

Palliative Care in the Surgical Intensive Care Unit

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Seventy-year-old Mary was admitted to the surgical ICU immediately after surgery for repair of a thoraco-abdominal aneurysm and renal artery stenosis. Within 24 hours of postoperative care, it became clear she had become paraplegic, unresponsive, and was in acute renal failure. What was the likelihood she would survive all this? And if she did, would she be in a nursing home for her remaining days. Should she be started on dialysis? What would Mary, who now could not say, want for herself if this was the end of her life?

Interview with her family revealed that Mary had initially refused operative intervention for her aneurysm but agreed to serial surveillance. Then she developed increasing abdominal pain. Evaluation revealed a marked increase in aortic diameter with significant risk of rupture. Mary was frightened living with this "time bomb," but worried about undergoing such major surgery at her age—especially an operation with risks of mechanical ventilation, renal failure, paralysis, or even death. After a lengthy discussion with her surgeon and family, she hesitantly consented, but made it clear that "if the worst happened" she did not want to "be kept alive by machines."

Now, in the ICU, was this "the worst" that Mary had alluded to, or not? The surgeon met with her husband and daughters to discuss this question. Much of her organ failure was potentially reversible, perhaps she would recover with aggressive care. But the paraplegia seemed unlikely to resolve. The family agreed to hemodialysis on a short-term basis. Her family was reassured that she would be given adequate pain relief with a continuous morphine drip.

In 2 weeks, Mary's renal function improved, and hemodialysis was discontinued. She remained ventilator dependent. She now suffered from incontinence and diarrhea that caused a nonhealing sacral wound. She was still being "kept alive by machines" that she had not

previously wanted, but this seemed appropriate because she was now more responsive and enjoyed interacting with her ever vigilant family. She smiled at photos of her grandson's first communion, but coughed and gagged as she tried to talk around the oral endotracheal and orogastric feeding tube. She was embarrassed by her continual incontinence. A third family meeting was held to discuss her physical and psychological discomforts. Even though Mary had not wanted more surgery, in an effort to palliate her extended recovery period, a tracheostomy, gastrostomy feeding tube, and diverting colostomy were performed.

Mary's husband was an attentive daily visitor, spending hours at her bedside. Her daughters, both held full time jobs and had young children, but alternated daily visits and brought her grandchildren to visit on Sundays. For a brief time Mary rallied, slowly weaning from the ventilator, tolerating feedings, and healing her wounds. She watched her "soaps" on TV and told her family she wanted to go home.

But she became septic from breakdown of an enteric suture line. Delirious, she no longer recognized her worried husband. Pressors were initiated to support her blood pressure, and she developed arrhythmias. Surgery was indicated for intraabdominal sepsis but after a fourth family meeting, her family declined operative intervention. They agreed to CT-guided drainage and antibiotic therapy. A do-not-resuscitate order was placed in the event of a cardiac arrest, but the ventilator and pressors were continued.

Mary became agitated, grimacing and bucking the ventilator. Her opiate dose was increased, intravenous sedation was added, and ventilator parameters were adjusted. Again, her kidneys failed. At a final meeting with the surgeon, her daughters insisted that Mary's wishes "not to be kept alive by machines" be honored. Soon thereafter, pressors and ventilator support were withdrawn. She died an hour later surrounded by her family after a 6-week ICU stay.

Although the specifics are unique, this scenario is commonly faced by many surgeons caring for patients in the ICU. After major surgery, complications or multiple organ failure leave patients lingering in the ICU, with unclear prognosis and unclear direction about their pref-

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erences for end-of-life care. As in Mary's case, multiple points can arise during the trajectory of the illness when decisions about life support versus palliative care must be made. Are we merely prolonging suffering at the end of life, or will the patient survive to justify a prolonged ICU course on the ventilator? Should more surgery be performed, or should life support be withdrawn? Is the patient in pain and can it be treated adequately? When should the focus of critical care be palliation rather than cure?

