Providing a “Good Death” for Oncology Patients During the Final Hours of Life in the Intensive Care Unit

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ABSTRACT

Cancer is a leading cause of death in the United States. Aggressiveness of cancer care continues to rise in parallel with scientific discoveries in the treatment of a variety of malignancies. As a result, patients with cancer often require care in intensive care units (ICUs). Although growth in hospice and palliative care programs has occurred nationwide, access to these programs varies by geographic region and hospital type. Thus, critical care nurses may be caring for patients with cancer during the final hours of life in the ICU without the support of palliative care experts. This article provides an overview of the meaning of the final hours of life for cancer patients and uses principles of a “good death” and the tenets of hospice care to organize recommendations for critical care nurses for providing high quality end-of-life care to patients with cancer in the ICU.

Keywords: “good death,” hospice, intensive care unit, oncology

Although overall cancer-related death rates have steadily declined since 1992, cancer remains the second cause of death after heart disease and accounts for approximately 1 of every 4 deaths in the United States. Evidence from Medicare data demonstrates that aggressiveness of cancer care continues to rise, with an increase in the proportion of patients receiving chemotherapy within 14 days of death and delays in hospice admissions. The Medicare Hospice Benefit aims to provide health care coverage for persons whose survival is predicted to be less than 6 months, but the median length of stay in hospice has remained consistent at approximately 20 days for the last 3 years. Data from 6 states revealed that 33% of intensive care unit (ICU) deaths were patients with metastatic cancer. In addition, in a study of 342 patient and caregiver dyads, Wright and colleagues found that patients with advanced cancer who die in the hospital or ICU have lower quality of life (QOL) ratings and their informal caregivers are at increased risk for psychiatric illness compared with patients who die at home or with hospice services. According to its authors, this study was the first to demonstrate that experiencing the death of a loved one with cancer in an ICU setting can lead to symptoms of posttraumatic stress disorder. The...
critical care nurse cares for critically ill patients with cancer and their families during a time when these trends are converging and resources may be limited for providing quality end-of-life (EOL) care.

One potential strategy for improving EOL care in the ICU is to integrate palliative care more fully or earlier in the ICU course. Palliative care focuses on effective pain and symptom management and incorporation of psychosocial and spiritual needs into the patient and family’s plan of care, with the goal of preventing and relieving suffering for patients with life-threatening or debilitating illnesses, regardless of the stage of disease. Efforts to integrate palliative care into ICU care include providing ICU clinicians with training through the End-of-Life Nursing Education Consortium and Education for Physicians on End-of-Life Care, and access to a hospital-based palliative care consult service. The Improving Palliative Care in the ICU Project recently published a review of the 2 main models of providing palliative care in the ICU. The consultative model consists of palliative care consultants who provide recommendations for caring for patients in the ICU, whereas the integrative model involves embedding palliative care principles into daily practices of the ICU team.

Although integration of palliative care has the potential to reduce the number of patients with cancer dying in the ICU, much of the growth in palliative care programs has occurred in large academic medical centers, and critical care nurses who work in smaller for-profit or community hospitals may not have access to palliative care programs. Although palliative care programs have grown tremendously in the past decade, with increasing evidence of their effectiveness in improving quality and length of life, many patients with cancer are not being managed by palliative care experts at the EOL. Experienced critical care nurses need the knowledge and skills to provide quality EOL care for patients with cancer and to preserve a good memory of the final hours for family members.

The aim of this article is to provide guidance to nurses who are caring for oncology patients and their families during the final hours of life in the ICU setting, using the tenets of a “good death” described by Kehl as an organizing framework for recommendations. These tenets are derived from Kehl’s extensive review of the literature, but there is individual variation among patients and families with regard to what a “good death” entails, based on their respective goals, values, and customs. This article will also review the context and meaning of EOL in the oncology population and discuss common barriers to providing a “good death” in the ICU. In addition, this article aims to summarize the principles of hospice care and provide recommendations for addressing spiritual, existential, psychosocial, and physical needs at EOL, facilitating communication, fostering positive coping for family members and health care providers, and promoting system change. Lastly, specific interventions that critical care nurses can implement will be listed in accordance with current guidelines for providing EOL care in the ICU.

Conceptual Framework

Kehl’s concept analysis of a “good death” serves as the guiding framework for this article. Kehl’s extensive review of the literature identified the following attributes of a “good death”: being in control, being comfortable, having a sense of closure, having trust in care providers, recognizing the impending death, and leaving a legacy. Kehl also specified the importance of minimizing burden, optimizing relationships, affirming/recognizing the value of the dying person, honoring beliefs and values, caring for family, and acknowledging the level of appropriateness of the death (eg, whether the dying person is young or the death is unexpected). Kehl also presented elements of each attribute that are important to take into consideration when caring for the dying patient.

Context and Meaning of EOL Care in the Oncology Population

There is no empirical evidence that EOL care needs are different in the oncology population than in patients with other terminal diagnoses. However, there are important characteristics specific to the context and meaning of the transition from curative care to EOL care in the oncology population. These characteristics include the societal and family expectations of cure, use of metaphors that liken cancer to a battle, providers’ discomfort with prognostication and EOL discussions, and the existence of well-formed, often longstanding relationships with oncology providers. Each characteristic is described here, with the
goal of increasing critical care nurses’ awareness and understanding of how the context and meaning of EOL care may affect the final hours of life for oncology patients and their families.

Expectations of Cure
More often than not, cure is the main goal and expectation of patients, families, oncologists and other clinicians, and society as a whole when a person is diagnosed with cancer. Even in the setting of advanced disease, scientific advancements in the treatment of cancer, such as the discovery of monoclonal antibodies, immunotherapies, and other oral chemotherapy agents, have created a norm in which there is almost always another treatment or combination of treatments to offer the patient with cancer. The reader is referred to the companion article in this symposium by Beatty and colleagues for a full discussion of the biologic basis of current cancer treatments. Although the goal of treatment may have shifted to control or stabilization of the disease, many patients perceive all treatments as cure directed. Although the ideal is simultaneous disease treatment and palliative care from the time of diagnosis, the concept of needing to transition away from cancer treatment to focus on more palliative-oriented goals, such as comfort, aggressive pain management, or a peaceful death at home, may seem like “giving up” to many patients with cancer.

