of the unknown. Nonmaleficence is the ethical concept that directs action to do the least harm or to remove causes of harm, while beneficence involves acting to benefit a patient and to maximize the individual's best interests (Rosenblum, 2005). Knowledge and personal reflection on these guiding ethical principles are vital when faced with ethical dilemmas in providing palliative or end-of-life care.

Ethical Dilemmas: The Decision-Making Process

Nurses' care must follow the ideals and moral norms of the profession of nursing, and it is these ideals that have come to define the meaning of being a nurse ([ANA, 2001](#)). In some situations in which a nurse is providing palliative or end-of-life care, the optimal response and actions may be unclear. [Jonsen, Siegler, and Winslade \(2006\)](#) developed a bioethical tool, the "4 Squares" Model, to guide the healthcare professional through the decision-making process in difficult cases. The authors identify four concepts that are inherent to every clinical encounter. By focusing interdisciplinary team discussions around these four concepts, facts surrounding a complicated case at hand may be better organized. The concepts include medical indications, patient preferences, quality of life, and contextual features. Medical indications include a review of the diagnosis, treatment options, risks, and benefits, as well as probable outcomes of treatment. Patient preferences identify the patient's values, goals, and wishes, and also include the patient's assessment of benefits and burdens from the potential treatment. Quality of life reflects the concept that all interventions should improve or maintain the quality of life for the individual. Contextual features identify the wider context and the conditions specific to an individual case; these features include the family's wishes, cultural values, religious values, social issues, the law, hospital policy, and conscientious objection by providers. Each of the four concepts is considered equally important in the decision-making process. This method requires interdisciplinary involvement and excellent communication with the patient and family to delineate clear goals of care to guide the provision of palliative or end-of-life care ([Jonsen et al., 2006](#)).

How Do We Best Identify Which Actions Will Provide the Greatest Benefit for Patients?

In addition to considering ethical principles, professional guidelines such as the ANA Code of Ethics, and decision-making tools, it is important for nurses to reflect on their own values and beliefs, as well as come to the realization that these personal opinions are not always the same as the values and beliefs of patients and their families (Kline, 2005). In determining how to proceed in providing palliative or end-of-life care to an individual, it is vitally important to address the patient's goals and wishes, for hope of attaining these goals may provide a dying patient and their family with something to look forward to once the hope for cure is gone. These smaller goals or accomplishments often involve relationships with friends or family. For example, relationships with family and friends provide protection, care, and comfort to the child with cancer at the end of life and serve as a source of love, compassion, distraction, and support (Monterosso & Kristjanson, 2008). In my work with children with cancer at the end of life, I saw firsthand the importance of attaining personal goals when I visited a young man who was dying of progressive osteosarcoma. He had two important goals to attend to before his life was done: he wanted to attend the opening night of the movie "Hunger Games" with his friends and make a trip to his aunt's house for a rib dinner with all of his cousins. After discussions of the potential risks and benefits with his healthcare team, he decided to undergo a thoracentesis to combat his worsening dyspnea in hopes that he could attain these last goals. Fortunately, the temporary improvement in his respiratory status that resulted from the procedure allowed him to attend these events that meant so much to him and to his family. In this case, a palliative procedure had a great positive effect on this young man's emotional well-being, for he was smiling ear-to-ear the last time I saw him, for he was leaving that afternoon to enjoy one last outing with the companionship of his closest friends.

Ethical Dilemmas Encountered in Palliative and End-of-Life Care

Withdrawal or Withholding of Treatment

Recent advancements in research and technology have led to better health outcomes and the improved ability to prolong life (O'Brien, Duffy, & O'Shea, 2010). As a result, a failure of these advancements to cure a loved one is often unexpected. The decision-making process regarding the withdrawal or the withholding of treatment is difficult and often full of emotion. In the process of withholding or withdrawing treatment, extraordinary means are not utilized for the support of life if it is decided that the intervention is simply prolonging death (Porter, Johnson, & Warren, 2005). Withdrawal of treatment may occur with a comprehensive decision to stop many treatments at once or may occur more gradually as specific treatments are slowly discontinued in a patient with a terminal or chronic illness. Withholding or withdrawal of treatment allows for the disease to naturally progress; the action of withdrawing or withholding treatment does not directly cause the patient's death. There is no ethical distinction between withdrawing and withholding of treatment (Russell & Williams, 2010). The most commonly identified causes for the withdrawal or withholding of treatment are patient choice, unacceptable quality of life, unacceptable level of benefit from the considered medical intervention, as well as anticipated prolongation of the dying process (Laporte-Matzo, Witt-Sherman, Nelson-Marten, Rhome, & Grant, 2004).

