End-of-Life Issues in Critically Ill Cancer Patients

Susan Gaeta, MD*, Kristen J. Price, MD

“To cure sometimes, to relieve often, to comfort always”
15th Century French proverb

Over the past decade, the probability of surviving an admission to the ICU for a cancer patient has improved. This trend can be attributed to three factors. First, improvement in the treatment of solid tumors and hematological malignancies has led to a 20% overall decrease in mortality from 1978 to 1998. Second, earlier admission to the ICU has resulted in better survival rates. Third, there has been some improvement in selecting patients likely to benefit from ICU admission.1

Despite the above factors, some critically ill cancer patients will die during a hospital admission that includes an ICU admission. A review of an epidemiologic study demonstrated that one in five patients will die during a hospitalization that included an ICU admission.2 This number includes all patients, not just cancer patients, and does not necessarily indicate a death in the ICU. One may conclude that this percentage may be higher or lower depending on the type of ICU—medical, surgical, open or closed, rural or urban, and their respective admission criteria for cancer patients. Most of the deaths in the ICU will follow withholding or withdrawing of life support.3

Before discussing end-of-life issues in critically ill cancer patients it is beneficial to review those factors or barriers that may lead to a greater probability of death in a critically ill cancer patient admitted to the ICU.

ADMISSION CRITERIA TO ICU AND TRANSITIONING TO PALLIATION AFTER A TRIAL OF AGGRESSIVE SUPPORT

The first factor to consider is the criteria used in determining admission of a cancer patient to an ICU. The criteria may vary depending on the type of hospital: community,
tertiary, or a comprehensive cancer center. In general, most physicians will admit cancer patients to the ICU if their condition is medically reversible, but will not admit cancer patients with only palliative care treatment options. However, a great deal of variation exists between these two admission options. This variation can, in part, be explained by the uncertainty of the reversibility of the condition. Thus, some cancer patients are admitted to the ICU with the intent to give a trial of aggressive support.

The timing of the transition from cure to palliation after a trial of aggressive support is seemingly straightforward; however, this decision is delayed at times for different reasons. Depending on the type of ICU administrative model—closed, semi-closed, or open—the intensivist’s role may be that of a consultant to the primary oncologist and he or she may not be willing to discuss end-of-life issues. In a survey of oncologists attending a meeting of the American Society of Clinical Oncology, 18% of the respondents stated that they would have a discussion about do-not-resuscitate (DNR) orders “a few days or few hours before the patient’s death.” Based on these findings, approximately one in five oncologists potentially may not discuss DNR status until after the patient has had a cardiac arrest or has been on life support for some time. On the other hand, when the ICU is a closed unit with the intensivist serving as the primary attending, he or she may feel that it is not his or her role to discuss end-of-life issues. Also changing from one intensivist to another affects the timing of the decision because of varying viewpoints and approaches between intensivists.

USE OF ADVANCE DIRECTIVES IN CRITICALLY ILL CANCER PATIENTS

Confounding the decision of when to transition from intensive care to palliation is the lack of patients’ advance directives as to when to limit or withhold aggressive support. The Patient Self Determination Act (PSDA) signed into law on November 5, 1990, and effective December 1, 1991, was to have addressed the increased use of advance directives. The law was in response to the US Supreme Court case Cruzan v Director, Missouri Department of Health and Human Services. In brief, Ms Cruzan was a 26-year-old who was rendered comatose after a motor vehicle accident in 1983. In 1986, after not recovering and remaining in a persistent vegetated state, her parents asked that artificial nutrition be stopped. However, the Missouri State Hospital insisted that a court order was needed to stop enteral feeding. The trial court ruled to stop enteral feeding, but the Missouri Supreme Court reversed the lower court’s ruling. Subsequently, in 1990, the US Supreme Court reviewed the Missouri Supreme Court ruling and upheld the ruling in regard to incompetent patients, but also added that competent patients would be allowed to refuse unwanted medical treatment. Furthermore, in incompetent patients, like Nancy Cruzan, the US Supreme Court allowed individual states to determine requirements for surrogate decision making regarding withdrawal of life-sustaining therapy. In response to this ruling, Senator Danforth of Missouri sponsored the PSDA.