Continued clinical research and scientific development toward finding a cure for cancer provides opportunities for patients to participate in clinical trials. Sulmasy and colleagues conducted a qualitative study of 45 patients that investigated patients’ reasons for enrolling in an early-phase clinical trial for cancer, and they found that patients described optimism and hope—but also societal, provider, and family expectations to maintain hope—as main drivers of their decision to enroll in clinical trials, and thus not to “give up” hope. Sulmasy et al also described the language patients used that likened cancer treatment to being in a battle or a fight and that not enrolling in a clinical trial was equated to losing the battle or giving in to the fight. Similarly, altruism played a role in patients’ decisions to enroll in clinical trials, such that “individual battles are part of a greater battle by society against cancer.”

Cancer as a Battle
Thus, there is a sense from patients with cancer that not accepting treatment is congruent with giving up hope and optimism in their fight against the disease, as well as giving up on their family’s and society’s expectations that they will “soldier on.” The metaphor of cancer as a battle has strong implications for the patient with cancer who may be facing the reality that not only is there not a cure but that death may be imminent. The decision to stop treatment may be shocking to patients and families given the perception that there is always another treatment to consider. When the goals of care shift from cure to control and then to comfort, there may be a sense that all hope is lost and that cancer has won the battle. In the face of an illness crisis requiring critical care support, there is often very little time for patients and families to transition from a curative/treatment mind-set to newly adjusted goals and expectations that focus more on comfort, life closure, minimization of suffering, and a “good” or peaceful death. The ICU setting and the critical care nurse may be ill-equipped to meet the needs of patients and families during this rapid transition in goals.

Prognostication and EOL Discussions
Prognostication and EOL discussions take a great deal of time and skill to master. Without proper training and practice, providers often struggle with having prognosis and EOL discussions and may avoid them as a result. In a review by Campbell and colleagues, the authors reported that there is often a disconnect between the cancer patient’s desire for complete disclosure about prognosis and the oncologist’s comfort with fully communicating the terminal nature of the patient’s disease. Thus, cancer patients whose final hours are spent in the ICU may not be fully prepared or have adequate time to accept that their disease is terminal. Chaitin and colleagues note that oncologists’ prognoses are often inaccurate and tend to be overly optimistic. Because of this, the oncologists who were surveyed generally preferred not to disclose their estimates on prognosis. They reported that they were not confident in their prognostication abilities and viewed that maintaining hope was more important than providing less-than-accurate prognostic data. There is evidence of a similar trend in ICU physicians.
Mack and colleagues sought to measure the collaborative bond between oncologists and patients with cancer and found no evidence that EOL discussions diminished the bond. Oncologists who had close bonds with patients were as likely as those without close bonds to engage in EOL discussions. In addition, the authors reported greater existential well-being and emotional acceptance of terminal illness in patients who had a strong bond with their oncologist. This evidence can be used to encourage oncologists to seek out training in prognostication and to collaborate with palliative care providers, including nurses, social workers, and spiritual care providers, to ensure that prognosis and EOL discussions occur on an ongoing basis with patients and their families. As providers’ comfort and training with these discussions increase, patients and families will potentially be better equipped to incorporate this information into decisions about care, and the number of patients with cancer dying in the ICU may decrease. Until then, awareness of both the complex nature of societal pressure to fight the battle of cancer, and the skill level necessary for having effective prognosis and EOL discussions will help acute and critical care nurses better understand the context and meaning of EOL needs of oncology patients dying in the ICU, as well as the needs of these patients’ families.

Barriers to Providing EOL Care in the ICU

Some of the barriers to providing EOL care in the ICU setting include the mission, culture, and goal of the ICU, the physical environment of the ICU, and competing priorities for nurses’ time. The mission of ICU care is to help patients survive a life-threatening event while preserving or restoring QOL. Thus, death and ICU care seem by definition mutually exclusive. However, ICU admission often occurs as a therapeutic trial and requires a change in goals from restorative care to EOL care when that trial fails. When this occurs, the oncology patient and family in the ICU may be faced with the realities that cancer-specific treatment is no longer viable and that the problem for which the patient was admitted to the ICU is neither reversible nor survivable.

The ICU culture is influenced in part by the death-denying paradigm that exists in Western culture, which can make an ICU death extremely challenging for patients and families, especially when combined with clinicians’ discomfort with prognostication. Cook and colleagues succinctly summarized the modern American attitude toward death as being death denying, “consumerist,” or focused heavily on demand for all that health care technology offers, and rife with providers’ desire for heroism and thus prohibitive of conversations about death and dying. Rather than...
viewing death as natural, inevitable, expected, and perhaps imminent, the goal in the ICU is to prevent or delay death in every way. ICU care for critically ill cancer patients usually focuses on a goal of correcting or reversing a life-threatening event, thus broader goals of care may become a lower priority. Typically, ICU care is aimed at using technology to its fullest—or “doing”—to achieve physiologic goals and stability rather than focusing holistically on the patient's and family's goals and preferences. Therefore, making the transition from “doing” for the patient to “being” with the dying cancer patient and his or her family can be a challenge for the critical care nurse.

The open physical layout of most ICUs, though optimal for close monitoring of critically ill patients and quick access and reaction to emergent events, is certainly less than optimal for a quiet and peaceful death. Critical care nurses must understand this high-tech, low-touch setting and modify it to the extent possible, for the final hours of life of critically ill patients with cancer and their families. The life-saving technology in the ICU creates a noisy environment with alarms, intense lighting, fast-paced movements between and among patients, and verbal communication among clinicians that may be distressing. In addition, restrictive visiting hours, lack of space, and less privacy are challenging environmental factors in the ICU. An encouraging trend is adoption of more liberal ICU visiting hours, as recommended by accrediting bodies such as The Joint Commission.