Withholding or withdrawing treatment is considered ethically acceptable in certain cases, even though it may seem to conflict with the role of the nurse as a caregiver (Holmes, 2010). The courts have consistently decided that it is ethically and legally acceptable for life-sustaining treatment to be discontinued if this care is considered medically futile (Roberts et al., 2004). Medically futile care cannot, with reasonable certainty, improve a patient's status or restore an acceptable quality of life (Porter et al., 2005). Care that is deemed futile results in a prolongation of suffering and fails to improve a patient's quality of life. To protect patient autonomy, the Patient Self-Determination Act was implemented in 1991 to ensure the legal rights

of individuals to make healthcare decisions about treatments that affect their own bodies ([Porter et al., 2005](#)). The ANA indicates that honoring a patient's refusal of a nonbeneficial or burdensome treatment is ethically required ([ANA, 2010](#)). In fact, for some dying patients, withholding or withdrawing treatment may have benefit. For example, withdrawal or withholding of fluids in a patient who is at the end of life results in dehydration; dehydration at the end of life is known to have analgesic and anesthetic effects ([Blakely & Millward, 2007](#)). In contrast, the provision of parenteral fluids during the dying process may cause fluid overload and aspiration pneumonia, which results in additional patient suffering and distress for the patient's loved ones ([Holmes, 2010](#)).

While withholding or withdrawing treatment may be ethically acceptable in certain circumstances, patients may, at times, choose to continue treatment that may be identified by healthcare professionals as futile. These decisions may be based on a lack of understanding of the current illness and prognosis or a belief that dignity results from battling for life until the time of death ([Volker & Limerick, 2007](#)). Physical or psychological benefits may be obtained by continuing futile treatment in certain circumstances. These treatments may allow a patient to become spiritually or emotionally ready to die, for example. Benefits may also be seen for the patient's loved ones, for life-sustaining treatments may allow time for family members to say good-bye to the dying individual. A time-limited trial of a life-sustaining intervention may allow for reevaluation at a later time to truly identify if there are any unforeseen benefits to a life-sustaining treatment for a dying patient ([Laporte-Matzo et al., 2004](#)).

The goals of care identified by the patient or a decision-making surrogate guide discussions between nurses and patients regarding withdrawal or withholding of treatment. Each treatment should be evaluated individually to determine the likelihood that the treatment will meet with the patient's expressed values and beliefs and assist the patient to achieve future goals ([Lo, 2009](#)). Anticipated comfort or alleviation of suffering must also be assessed. The ethical principles of nonmaleficence and beneficence are upheld by determining the benefits of each specific intervention and identifying if any harm will result from that intervention. By ensuring that all patients are treated

fairly and justly with equal access to these medical interventions, the ethical principle of justice is addressed, as well ([Holmes, 2010](#)).

Do-Not-Resuscitate Status

Another ethical dilemma that nurses may face in providing palliative and end-of-life care surrounds a patient's resuscitation status and their advance directives. The Patient Self-Determination Act supports the right of patients to refuse life-sustaining treatment, and this right includes the ability to refuse cardiopulmonary resuscitation (CPR) ([Morrell, Qi, & Helft, 2008](#)). Patients, as well as the general public, overestimate the efficacy and outcomes of CPR. In severe illness, it is most likely that CPR will prolong dying, rather than maintain life. When CPR is utilized in patients on a general inpatient hospital unit, 86% of these patients will die. Survival is even lower in patients with metastatic cancer, sepsis, or kidney failure ([Lo, 2009](#)). Mechanical ventilation is often required after CPR, and outcomes for those who survive may include a persistent vegetative state or permanent brain damage ([Schroeter, Derse, Junkerman, & Schneidermayer, 2002](#)).