The purpose of the PSDA was to give patients the right to make decisions regarding their medical care, including the right to accept or refuse treatment, and to make an advance directive. The law also requires that health care facilities and agencies discuss advance health care directives with patients when they are admitted. Soon after the PSDA went into effect, research was conducted to evaluate its impact on completion of advance directives and decision making with regards to end-of-life decisions. The studies on the impact of PSDA on decision making for the most part have demonstrated negative results. The most widely known of these studies is the Study to Understand Prognosis and Preferences for Outcomes and Risk of Treatments (SUPPORT) which demonstrated that the intervention did not
facilitate informed end-of-life decision making. The SUPPORT study was a multicenter study looking at whether advance directives assist in decision making with regard to end-of-life decisions in the general population. The study was conducted at five US teaching hospitals and included a total of 9,105 patients. This study was conducted in two phases: an observational phase and an interventional phase. The interventional phase was a randomization of 4,804 patients to a treatment or control group. The patients in the treatment group were intervened via the “presence of a trained nurse facilitator to provide detailed prognostic information to the patients and medical staff, to work with patients and families to elicit and document patient preferences, and to facilitate communication between patients and physicians.” No difference was noted between the two groups with regard to any of the five major measured outcomes: incidence and timing of DNR orders; patient-physician agreement on preferences for cardiopulmonary resuscitation (CPR); days in an ICU, in a coma, or ventilated before death; presence of pain; and hospital resource use.6

In SUPPORT, the maximum number of cancer patients that were enrolled was 16.9%. This low percentage of enrollment of cancer would make one wonder if, in a larger cohort of cancer patients, advance directives would have an effect on decision making with regard to end-of-life decisions when admitted to an ICU.

Kish and colleagues7 conducted a prospective study as part of a Multicenter Outcomes Study of Critically Ill Cancer Patients on consecutive admissions to the medical ICU from July 1994 to March 1996 at a tertiary cancer center. The study objectives were to determine the incidence of critically ill cancer patients admitted to the ICU with advance directives and the characteristics of those patients and their hospital outcomes. Only 27% of the 872 patients admitted to the ICU had advance directives. The demographics of the patients who had advance directives tended to be Caucasian and older. The study concluded that advance directives are infrequently established in critically ill cancer patients and that, since the majority of the patients tended to be Caucasian, cultural differences might need to be taken into consideration when discussing end-of-life decisions in the ICU. Additionally, they found that patients with hematological malignancies and those with relapse and progressive disease tended to have more advance directives. There was an association between advance directives and actual mortality. Upon review of the data, using logistic regression, severity of illness was the most important predictor of mortality in comparison to type of malignancy, disease status, and presence of an advance directive.

Wallace and colleagues,8 using the data from the study by Kish and colleagues,7 examined matched pairs with the same characteristics except for the presence of advance directives, then analyzed their cases to determine if the presence of an advance directive at the time of ICU admission influenced the decision to initiate life-support therapy. The investigators showed that the presence of an advance directive was not statistically significant to affect the decision of initiating life-supporting therapy. However, the presence of the advance directive was helpful in making decisions regarding resuscitation status, withdrawal of support, and discharge from the ICU. These patients had more DNR orders written and shorter length of stay in the ICU.8

The majority of studies that have been conducted to determine if advance directives facilitate end-of-life decisions have shown that they have a negative effect both in cancer and noncancer patients. However, a retrospective study by Hammes and colleagues evaluated a program titled Respecting Your Choices, an intervention focused on advance care planning as an “ongoing process” rather than an event to produce a product such as an advance directive. In addition, the program facilitated discussions about values and preferences instead of completing a document. “The
study demonstrated that 85% of the individuals had advance directives and 95% of these were available in the medical record.” Furthermore, the advance directives were completed long in advance of death (median time was 1.2 years). The focus on patient’s values and preferences, a dynamic process based on the current patient’s status, is probably the reason why the Hammes program is successful.