Lastly, competing priorities for critical care nurses’ time create a barrier to EOL care in the ICU. A survey of 1400 critical care nurses identified several barriers to providing EOL care in the ICU, including having family members continually call the nurse for updates, which stopped the nurse from providing direct care; family members not understanding what lifesaving measures really meant; and nurses’ perceptions that physicians involved in caring for patients often disagreed about the goals of care. Another survey of nurses yielded similar results, with the addition of time constraints, lack of adequate staff, and the perspective that the dying patient is lower priority and is often assigned to a travel nurse or float nurse rather than being assigned 1-on-1 with a nurse who is highly skilled in providing EOL care.

Recommendations for Providing a “Good Death” in the ICU

Despite these barriers, critical care nurses play an integral role in helping cancer patients and families find closure and peace during the final hours of life. Nursing interventions during the final hours of life must optimize the time the patient has left and minimize distress to family members. The remainder of this article aims to serve as a guide for critical care nurses for providing a “good death” for oncology patients and their families in the ICU. Recommendations for doing so are organized by the following categories: tenets of hospice care, creating sacred spaces, spiritual/existential care, communication and psychosocial care, physical care, after death care, and system change/quality improvement (QI). Table 1 lists recommended nurse-led interventions, organized according to Kehl’s attributes and elements of a good death and the corresponding recommendations from the American College of Critical Care Medicine’s consensus statement for quality EOL care in the ICU.

Tenets of Hospice Care

The fundamental tenets of hospice care include an interprofessional approach, whole person care, and attention to the biopsychosocial and spiritual needs of the patient and family, all of which can be achieved in the ICU setting. Critical conversations and family discussions outlining and establishing goals of care are the cornerstone of care delivery as oncology patients live their final hours in the ICU setting. The goal of this care delivery is not to prolong life or hasten death, but to maximize QOL and promote a dignified death. By attending to physical symptoms, spiritual needs, psychological concerns, and communication issues, critical care nurses can extend these underlying core principles of hospice care into the ICU setting and apply them to the patient and family experience.

Another distinguishing characteristic of the hospice care delivery model is formal, ongoing bereavement support. Unfortunately, this service is not usually offered in the ICU setting unless a patient has been officially enrolled in a hospice benefit. As hospice care is patient- and family-centered care, this benefit allows surviving family members to receive formal bereavement follow-up for 1 year after the
Table 1: Recommendations for Nurse-Led Interventions, Organized by Kehl’s Attributes of a Good Death and American College of Critical Care Medicine Guidelines

<table>
<thead>
<tr>
<th>Attributes and Elements of a “Good Death” (based on patients’, families’, and providers’ perceptions)</th>
<th>American College of Critical Care Medicine Guideline20</th>
<th>Critical Care Nurse–Led Interventions</th>
</tr>
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<tbody>
<tr>
<td><strong>Being in control</strong></td>
<td>Initiate ongoing, direct communication at bedside and/or in formal family meetings, during which clinicians increase proportion of time listening to patient and family</td>
<td>Coordinate family meeting</td>
</tr>
<tr>
<td>Choices/wishes honored and communicated</td>
<td>Obtain clarity on goals of care by asking what the patient/family is hoping to achieve</td>
<td>Option for assisted suicide is legal in Oregon and Washington and requires that the patient has ability to take the medication27,28</td>
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<tr>
<td>Clear decision making</td>
<td>Provide prognosis information</td>
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<tr>
<td>Option for suicide/euthanasia</td>
<td>Discuss which goals are realistic to achieve and which interventions will help achieve them</td>
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<tr>
<td>Control over death (location, timing, presence or absence of others)</td>
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**Being comfortable**

| Lack of distress | Assess symptoms through family members25 | Convey to the family that priority has moved from hemodynamic stability to goal of comfort and dignity |
| Symptom management (physical: pain, dyspnea; emotional/psychosocial: fear, anxiety; cognitive: remaining mentally alert; spiritual distress) | When possible, assess pain through use of the Behavioral Pain Scale or the Pain Assessment Behavior Scale | Conduct symptom assessments at least every 1 to 2 hours |
| Comforting (hugging) | Assess dyspnea via behavioral correlates such as tachypnea, tachycardia, accessory muscle use, diaphragmatic breathing, nasal flaring, and fearful facial expression | Advocate for adequate symptom management, according to patient’s and family’s preferences |
| Hope | Use opioids, the recommended drug of choice, to treat pain and dyspnea in the dying patient | Minimize stimulation by dimming lights, moving the patient to a bed away from the nurses’ station, removing unnecessary equipment and lines |
| Managed to degree that patient wishes | See work by Truog and colleagues20 for full description of symptom assessment and treatment at end of life | Reassure family that the goal of morphine use is for symptom management, and that vigilant symptom assessment and appropriate titration will occur to minimize risk of hastening death29 |

**Sense of closure**

| Saying goodbye | Communicate openly with family about timing of death by using language that demonstrates “hoping for the best, preparing for the worst” | Coordinate with social worker regarding patient’s and family’s needs |
| Completion of unfinished business (work, family events, funeral arrangements; financial, legal affairs in order) | Be compassionate by honoring family’s hopes while also preparing them for possibility of death | Educate patient and family on what to expect during the final hours |
| Preparation for death | | Remind family that hearing remains present longer than other senses and encourage them to continue talking to or reading to the patient and playing music, if preferred25,26 |
| Communication of words of healing and affirmation31-34 | | |