There was a time when the concept of palliative care was anathema to practice in the surgical intensive care unit (SICU). Palliative care is defined by the World Health Organization as "The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount." In contrast, we think of the SICU as a place of high technology, invasive procedures, and advanced life support, where the priority is to cure illness and prolong life no matter the cost in suffering or resources. Despite the burdens of some of these therapies, this aggressive, curative approach has always been justified by the ultimate outcome, a longer life. Where then, does palliative care fit in the SICU? In reality, 10% to 20% of ICU patients die, either in the ICU itself or before discharge from the hospital.¹ The 6-month mortality after an ICU stay is even higher, especially in the elderly, depending on the underlying disease process.^{2,3} Multiple studies on end-of-life care have reported that many patients who die in the ICU do so with unnecessary, unrecognized, and untreated pain and suffering, amidst unwanted therapies.^{4,5} This despite the fact that in recent years, withholding or withdrawal of life support is instituted in the majority of dying intensive care patients.⁶⁻¹⁰ If the ICU remains the site of death for so many patients, part of our mission as physicians and surgeons is to provide them with good palliative care and good curative therapy.

Recent initiatives in professional organizations confirm that the principles of palliative care will increasingly influence the care of critically ill patients, including that of surgical patients. In its 1998 *Principles Guiding Care at the End of Life*, The American College of Surgeons Committee on Ethics stated that surgeons should "Ensure alleviation of pain and management of other physical symptoms in dying patients."¹¹ In a 1997 position

paper on ICU resource allocation, the American Thoracic Society affirmed that although preservation of human life is a major objective of critical care, "compassionate" and "attentive" alleviation of suffering of a dying patient is an important alternate goal.¹² An Intensive Care Working Group, as part of a 1997 national consensus conference in medical education, recommended that palliative care should be incorporated into critical care education.⁷ Lastly, the theme of this year's International Educational and Scientific Symposium of the Society of Critical Care Medicine was "Blending Science and Compassion," highlighting the society's acceptance of the importance of palliation of symptoms alongside the technologic interventions to prolong life in the ICU. There have been other institutional statements that have issued similar positions on the management of critically ill, dying patients.

This movement toward palliative care portends a fundamental shift in clinical care and surgical culture. Surgical culture stereotypically tends to be dominated by "aggressive" curative intent; the goals of care are often focused on procedural endpoints, morbidities, and mortalities, rather than patient-oriented goals or quality of life. Death can be seen as a failure, and the worst possible outcome, particularly if surgical complications or iatrogenic disease are present. This can lead to avoidance of communication with family about prognosis, end of life, and a view that the transition to palliative care is "giving up." Palliative care, in reality, is a constellation of specific therapies, focused on different goals, not "giving up." Surgeons have little formal expertise or training in these concepts. Management of death in the ICU requires specific knowledge and skills on the part of physicians, just as other techniques do. Surgeons who care for the critically ill must now be versed in the management of death; we must understand how and when the transition from curative to comfort care should occur, and be skilled in the management of pain and other distressing symptoms, the appropriate withdrawal of life sustaining treatments, and communication and support for patients and families. This article describes the fundamental principles and skills of palliative care in the ICU: how to redefine goals of care; how to combine comfort with ongoing therapies; when and how to withdraw therapy; and the importance of emotional, spiritual, and bereavement support.

TRANSITION IN GOALS OF CARE

In many ways, surgeons have always cared for patients at the end of life, but it is not intuitively obvious how or when to accomplish the transition from curative therapy to palliative care in the ICU. Several features of surgical critical illness make this transition and practice of palliative care unique and potentially difficult in the ICU. To effectively manage death and the end-of-life period the following must be addressed. First, palliative care principles have generally focused on patients with clear prolonged terminal illnesses, but in the SICU there are many patients (like Mary in the previously described case) who have become ill acutely, often after a catastrophe such as traumatic injury, a complication of surgery, or acute progression of a chronic disease. Because of the unanticipated nature of their illness, patients have not discussed their wishes for end-of-life care in sufficient detail and lack capacity to make decisions or tell their physicians their preferences for ongoing aggressive therapy if the outcomes are likely to be poor. Evidence suggests that the majority of dying patients in the ICU cannot participate in these decisions.⁹ Families must be surrogates for end-of-life decisions. Families can be unprepared for the rapid progression from a well patient to one who is critically and terminally ill; they can be overwhelmed by confusing clinical information and a patient condition that changes often. They can have little or no relationship with the patient's surgeon or intensivist.