CONVENING MULTIDISCIPLINARY FAMILY MEETINGS

Once the decision has been made to transition to comfort care it is important that a family meeting be convened that includes members from the multidisciplinary team. Ideally, this is not the first family meeting to be convened since the patient’s admission to the ICU. Mularski and colleagues recommend that discussions be held with the patient and the patient’s family to discuss goals of ICU care, advance planning, and identification of a surrogate decision maker before transfer to the ICU. In another study focusing on an intensive communication intervention, Lilly and colleagues recommended that a family meeting be convened within 72 hours of admission to the ICU. The purpose of the meeting is to discuss the facts, options for treatments, the patient’s perspective on death and dying, and to agree on the care plan and on the criteria that would determine success or failure of the care plan. Furthermore, having frequent family meetings during an ICU admission—as opposed to having only one to discuss end-of-life issues—may provide an opportunity to build trust between the intensivist and the patient’s family.

The presence of the multidisciplinary team at the family meeting is recommended to provide emotional support to patient’s family, and the team can gain insight into their values and beliefs. This multidisciplinary team makeup may include individuals from the social work, chaplaincy, ethics, and palliative care departments. Also helpful is to have both the primary attending and intensivist present at the family meeting. It is important that before convening the family meeting, the various health care providers meet to discuss the patient’s disease, prognosis, and treatment options and resolve any disagreements before the family meeting. If disagreements still persist, avoid debating these issues in front of patient’s family since it may lead to family members becoming confused and frustrated.

ADDRESSING PATIENT’S AND PATIENT’S FAMILY CULTURAL BELIEFS AND SPIRITUAL VALUES

As alluded to above, it is important to ascertain the patient’s and patient’s family values and beliefs to help facilitate end-of-life decisions. Furthermore, acknowledging and supporting cultural beliefs and spiritual values have been identified as measures that can be used as indicators of providing quality end-of-life care within the ICU. Cultural beliefs need to be taken into consideration when family meetings are convened to discuss end-of-life decisions. This consideration is very evident in health care centers that take care of international patients. Even patients who reside in the United States may still have a multicultural background differing from that of the treating health care provider. One must be careful in assuming that if a patient is identified as belonging to a certain ethnic group that they follow the culture beliefs of that particular ethnic group. Cultural beliefs may influence communication about end-of-life issues, decision making within the patients family, or attitudes about DNR orders. A reference book that may be useful is Culture and Clinical Care, which gives overviews of culture or ethnic identity, spiritual or religious orientation, symptom management, family relationships, illness beliefs, and death rituals of 35 different ethnic and regional groups.
Religious and spiritual values also need to be taken into consideration when discussing end-of-life decisions with patients and their families. Silvestri and colleagues\textsuperscript{14} suggest that religious beliefs may influence medical decisions. In this study of a group of newly diagnosed, advanced lung cancer patients and their caregivers, faith in God was ranked second only to the recommendation of the oncologist in deciding between different treatment options. An assessment of the spiritual beliefs of both the patient and the patient’s family should be obtained. This assessment can be performed by any member of the health care team.\textsuperscript{15}

**PATIENTS WITH CHILDREN AND AFFECT ON END-OF-LIFE DECISION MAKING**

In discussing end-of-life issues, decisions may be made by the patient or patient’s family based on consideration that the patient may consider more aggressive care to attempt to spend more time with their children. It is estimated that 24\% of cancer patients have children less than 18 years old. A study by Nilsson and colleagues\textsuperscript{16} concluded that patients with advanced cancer and dependent children are more likely to favor a course of treatment that would extend life rather than relieve pain and discomfort. The study also concluded that these patients had a worse quality of life during the last week of life. Based on these findings, the recommendations are to consider providing enhanced psychosocial support and that the patients may need guidance on how to discuss their illness with children.

**FACILITATING A “GOOD DEATH” IN THE ICU**

Since most end-of-life decisions in the ICU will involve withholding or withdrawing support, transferring a patient out of the ICU to either an inpatient palliative care unit, inpatient hospice, or home hospice may at times be difficult. In anticipation that the patient may not be transferred out of the ICU, one must be prepared for the patient to die in the ICU. The timing of a death in the ICU varies from shortly after admission to a short or prolonged stay. As much effort as goes into resuscitating a patient—if not more—should be put into ensuring that an ICU death is a good death. A statement that is often used to emphasize the effort needed to ensure quality end-of-life care is “there is no second chance to get it right.”\textsuperscript{17} Also Dame Cicely Saunders,\textsuperscript{18,19} British physician and founder of hospice care is quoted, “How people die will remain in the memories of those who live on.” An article by Beckstrand and colleagues\textsuperscript{20} gives recommendations on how to facilitate a good death. These were derived from a survey focusing on perceptions on end-of-life care. The survey was sent to a random sample of members of the American Association of Critical Care Nurses, and the results are summarized in Box 1.