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<td>Affirmation or value of dying person recognized</td>
<td>Attempt to understand who the patient is as a person</td>
<td>Assess patient’s needs from a holistic perspective</td>
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<tr>
<td>Dignity</td>
<td>Tailor interventions accordingly</td>
<td>Assess for rituals before final hours to prepare for patient’s individual preferences</td>
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<tr>
<td>Being a whole person with physical, emotional, social, spiritual needs</td>
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<tr>
<td>Quality of life, living fully</td>
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<tr>
<td>Individuality</td>
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<tr>
<td>Living until one dies</td>
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<tr>
<td>Trust in care providers</td>
<td>Conduct regular interprofessional team rounds</td>
<td>Communicate with oncology team and PCP upon patient’s admission to ICU</td>
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<tr>
<td>Access to care</td>
<td>Prepare with interprofessional team members in advance of family meetings</td>
<td>Invite oncology team to family meetings</td>
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<tr>
<td>Good communication among providers and with family</td>
<td>Consult palliative care and ethics teams as needed</td>
<td>Provide updates to other providers as needed throughout ICU stay and during final hours</td>
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<tr>
<td>Care providers are those who know patient well, serve as patient advocates, and are nonjudgmental about patient/family decisions</td>
<td>Promote an ICU culture that supports principles of effective communication</td>
<td>Contact oncology providers and PCP upon death</td>
</tr>
<tr>
<td>Recognition of impending death</td>
<td>Focus on appropriate word choice and use layperson terms, eg, “breathing pattern near death” rather than “agonal respirations”</td>
<td>Be present and available to the family after withdrawal of life-sustaining treatments</td>
</tr>
<tr>
<td>Awareness</td>
<td></td>
<td>Explain that exact time of death is difficult to predict, but that symptoms will be controlled and death typically occurs within minutes to hours after withdrawal of mechanical ventilation</td>
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<td>Acceptance</td>
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<tr>
<td>Beliefs and values honored</td>
<td>Ask about the patient and family’s spiritual beliefs and needs</td>
<td>Elicit patient and family’s values, cultural practices</td>
</tr>
<tr>
<td>Honoring beliefs, values, practices of personal, cultural, spiritual nature</td>
<td>Make an effort to distinguish between spirituality and religion</td>
<td>Work to assist family in carrying out any practices they wish to conduct at the bedside</td>
</tr>
<tr>
<td>Desires different from dominant culture are honored</td>
<td>Remember that spiritual assessment is not the sole responsibility of chaplains, but rather all critical care clinicians</td>
<td>Verbally recognize that patients and families experience the final hours in their own unique way and form their own unique meaning from the experience</td>
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<td>Burden minimized</td>
<td>Minimizing burden on family</td>
<td>Listen to and value family input</td>
</tr>
<tr>
<td>Freedom from financial burden</td>
<td>Support family’s emotions</td>
<td>Explicitly recognize and directly support family’s decisions</td>
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<tr>
<td>Independence on part of patient</td>
<td></td>
<td>Encourage family to rotate visitation and take breaks to eat and sleep</td>
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**Relationships optimized**

- Having enough time and communication with family and friends
- Reconciliation
- Forgiveness, gratitude, and love
- Good social support from family, friends, and community

- Recognize that some family members may wish to be present during resuscitation, invasive procedures, or withdrawal of them
- Provide a quiet space, free from technology and alarms
- Encourage family to maximize time with patient, especially if/when the patient is lucid
- Discuss turning off sedative medications to promote increase in patient’s level of consciousness, if aligned with goals of care

**Appropriateness of death**

- Age
- Terminal disease state
- Appropriate use of technology and medical interventions

- Make an effort to communicate that life-sustaining treatments may be withdrawn, but care itself is not being withdrawn and the patient and family will not be abandoned
- Continue to discuss whether specific treatments and drugs will contribute to or take away from the goal of comfort
- Be aware of the level of “appropriateness” of the death, such as the age of the patient, length of time since diagnosis, and whether the patient and family were aware of the terminal nature of the cancer diagnosis
- Focus on benefit/burden and goals of care when making decisions about interventions
- Discuss the meaning of the circumstances around the patient’s death with family members. Ask family to tell the story of the patient’s illness, if they are willing
- Provide empathy and emotional support

**Leaving a legacy**

- Being remembered and contributing to others, especially for elders
- Leaving behind emotional, physical, financial, or social legacy

- Create “get to know you” posters on the unit
- Use materials such as hand molds, journals, quilts, and music to facilitate leaving a legacy
- Arrange for the music therapist to assist with making a CD of the patient’s favorite music
- Honor patients after they die by observing a moment of silence or reading a prayer or poem together

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<td>Family care</td>
<td>Recognize that a large proportion of ICU patients are unable to make their own decisions because of illness or sedation</td>
<td>Elicit family members’ preferences for being present for withdrawal of technology, such as mechanical ventilation, and for the actual death</td>
</tr>
<tr>
<td>Family choose level of involvement in care of dying person and in death</td>
<td>Ensure that shared decision making occurs among clinicians and family members and/or health-care proxy, guardian, or hospital ethics committee</td>
<td>Ask family members if they would like to be involved in the physical care of their loved one (washing face, turning and repositioning, etc) and whether they would like to bring personal items from home (blankets, toiletries, etc)</td>
</tr>
<tr>
<td>Family as care recipients</td>
<td></td>
<td>Provide privacy but remain in visual contact so that family can ask questions as needed</td>
</tr>
<tr>
<td>Preparation of family for death</td>
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<td>Focus on symptom management, promote comfort, and provide a peaceful environment, which may help family members perceive the death as a good one</td>
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<td></td>
<td></td>
<td>Offer for family members to lie with or hold their loved one in bed</td>
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*Creating “get to know you posters” may include asking the patient’s family to bring in photos, artwork, poetry, or other artifacts important to the patient. These posters are an opportunity for the staff to get to know the patient and what is important to him or her. The posters can also include a note from the patient about what he or she wanted to achieve during life.*

Abbreviations: ICU, intensive care unit; PCP, primary care provider.

death of the loved one. Therefore, the ICU team should pay particular attention to the anticipatory grief needs of the family members and/or family unit to ensure proper referral for grief and bereavement support resources.

**Creating Sacred Spaces**

A good death is a *sacred* act. When goals of care shift from one of aggressive treatments to more comfort-oriented care, a shift of environmental space is also warranted. Hospice care is usually provided in patients’ homes or in another home-like setting, such as a nursing home or residential hospice. A striking contrast exists between the characteristics of these home-like environments and those of the high technology environment of the ICU. When it is not possible or there is not enough time to transfer a patient out of the ICU, critical care nurses must know how to create a calm, peaceful, more home-like environment within the ICU setting.