Second, there is great uncertainty in the ICU about who is actually dying. Certainly, many patients dwindle with multiple organ failure and linger on life support despite the initial acute illness. Although mortality rates in ICUs are well known, neither when nor who falls into that 10% who ultimately die are always clear. Many see this as a barrier to effective palliative care because even a 1% to 2% chance of survival is viewed by some as reason to continue aggressive therapies; better to err on the side of doing "too much" than "too little." Others consider such odds for survival to constitute futility. Multiple studies on physician practice with respect to DNR orders, withdrawal of life support, end-of-life decisions, and futility in ICUs reveal a wide variation both within and across institutions.^{6,7,9,13,14} Despite a large literature on prognostication in the ICU, the prediction of time or occurrence of death with certainty is fraught with difficulty. Available scoring systems such as APACHE,

MPM, MODS, ISS, and others are useful in stratifying groups of patients with similar diagnoses, but they cannot be applied to predict death with certainty in individual patients.¹⁵⁻¹⁷ Most clinicians use experience and clinical judgment rather than objective prognostic instruments to determine prognosis. Often in the ICU, clinicians feel certain about mortality only when death is imminent and there is little time for palliative care. This notion is confirmed by multiple studies that found DNR orders instituted, on average, 1 to 2 days before death.^{18,19} Again there is variability in this area. The timing of DNR orders depended on the specialty service (surgical versus medical) or the institution caring for the patient. Others reported decisions to withdraw life support in the ICU were made 5 to 10 days after admission to the ICU.^{14,29} Whether it is uncertainty about prognosis or other patient and provider factors that create this variability is unclear. But the available literature does not support the notion that improving prognostic information will enhance physician practice of palliative care. The SUPPORT study, which examined the effect of improved communication of prognosis and patient preferences to physicians, failed to show a change in palliative care in terms of ICU days and ventilator days before death.⁵

In the face of this uncertainty, when and how should physicians institute palliative care in the critically ill? Regardless of prognosis or likelihood of dying, a focus on the goals of care will facilitate this transition, so that palliative care can be provided alongside other therapy, not in an either/or fashion. For many critically ill patients death is a possible outcome, even if not a certain one. Attention to relief of suffering and pain control alongside aggressive resuscitation, mechanical ventilation, and insertion of lines is really just good medical care.

Goals at the end of life are usually one or more of the following: comfort and relief of symptoms; removal or avoidance of burdensome, painful therapies; communication with and proximity to family; and spiritual closure. Goals might be different for different patients and their families, and depend on the likely outcomes and the patient's preferences. If survival is possible but only in a vegetative state, goals might be relief of suffering, closure, bereavement support for the family, and no prolongation of the dying process. If death is likely and the patient is conscious, the goals might include a comfortable death with minimal pain and suffering, avoidance

of painful procedures, opportunity to be with family and friends as much as possible at the end of life, alertness and the ability to communicate to facilitate these visits, and spiritual closure. Sometimes the goal of intensive care can be only to bring the patient to a condition to leave the hospital to go home with hospice. These goals are dynamic and can change as the condition of the patient changes, and communication with the patient or family, because many critically ill patients are comatose, should be ongoing. The physician's role is to communicate clearly the potential outcomes, their uncertainty, if any, and the treatment and care options for each outcome. Communication with the family about the changing nature of goals with the changing nature of the patient's condition is essential so the family can be prepared in advance for decision making. Many patients and families fear that once a treatment is initiated, it cannot be withdrawn or that if they refuse treatment their physician will abandon them; physicians need to make clear that this is not so.