Some of these recommendations have already been addressed above. When considering withdrawing aggressive support, protocols should be used to facilitate this process that prevent the patient and family members from experiencing discomfort. Furthermore, some of the health care providers may be concerned that the treatments being administered to relieve suffering may also be hastening death. This concern and the importance of using protocols were discussed in an article by Kuschner and colleagues.\textsuperscript{21} Using protocols may help avoid the ethical tensions that may arise between health care providers during the withdrawal of life support.

Kuschner and colleagues\textsuperscript{21} also added an educational process to promote consensus building and to strengthen communication. Effective communication at the end of life is essential during the process of withdrawing life support. The communication process begins during the family meeting that is convened to discuss transitioning to palliation. The process and any anticipated changes should be discussed
with the patient’s family. Communication should take place between the nurse, the respiratory therapist, and the ICU physician with regard to the process of withdrawing life support. Furthermore, health care providers should be given the opportunity to voice their discomfort if they have any religious or moral objections with the process, and to move to another assignment if they choose.

### PROTOCOLS FOR WITHDRAWING LIFE SUPPORT AND TRANSITIONING TO COMFORT CARE

Protocols for withdrawing life support or transitioning to comfort care should include: ensuring that DNR orders have been written, documentation in the medical record about the plan to transition to comfort care, arrangement to make the surroundings as comfortable as possible, liberal visitation periods, symptom management, ventilator or noninvasive ventilator withdrawal, and deactivation of implantable devices.

### Symptom Management

Symptom management, particularly pain management, during the transition to comfort care needs to include tools to assess pain symptoms and recognition of potential barriers to providing good pain management. A concern that is commonly voiced by health care providers and patient’s families is how to assess pain symptoms in a patient who may not be able to self report symptoms. This scenario is common in ICU patients since they may be on ventilator support, sedated, or unable to communicate for other reasons. In a recent article by Mularski and colleagues, recommendations were made to use the Behavioral Pain Scale or the Critical-Care Pain Observation Tool, which have had the most validity testing. Another option is to “develop a brief pain-behaviors checklist that includes specific behaviors that have been noted in research that correlate with patients’ self-report of pain: grimacing, rigidity, wincing, shutting of eyes, clenching of fist, verbalization, and moaning.” Along with using this tool or checklist, the recommendation is to not overlook family member’s estimates of the patient’s pain score. In SUPPORT, “the surrogates had a 73.5% accuracy rate in estimating presence or absence of patient’s pain. The tendency was for the surrogates to overestimate patient pain.” Mularski and colleagues further recommend using multiple proxy raters of patient pain symptoms to make a more accurate assessment of the pain symptoms.

Reviewing the above recommendations on pain management in critically ill patients at end of life, the assumption could be made that it would be easy to manage pain.

<table>
<thead>
<tr>
<th>Box 1</th>
<th>Measures that can facilitate a good death</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Facilitators to providing a good death</strong></td>
<td></td>
</tr>
<tr>
<td>Making environmental changes to promote dying with dignity</td>
<td></td>
</tr>
<tr>
<td>Being present</td>
<td></td>
</tr>
<tr>
<td>Managing patients’ pain and discomfort</td>
<td></td>
</tr>
<tr>
<td>Knowing and following patients’ wishes for end-of-life care</td>
<td></td>
</tr>
<tr>
<td>Promoting earlier cessation of treatment or not initiating aggressive treatment at all</td>
<td></td>
</tr>
<tr>
<td>Communicating effectively as a health care team</td>
<td></td>
</tr>
</tbody>
</table>

However a major barrier to providing good pain management is the concern by some health care providers of ethical or legal concerns about the escalation of opiates or other palliative measures and the hastening of death. In dealing with this concern, it is necessary for both the health care providers and patient’s family to understand that in providing pain medications and other palliative measures, the intent is the relief of symptoms. This requires communication with patient’s family members stressing this goal. It is also important to note that research on aggressive pain management at end of life does not shorten life but instead “may be life prolonging because it decreases the systemic effects of uncontrolled pain that can compromise vital organ functions.” Furthermore, in a study by Chan and colleagues there was no statistically significant relationship between doses of opiates and time to death in a group of critically ill patients. Research has also demonstrated great variation in types and amounts of medications used during withdrawal of life support. Therefore it is important to include guidelines for use of opiates and benzodiazepines in the protocols, and information about patient conditions that may necessitate increasing or decreasing dosages.