However, this can be very challenging due to space limitations and lack of open access to the ICU. Nurses play a central role in helping to create this space. Following are suggestions that may allow for a home-like environment in the ICU setting: moving the bed to the area of the unit farthest away from high traffic areas, reassuring the family that the relocation does not mean abandonment, but rather privacy and comfort; dimming lights and playing the patient’s favorite music or involving a music therapist from the hospital to play a favorite instrument; displaying pictures of special memories or people in the patient’s life; and encouraging the family and significant others to share important messages in a calm, therapeutic tone of voice. In turn, this environment may set the tone for health care providers to
increase their skills in recognizing patient and family concerns as well as to communicate effectively. By creating this space, it allows our own humanity to touch the humanity of another. 42

Spiritual/Existential Care
Researchers across the country have begun to understand the influence of spirituality on health-related outcomes and how spiritual and religious needs influence care decisions in serious illness. Phelps and colleagues43 interviewed 345 advanced cancer patients over 6 years in 7 tertiary care centers representing multiple geographical locations within the United States. This study, known as the “Coping With Cancer Study,” sought to determine the support of spiritual needs by the medical system and the religious community, the relationship between spiritual support and QOL, and the relationship of religiousness and spirituality to treatment preferences at the EOL. Spiritual needs of these patients were minimally or not at all supported by both the religious community and the medical system (47% and 72%, respectively) and higher levels of religiousness were associated with wanting all measures to extend life, particularly in the African American and Hispanic populations. Lower rates of advanced care planning among minority patients may arise in part from spiritual appraisals of illness and healing; for example, the belief that there will be a divine miracle and that only God knows one’s time to die. To better understand this phenomenon, Balboni and colleagues44 observed the earlier-referenced patients until their death. They concluded that patients whose spiritual needs were largely or completely supported by the medical and spiritual community received more hospice care and had higher QOL scores near death. In fact, high religious coping, or patients whose spiritual needs were largely or completely supported, were more likely to receive hospice level of care and less likely to receive aggressive and life-prolonging care than patients whose spiritual needs were not supported.

Although there has been a growing body of literature, as well as attention from the press about the role of spirituality in health care, these data have illuminated the critical need to address an area of human care that is often neglected and simply ignored—the gap between the provision of spiritual care from the community and the provision of medical care to patients with serious illness. Unfortunately, there are critical issues concerning who should deliver the care, the role of the health care provider, and the appropriate application of spiritual care in advanced illness. A 2009 white paper, 45 “Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference,” attempted to address these issues. The premise of the article was that spiritual care is a fundamental component of quality palliative care and that providing spiritual care is within the purview of everyone involved in the care of the patient with serious illness and his or her family. In addition to collaborating with spiritual care providers and chaplains, ICU nurses caring for patients during the final hours of life are encouraged to use this white paper as a resource for providing spiritual care at the EOL.

Communication and Psychosocial Care
Because nurses are present at the bedside 24 hours a day, they need expert communication skills, compassionate presence, and therapeutic listening to develop relational bonds with the patient and family. Berry and Griffie24(p630) describe 4 characteristics of the nurse’s approach to patients and families that are essential to providing care during the final hours: empathy, or putting oneself in the other’s place and setting aside one’s own biases; unconditional positive regard, or nonjudgmental acceptance and respect; genuineness, or being real, trustworthy, and open rather than using a professional façade, as well as admitting to one’s own limitations and inability to have all the answers; and attention to detail, which includes critical thinking, avoiding making assumptions, and being aware of how one’s actions and words will be interpreted by others. Nurse-led interventions during the final hours should be centered on communication that incorporates these 4 characteristics. Specific areas of communication that are important to consider during the final hours are described below and include a shift from “doing” to “being,” family dynamics, responses to family’s questions, and continuous goals of care discussions.

During the final hours, critical care nurses need to shift from a mind-set of “doing” to a mind-set of “being” to meet the EOL care needs of patients. 23 A first step in making this shift that may be helpful is to conduct a self-reflection on one’s own comfort level with contemplating and discussing death and one’s
<table>
<thead>
<tr>
<th>Questions</th>
<th>Recommended Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>When will my family member die?</td>
<td>It is difficult to predict exactly when a person will take his or her last breath. We encourage people to call any loved ones who would like to see the patient and to say a final goodbye when they leave, in case their loved one dies before they return to the hospital. Sometimes patients wait for specific family or friends to visit or sometimes wait for everyone to leave.</td>
</tr>
<tr>
<td>Is my family member thirsty/hungry? Is he/she going to starve to death?</td>
<td>We know from research that patients often stop eating and drinking as part of the natural process as they near death. We also know that providing artificial nutrition and intravenous fluids may cause discomfort. We do provide food and water orally for comfort if the patient is awake enough to do so and asks for it or if we think it will improve comfort. The cause of death will be the natural course of disease, not dehydration or starvation.</td>
</tr>
<tr>
<td>Is the oxygen necessary?</td>
<td>It is important to discuss the benefit versus the burden that the oxygen is posing to your family member at this time. If you think your family member is more comfortable with the oxygen on, we can keep it on, but it may not be necessary to keep it in place at this point, especially if it is causing your family member discomfort.</td>
</tr>
<tr>
<td>My family member’s breathing is loud and gurgling. Is it painful? Is he or she choking?</td>
<td>This congestion is normal at the end of life. We can elevate the head of the bed, do some gentle suctioning of the mouth, and administer a drug that will help dry up some of the secretions. This symptom tends to be more uncomfortable to us as observers than to the patient.</td>
</tr>
<tr>
<td>Can you just give my family member something to “end it”?</td>
<td>Legally and ethically, I am unable to do this. But what I can do with the rest of the interprofessional team is work to relieve your loved one’s pain and suffering and to help him/her die comfortably and with dignity.</td>
</tr>
<tr>
<td>Will giving my family member morphine hasten his or her death?</td>
<td>When we administer pain medications and other therapies, our intent is to relieve unnecessary suffering, pain, and other symptoms—not to hasten death.</td>
</tr>
<tr>
<td>My family member seems to be improving today compared with yesterday. Does this mean he/she is getting better?</td>
<td>As your family member continues to take in less fluid, we expect the swelling to go down in his/her body, especially around any tumors he/she has and in the lungs—he/she therefore breathes a little more easily and his/her pain decreases. These are temporary improvements that we expect and we encourage you to spend time with your loved one during this time of relief of symptoms.</td>
</tr>
<tr>
<td>My grandfather died of cancer years ago and it was horrible to watch him suffer. Will my grandmother also die like that?</td>
<td>We will do everything we can to make your grandmother comfortable and we have a variety of medications and techniques available to help relieve her pain. We will check on your grandmother frequently to ensure that she is comfortable. If you perceive that your family member is experiencing discomfort, please let me know and we will work to provide her with relief.</td>
</tr>
</tbody>
</table>
own acceptance of the inevitable nature of death. By directly facing the uncertainties and discomforts of dealing with death, clinicians are better equipped to engage in honest, direct conversations with patients and families at the EOL and thereby provide compassionate, respectful, and effective care.