Patients who suffer from terminal or chronic illnesses may hope to die peacefully and may request a do-not-resuscitate (DNR) order. A DNR order necessitates that a patient or his or her decision-making surrogate identifies the specific interventions that will not be initiated in case of a cardiopulmonary arrest. Discussions about DNR status must include a review of patient preferences regarding mechanical ventilation and treatment of health conditions such as infection, heart arrhythmias, hypotension, and hematologic abnormalities ([Lo, 2009](#)). Healthcare providers may erroneously think that patients do not want to discuss the option of DNR status; they may fear that a patient will lose hope and become depressed or suicidal ([Lo, 2009](#)). To the contrary, it is important for healthcare professionals to discuss the option of DNR status early before the disease progresses so a patient is capable of making an informed decision, thereby protecting the patient's autonomy ([Schroeter et al., 2002](#)). It is imperative that the healthcare professional provides accurate, understandable information to ensure that the patient or the decision-making surrogate is fully informed of medical status and prognosis during discussions about DNR status. Recommendations and reassurance should be provided to the patient or family that comfort care will still continue ([Lo, 2009](#)).

Discussions should be repeated as the disease progresses to ensure that the principles of nonmaleficence and beneficence are revisited as the patient's condition changes.

A nurse's ethical obligations are to the patient. When advance directives are appropriately in place and a patient's wishes have been repeatedly addressed as a disease progresses, the appropriate actions in resuscitative attempts are more straightforward. Unfortunately, this is not always the case in the care of patients requiring end-of-life care. Most families wish for a peaceful death for their loved one, but others may believe that it is of the utmost importance to fight until the end. Most importantly, CPR should never be performed if it is against the best interests of the patient or if it causes the patient to suffer. In these cases, judgment must determine the appropriate length and intensity of any resuscitation efforts (Truog, 2010).

Pain Control

In addition to withdrawal/withholding of treatment and do-not-resuscitate status, pain control may be at the center of ethical dilemmas in patients who are receiving palliative or end-of-life care. Nurses must understand that pain is not only a physiologic response in a patient with a chronic or life-threatening illness; it is a reflection of psychological, spiritual, and social health or suffering, as well. Nurses must possess knowledge, first and foremost, to provide the best management of pain for individuals receiving palliative or end-of-life care, and this knowledge is obtained by keeping up to date with the latest research and evidence-based practices. It is vital for nurses to possess knowledge of means to manage side effects of medications to ensure the patient's overall comfort. Knowledge must include the fact that opioid addiction is rare, and fear of addiction should not prevent any healthcare provider from utilizing an appropriate dosage to alleviate suffering (Schroeter et al., 2002). Nurses must be prepared not only with knowledge of the appropriate drugs and dosing intervals but also with the skills necessary to assess factors that contribute to the patient's underlying distress. Assessment must also include religious or cultural factors that may affect the decision-making process regarding care or make certain options unacceptable to the patient or family. Through effective communication and listening to the voices of their patients regarding goals, wishes, and

desires, nurses respect patient autonomy. By ensuring aggressive control of pain in patients with chronic and life-threatening illnesses, nurses fulfill their responsibility to care for the best interest of the patient as a whole, for uncontrolled pain may affect the individual's physical, psychological, social, and spiritual well-being.

As a result of the many challenges that may be faced when providing palliative or end-of-life care, additional research, educational support for nurses, and development of care models are imperative to strengthen the evidence base. It is often difficult to study the effect of only one variable in this population, for patients who are receiving palliative or end-of-life care are often facing a multitude of pharmacologic and pathologic variables. Well-controlled and well-powered studies are needed regarding both new and existing approaches to treat chronically and terminally ill patients with the most common symptoms, including pain. The lack of scientific evidence and research at the end of life results in wide variance in practice from one healthcare professional to another. In addition, it is important to continue to publish case reports to disseminate knowledge of new and innovative methods of providing palliative and end-of-life care.