Deactivation of Implantable Cardioverter Defibrillators and Permanent Pacemakers

Protocols for withdrawing life support should include statements regarding deactivation of implantable cardioverter defibrillators (ICD) and permanent pacemakers (PPM.) As indications for implantation of PPMs and ICDs have increased, it can only be anticipated that some patients who receive these devices may develop cancer or have cancer that becomes terminal. Therefore one must take into consideration whether deactivation of these devices is appropriate during the transition to comfort-care-only measures. Addressing these devices separately is appropriate owing to the functions that they serve. The published literature about ICDs has demonstrated that the patient may experience pain when a shock is delivered appropriately or inappropriately at the end of life. Discussing end-of-life issues is difficult, but even more difficult when discussing when to deactivate an ICD. In a study by Goldstein and colleagues, only 27% of physicians had a discussion about deactivating the ICD. The timing of this conversation in 75% of cases occurred during the last few days of life and, at times, in the last hours or even last minutes of life. Even in patients who had DNR orders, less than 45% had conversations discussing the deactivation of the ICD. The study concluded that guidelines addressing indications for implantation of ICDs should also include recommendations of when to deactivate them. However, a review of the current literature on recommendations regarding the deactivation of PPM demonstrates a disagreement on whether it is ethically permissible to deactivate a PPM in a dying patient. This disagreement is based on claims that a PPM neither prolongs the dying process nor causes discomfort. In addition, in an article by Braun and colleagues, the argument is made that deactivating a PPM may cause bradycardia, rate-related congested heart failure, and dyspnea resulting in increased suffering. They concluded that decisions to deactivate a PPM should be made on an individual basis and education should be provided to the patient and the patient’s family to help alleviate anxiety associated with the decision of deactivation of PPM and ICD. The PPM should be removed before cremation to decrease the risk of injury from explosion.

Providing Emotional and Organizational Support for ICU Clinicians

Along with instituting the practices to facilitate transitioning from cure to comfort care discussed above, another issue is providing emotional and organizational support for ICU clinicians that provide care to dying patients. Addressing this issue has been
identified as one of the domains that can be used to assess the quality of end-of-life care that is provided in an ICU. One useful measure is convening a debriefing session after a particularly difficult case. It is useful to have someone present that can facilitate the discussion and provide the opportunity for those present to discuss their feelings about the patient’s death. Ideally, the participants should come from multiple disciplines and the session should provide an opportunity to improve staff morale, enhance team work, and improve satisfaction. Another measure that may be useful is to have a staff support group that meets regularly with meeting times integrated into the routine of the ICU. Developing measures that will assist health care providers in coping with the care of a dying patient is important to decrease moral distress or emotional burnout. Moral distress can occur when the “practitioner feels certain of the ethical course of action but is constrained from taking that action.” In a study by Hamric and Blackhall, exploring the perspectives and experiences of registered nurses and physicians working together with dying patients in an ICU, the most distressing situations for both groups was feeling pressured to continue aggressive treatment when the providers felt that such treatment was not warranted. If not relieved, moral distress can potentially lead to decrease in retention of the health care providers in a workforce that is already forecasting a shortage of providers.

SUMMARY

Since the majority of deaths will occur after limiting or withdrawing life support, when dealing with end-of-life issues in critically ill cancer patients focus should be given to ensuring that multidisciplinary family meetings are convened to discuss end-of-life decision making. Furthermore, throughout the process of transitioning from cure to comfort care, it is essential to support the patient and the patient’s family cultural beliefs and spiritual values, and ensure good pain and symptom management. The use of protocols facilitates a smooth transition and potentially reduces variability between health care providers. Finally, integrating measures into the ICU routine that will help health care providers cope with the care of a dying patient is recommended to avoid moral distress or emotional burnout.

REFERENCES