**Family Dynamics**

“Family” should be thought of, in broad terms, as the people patients depend on for social, economic, and psychological support, which often includes close friends and coworkers. Family members are often the surrogate decision makers for patients in the ICU who can no longer communicate their own wishes. Adult children often become primary caregivers and take on the role of “parenting” their parents, which can be a difficult and emotional role reversal. Recent, long-standing, or unresolved family issues may resurface. It is important for the nurse to be sensitive to family dynamics that may arise, to be nonjudgmental in his or her approach to conflict, and to maintain clear, consistent communication with family members about the patient’s status. Prendergast and Puntillo recommend that clinicians “anticipate that some family members may respond with anger, emotional outbursts, or temporary inconsolable grief.” Other aspects of family dynamics that the nurse should seek to understand are the family structure and hierarchy, past and negative experiences with the health care system, and the fact that grief may include denial and false hopes, guilt and fear of letting go, depression and passivity, an inability to make decisions, anger, and/or irritability.

These emotional reactions can be complicated by the context of a long course of cancer treatment, which may include guilt or anger related to life choices, such as the patient with lung cancer who has a history of smoking. Many persons with cancer spend time focusing on leaving a legacy or creating something to leave behind, such as music, poetry, stories, or doing something they always wanted to do such as plant a garden or build a porch. Thus, during the final hours in the ICU, patients and their families may be facing the devastating reality that not only their hopes for a cure but also their ideas for leaving a legacy will not be fulfilled.

The critical care nurse at the bedside is the most likely team member to face family members’ questions, especially during the emotionally charged period when goals are shifting to EOL care. These questions arise from the complex interactions of the 4 domains of QOL at EOL: physical, psychological, social, and spiritual needs of the dying person. Skilled and empathic communication and honest answers are critical. Nurses’ skills vary in finding the right words to sensitively deliver responses to families’ questions and concerns. Some recommended responses to family members’ questions commonly asked at the EOL are provided in Table 2 as a resource for nurses responding to families of critically ill patients with cancer at the EOL.

**Continuous Goals of Care Discussions**

As previously mentioned, the dying patient in the ICU usually is not able to speak for himself or herself during the final hours of life because of high severity of illness, sedative medications, intubation, or other factors and as a result families often serve as surrogate decision makers in the ICU setting. A recent systematic review synthesized the findings of multiple randomized controlled trials that tested interventions designed to improve communication between ICU providers and families of adult patients. The researchers concluded that “the evidence supports the use of printed information and structured communication by the usual ICU team, ethics consultation, or palliative care consultation to improve family emotional outcomes and to reduce ICU length of stay and treatment intensity.” Other recommendations for decision making include using a consensus approach through family meetings, with the aim of establishing goals of care and continually revising goals as needed. Attendees at family meetings should include the patient’s family decision makers, physician or provider, critical care nurse, chaplain, and social worker. One of the most important parts of the meeting is to start by asking what the family members’ understanding of the patient’s status is and what the family would like to know, followed by more listening than talking on the part of the health care team members. Content of the discussion should include a review of the patient’s current symptoms and comfort level, options for alleviating symptoms, pros and cons of each option, and a prognostic estimate. Questions and concerns from family members should be elicited so that confusion...
or misunderstandings can be corrected. The plan for symptom relief should be verbally conveyed to the family at the end of the meeting, along with an offer to meet again when needed.

During the final hours of life for the cancer patient in the ICU, the nurse’s presence and communication skills take on primary importance. This switch in priorities can be challenging for the nurse, who must be mindful of the need to discuss this shift with families and colleagues. The rationale for activities such as monitoring vital signs should be discussed. If the goals of care no longer include intervening when changes in blood pressure or oxygen saturation occur, monitoring of these vital signs is no longer necessary. Traditional assessment of vital signs can be replaced with the nurse’s skilled assessment of comfort and symptoms, which may include assessment of pain, respiratory rate, level of dyspnea, amount of oral secretions, fever, and others that are aligned with goals of care. Rather than automatic withdrawal of all medical treatments, the nurse must base his or her care on a discussion of the expected benefit compared with the potential burden for administration of intravenous fluids, antibiotics and other medications, renal dialysis, deactivation of implantable cardioverter defibrillators, and oxygen.

If not already involved in the patient’s care, the palliative care service is an excellent resource for critical care nurses in providing recommendations for quality EOL care. Social workers and spiritual care providers can assist in goals of care discussions, social/emotional therapeutic interventions, and ongoing spiritual care assessments. Pharmacists may also be helpful in assisting with symptom management recommendations. Lastly, consulting hospice and accessing their services can be extremely valuable to both family members and clinicians, even if there is not enough time to transfer the patient out of the ICU.

**Physical Care**

Many critically ill patients will experience pain and other symptoms at some point during their ICU experience, so expert management and swift abatement are paramount. Although nurses and other interprofessional team members play a vital role in the management of physical pain and symptoms throughout the entire ICU admission, care provided in the hours before death is arguably the most critical and memorable in the family’s eyes. This is a crucial time to actively involve the family in the care of the patient, if they prefer. The following recommendations for physical care of the patient with cancer dying in the ICU are organized by family involvement, pain and symptom management, withdrawal of life-sustaining treatments, signs and symptoms of approaching death, care of the body after death, and care of the family and health care providers after death.