Palliative Care in Orthopaedic Nursing

The Last Acts: Precepts of Palliative Care was developed by the Last Acts Task Force on Palliative Care in 1997 to identify the core components of effective palliative care ([Last Acts Task Force, 1997](#)). This comprehensive report serves as the core of the NAON Palliative Care Consensus Document, delineating palliative care requirements in the orthopaedic population, as well as the commitment of orthopaedic nurses to the principles of palliative care ([NAON, 2005](#)). Key principles of the document address the diverse palliative care needs of orthopaedic patients with debilitating or life-threatening conditions. For example, respecting patient goals, preferences, and choices is vital if care is to be patient centered in the context of the family and the community. This focus is best achieved through attention to patients' values and priorities, as well as acknowledgment of their spiritual and cultural beliefs. Patients' understanding of their diagnosis and prognosis should be facilitated through effective communication and informed consent. Symptoms, including physical, psychological,

social, and spiritual suffering, should be expertly managed by the palliative care team. Patient relationships should be supported to alleviate isolation, and communication should be ongoing to assist with life review and to enhance personal growth. Support should also be extended to the family in their bereavement ([NAON, 2005](#)).

The NAON Palliative Care Consensus Document identifies the interdisciplinary resources that should be utilized to address the multidimensional aspects of palliative care. The document also places focus on addressing caregiver concerns and providing support due to the intense demands placed on individuals caring for a loved one who is chronically ill or dying. This support includes the provision of concrete services including respite, expert support by phone 24 hours a day, grief counseling, and identification of community resources. Finally, the document addresses the importance of organizational support of palliative care, as well as the establishment of policies and procedures to guide the provision of care. An infrastructure must be in place to promote the philosophy and practice of palliative care as well as research-based standards, guidelines, and outcome measures ([NAON, 2005](#)). In addition to the NAON Palliative Care Consensus Document, there are additional palliative care resources available for orthopaedic nurses, as listed in [Table 1](#).

Conclusion

It is vital for orthopaedic nurses to be aware of the palliative care needs of patients with chronic, life-threatening, or life-limiting conditions in their practice settings and to advocate for them in interactions with the interdisciplinary team to ensure that the philosophy of palliative care is followed. As a result, the quality of care for patients with musculoskeletal conditions can be dramatically improved, resulting in an environment that fosters healing, growth, and, optimally, peace at the end of life. As members of multidisciplinary teams caring for chronically ill and dying patients, orthopaedic nurses must reflect on the ethical principles of justice, respect for persons, beneficence, and nonmaleficence; communicate skillfully to identify patients' goals, values, and wishes; and examine the guidelines of professional nursing organizations when faced with ethical dilemmas in the provision of palliative and end-of-life care. In

addition, reflection on one's own opinions, values, and beliefs will allow nurses to best assist patients to make well-informed, ethical decisions that best meet their needs at an exceedingly difficult time.

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Table 1. Palliative Care Resources

	Website
<i>General organizations</i>	
American Academy of Hospice and Palliative Medicine	www.aahpm.org
Center for the Advancement of Palliative Care	www.capc.org
Duke Center for Spirituality, Theology, and Health	www.spiritualityandhealth.duke.edu
Duke Institute on Care at the End of Life	www.iceol.duke.edu
Education in Palliative and End-of-Life Care: EPEC Curricula	www.epec.net
ELNEC project	www.aacn.nche.edu
End-of-Life Palliative Education Resource Center	www.eperc.mcw.edu
Harvard Medical School Center for Palliative Care	www.hms.harvard.edu/pallcare/
Hospice and Palliative Nurses Association	www.hpna.org
Innovations in End-of-life Care (Last Acts online journal)	www2.edc.org/lastacts/
Journal of Hospice and Palliative Nursing	journals.hww.com/jhpn/
Last Acts	www.nwjl.org/content/nwjl/en.html
National Consensus Project for Quality Palliative Care	www.nationalconsensusproject.org
National Hospice and Palliative Care Organization (NHPCO)	www.nhpco.org
Journal of Palliative Medicine	journals.lww.com/jhpn/
Robert J. Wood End-of-Life Physician Education Resource center	www.eperc.mcw.edu
<i>Pediatric organizations</i>	
Children's Project on Palliative/Hospice Services and the National Hospice and Palliative Care Organization (CHPPS/NHPCO) Standards for Pediatric Palliative and Hospice Care	www.nhpco.org/resources/pediatric-hospice-and-palliative-care
ELNEC Pediatric Curriculum	www.aacn.nche.edu
Initiative for Pediatric Palliative Care curriculum	www.ippcweb.org