**Family Involvement**

The critical care nurse plays a key role in supporting family involvement in the physical care of the dying cancer patient. First, the nurse must assess the family’s personal, cultural, and/or ethnic preferences for providing physical care of the patient. Ideally, this assessment is conducted before the active dying phase so the nurse allows time to obtain the resources needed for EOL rituals. Second, it may be difficult for family members to become closely involved in caring for their loved one after days or weeks of being at a distance due to the patient’s acuity level, amount of technology attached to the patient and around the bedside, and/or the need for protective isolation clothing in the setting of multiple drug-resistant infections. The nurse will need to remove these barriers, physically or figuratively, and invite the family to resume normal relations with the dying patient, including physical care activities, if this is important to the family members. In the dying critically ill patient with cancer there is no evidence to support the optimal removal of protective isolation, and therefore, the nurse must use judgment that is consistent with institutional policy and meets the needs of the patient and family at the EOL. It should be noted that encouraging family involvement in care of the patient’s body can serve as a means for the family to feel useful and less helpless during the final hours.

Third, the nurse should ask the family if they would like to participate in activities such as washing the patient’s face and hands, combing his or her hair, applying lotion, and providing mouth care. If the patient is spontaneously breathing during the final hours, the nurse can show family members how to roll washcloths or towels and place them under the patient’s chin to provide support to the patient’s mouth as level of consciousness decreases. Fourth, family members should be encouraged to
Morphine is typically administered intra-venously by continuous infusion in the ICU setting, in adult doses ranging from 2 to 10 mg, depending in part on whether the patient is opioid naive or not. One hundred mcg of fentanyl and 1.5 to 2 mg of hydromorphone are approximate equivalent intravenous doses to 10 mg of morphine, but it is important to remember that onset and duration of each drug varies. Dosages and rates of continuous infusions are determined by weight and when the decision occurs to increase a continuous infusion of an opioid to relieve symptoms, bolus doses should be administered as well to prevent delays in symptom relief. Consultation with palliative care specialists and/or prescribers familiar with initiation and titration of opioids is advised to ensure maximum comfort. Although critical care and advanced practice nurses are experts at assessing and monitoring pain and dyspnea, concerns may arise about whether opioids hasten death. Clinically, careful monitoring can alleviate such concerns, as sedation precedes respiratory depression from opioids. In addition, morally and legally, death that is hastened from the use of opioids at the EOL for the purpose of symptom relief is deemed acceptable by virtue of the “double effect” phenomenon. Double effect means that the use of opioids for the purpose of avoiding suffering or distress may also have the additional effect of hastening death, which is acceptable because the intent of administering the opioids is to provide comfort, not to cause death. The principle of double effect provides moral guidance to the nurse’s role in administering medications that relieve distress and discomfort in the dying patient.

In addition to pain and dyspnea, the critical care nurse will encounter other frequent symptoms or physical changes during the final hours of life of the critically ill patient with cancer. If the patient has excess secretions, the nurse can advocate for decreasing intravenous fluids and gently suction these secretions from the oropharynx as needed and/or administer anticholinergic medications, such as atropine, glycopyrrolate (Robinul), or scopolamine. Repositioning the patient onto his or her side with the head of the bed elevated may discourage secretions from pooling in the back of the throat and causing “death rattle.” Haloperidol (Haldol) may be administered for restless or delirious, benzodiazepines for anxiety, and an antipyretic for fever. Typical adult dosing of haloperidol is 0.5 to 20 mg intravenously.
and of lorazepam is 1 to 3 mg intravenously, every 2 to 4 hours, for both drugs.  

**Withdrawal of Life-Sustaining Treatment**

The path leading to the decision to withdraw life-sustaining treatments in the critically ill patient with cancer can be a long and overwhelming one, especially because the patient has typically lost decisional capacity, thus putting family members in the position of being proxy decision makers. The critical care nurse plays a pivotal role in both the decision-making process and the actual withdrawal. When the shared decision occurs that continuing life-sustaining treatments is either no longer consistent with the patient’s preferences and/or the burden of such treatments outweighs the benefit, any and all treatments considered life sustaining, such as blood products, hemodialysis or continuous renal replacement therapy, vasopressors, mechanical ventilation, total parenteral nutrition, antibiotics, and artificial hydration and nutrition, may be withdrawn or withheld. These decisions are influenced by the patient’s religious, spiritual, cultural, and social values.  

Families may have grown accustomed to continuous monitoring of vital signs, regular blood draws, specific laboratory values, and other diagnostic tests. Again, the critical care nurse plays the key role in sensitively explaining to the family that the focus is no longer on the machines, bedside monitors, or vital signs, but on comfort. The nurse should explain to the family that turning off monitors in the room may be helpful way to create a more soothing, home-like environment, while also being sensitive to the fact that the family may be attached to watching the monitors and may not be immediately amenable to this recommendation. On the basis of the nurse’s assessment of the family’s needs in preparation for the death, the nurse can explain what to expect, in general, after withdrawal of various treatments. These discussions may help the family focus more attention on watching their treatments. These discussions may help the family be prepared for the dying experience for the family and loved ones.

Terminal weaning of mechanical ventilation is common at EOL and may include leaving the endotracheal tube in place if the patient cannot support his or her airway. As a result, dyspnea, air hunger, and discomfort should be anticipated. Terminal weaning with removal of the endotracheal tube, which helps to facilitate closer contact with family members, may occur if clinicians have confidence that the patient will be able to maintain his or her airway, or the dyspnea can be adequately managed with opioids. The critical care nurse must ensure that a plan, with adequate orders for appropriate medications, is in place to manage air hunger and respiratory distress, if it occurs. Authors of 2 recent reviews of the literature on the topic of terminal weaning concluded that more research is needed in this area in order to develop consensus guidelines and reduce geographic variation in practice. In the absence of strong evidence and consensus guidelines, the recommended practice for withdrawal of mechanical ventilation is to conduct a preliminary assessment of the patient’s symptoms and comfort, identify the likelihood that the patient’s airway will be maintained after extubation, make a decision about premedication needs and plans for full removal of the endotracheal tube, share the plan with the family and describe what can be expected throughout the process, and continually reassess the patient for symptoms and comfort and the family for distress. For example, the nurse should assess for symptoms such as the presence of tachypnea, tachycardia, accessory muscle use, restlessness, nasal flaring, grunting, and fearful facial expression, and treat symptoms with opioids and/or benzodiazepines using the “start low and go slow” philosophy, titrating up as needed. A brief interruption of sedatives may also be warranted for meaningful communicative interactions to occur between the family members and the patient. The goal is relief of symptoms and can be elicited in the form of family’s perceptions of their loved one’s comfort level.

It is important to discuss with family members that death tends to occur within minutes to hours after withdrawal of mechanical ventilation. Although studies have shown that there is no significant correlation between analgesia use and length of survival after withdrawal of mechanical ventilation, it is important to recognize that there may be a gray area between palliation and hastening death because patients are typically close to death before ventilation is withdrawn. Open communication with family members and clear documentation of these discussions, the patients’
symptoms, interventions initiated to promote their relief, and the outcome of the interventions is an important nursing role in the setting of withdrawal of mechanical ventilation.

After the Death
Family members may be interested in participating in postmortem care alone or with assistance from nurses and patient care assistants on the basis of their personal, cultural, or ethnic preferences. Again, the nurse is strongly encouraged to assess these preferences before the death occurs whenever possible. Facilitating the organ donation process is an important role for the critical care nurse. However, patients are not eligible for organ donation if they have a current malignancy or an infectious disease, which excludes most oncology patients dying in the ICU. However some patients with cancer can donate corneas. Critical care nurses need to be aware of the institutional policies and state regulations that apply to organ donation in their settings.

Family members may have differing perceptions about whether the patient experienced a “good death” or not. Few studies have been conducted to determine the bereavement needs of families after the death of a loved one in the ICU setting. In the absence of strong evidence, one suggestion is for ICUs to incorporate some of the underlying principles of grief and bereavement programs formally offered by hospice programs, keeping in mind that not all family members will need formal bereavement counseling. Another suggestion is for critical care units to develop resource lists that identify formal bereavement programs offered in their community. In addition, follow-up phone calls can be made to family members at defined times (eg, at 1, 3, and 6 months) and, most importantly, at the 1-year anniversary of the loved one’s death. Memorial services may also be held annually to honor and remember those who have died, thereby allowing the critical care unit team to reconnect with the family.

Health-care professionals typically do not receive formal training on how to cope with death in the workplace and are often ill prepared to deal with the emotions of death and dying. It is important, therefore, for clinicians to have access to hospital chaplains, ethics committee members, and unit managers/leaders to help them debrief after caring for a dying patient and family. Symptoms of posttraumatic stress disorder, burnout, and moral distress may occur after providing EOL care. Unit-based rituals such as support groups, regular debriefings, access to spiritual or psychological specialists, or writing in journals to share thoughts and feelings about the loss of a patient may be helpful for processing grief and preventing burnout associated with unresolved distress after caring for dying patients.

A companion article in this symposium by Wiencek et al offers a discussion of moral distress and resources for critical care nurses who care for critically ill patients with cancer.

System Change/QI
Although the hospital system can enhance and support EOL care, it can also create barriers and challenges related to the delivery of care not only for cancer patients at EOL, but for all patients. System changes, in terms of institutional policies and organizational structures and processes, are often sought to overcome such barriers and challenges. For example, Beckstrand and Kirchhoff instituted a 3-step process when a patient was admitted to an ICU that included introducing the patient and family to unit procedures for accessing information about the patient’s status, giving the family an informational pamphlet about unit procedures, and letting the family know that the nurse will call a designated family member daily to provide an update on the patient’s condition. This system change resulted in fewer incoming calls to the unit from family members, increased family satisfaction with care, and an increase in families’ information needs being met.

Another example of system change is incorporating EOL needs for patients and families into staffing and nurse assignment decisions, but a lack of data on this topic is a barrier to identifying the best methods for implementing such a practice, and is an area for future research.

A great deal of research has been conducted on the topic of QI in the ICU, with EOL care being identified as an important area. Research in this area has moved from identifying EOL care domains and the related QI indicators specific to the ICU to testing QI interventions aimed at improving the quality of EOL care in the ICU. Curtis and colleagues’ recent randomized controlled trial of an intervention that involved educating ICU clinicians on incorporating palliative care principles into their practice did not result in any improvement in patient or nurse outcomes.
The study provides evidence that palliative care delivered in an integrative model may be less effective than a consultative model, especially if clinicians are trained by individuals outside their facility: such outside training resulted in less institutional buy-in and “uptake” of the intervention in their study.51

Additional research in the area of system change and QI specific to EOL care in the ICU is needed. Acute and critical care nurses are integral to such research. The prospect of conducting QI and/or research may seem overwhelming, and therefore forming a committee with the support of the unit manager and other hospital leaders, such as the quality management department, may be useful. Nurses who want to improve EOL care in a specific ICU can consider conducting a QI project—such as creating a brochure with photos of staff, phone numbers, and communication procedures for families—as a feasible starting point that engages the team and potentially demonstrates improvements in patient and family satisfaction.

Conclusion
The final hours of life for the oncology patient in the ICU can be an emotional and overwhelming experience for patients and families, yet this is an opportunity for experienced critical care nurses to demonstrate skilled and compassionate care for patients at a sacred time as they make their final life’s transition and for families who will carry the memory of those final hours with them. Critical care nurses play a key role in ensuring that patients experience a “good death” in the ICU and in promoting an environment of shared decision making and effective interprofessional communication that minimizes distress for families.

This article describes the context and meaning of the transition from curative to EOL care for oncology patients and families, summarizes the tenets of hospice care and current evidence-based guidelines for EOL care in the ICU, and provides a list of recommendations for interventions nurses can implement while caring for patients at the bedside during the final hours. Areas for future research include identifying whether differences exist in cancer patients’ EOL experiences compared with other patients in the ICU, promoting consistency in withdrawal of mechanical ventilation practices across settings, and identifying additional system changes and QI interventions that improve the quality of EOL care for patients in the ICU.

REFERENCES