Therapy and interventions should be considered and evaluated individually based on their burdens and risks compared with the benefits they provide vis-à-vis the goals of care.²⁰ Procedures should not be recommended or withheld because they might be "heroic" or "extraordinary," but rather based on their ability to relieve pain or symptoms. For example, if the patient's paramount goal is to die at home with family, the burdens of surgery for malignant bowel obstruction might be considered even if the patient is DNR, because the expected palliation would allow the patient to be discharged from the hospital to home, but if the same palliation could be achieved with medical management that does not have the burdens, risks, or pain of surgery, the operation should be avoided. In the same patient intubation and ventilatory support for respiratory failure would not be used because it would only add discomfort, prolong suffering, and not further the goal of dying at home. But, if the patient decided to have surgery, a short-term ventilator course for the operation could be provided, with the understanding that if long-term respiratory failure occurred the ventilator could be withdrawn. Clearly, the choices the patient or family make are highly dependent on information and recommendation from the surgeon about the likelihood of all the potential outcomes. In another patient with multiple organ failure and pneumonia, transfusion and antibiotics could be helpful for some symptoms, even though withdrawal of the venti-

lator is planned to allow the patient to communicate with family while dying. Some interventions might achieve the goals of care for the short-term, but would need to be withdrawn later if conditions change. As in Mary's case, dialysis can be initiated for a short-term course, with the hope that correction of metabolic disturbances would improve mental status, bleeding, and infection, but can be discontinued if it fails to meet these goals later or other organ failure worsens the prognosis. Regardless of the major therapies planned, attention to pain and symptom management and communication with the patient and or family should be paramount and ongoing.

WITHDRAWAL AND WITHHOLDING OF LIFE SUPPORT

The majority of patients who need palliative care in the ICU will undergo withdrawal or withholding of some life support. In a national survey of 131 ICUs in 110 institutions from 38 states, there was a wide variation of practice, but the findings clearly indicated that limitation of life support before death has become the standard of practice.⁶ Of the 5,910 patients who died, only 23% received the full ICU care with failed CPR. Twenty-two percent received ICU care without CPR, and 48% of the patients who died had life support either withdrawn or withheld. How and when to withdraw support is not uniformly practiced and can be the cause of great confusion and anxiety on the part of physicians, nurses, and family. The literature suggests that physicians prefer to withdraw treatments such as vasopressors first and generally withdraw the ventilator last, if at all.²¹ Some physicians prefer to withhold a treatment, but once treatment is initiated are reluctant to withdraw it, especially if a complication or iatrogenic disease is involved.²² Again, patient, not physician, preferences are important in guiding practice. Attention to the goals and preferences of each patient, the burdens of the therapy, and the comfort or discomfort produced when withdrawn, should determine whether therapies are withdrawn or withheld, and in what sequence.²⁰ Ethical and legal precedents are clear that there is little difference between withdrawal and withholding a therapy and that the patients' autonomy and right to refuse treatment prevail over other concerns.²³

Specific clinical skills in the techniques and moral basis of withdrawal of life support are essential to the surgeon caring for the critically ill and can alleviate some

of the anxiety around this issue. Therapeutic modalities most often withdrawn in the ICU are vasopressors, nutrition, antibiotics, transfusions, dialysis, and ventilator. Monitoring devices and diagnostic tests can also be withdrawn and should be if they do not assist in relief of symptoms. These may include x-rays, laboratory tests, Swan-Ganz catheters, intravenous lines, or even frequent vital signs. The physician should be well versed in the consequences and possible outcomes for withdrawal of each of these modalities, especially what the resulting symptoms for the patient might be. The physician should be prepared to treat those symptoms that are amenable and advise the family and other staff of what to expect. Once the decision is made to withdraw the ventilator, for example, all staff caring for the patient and family members should be apprised of the procedure, the likely outcomes after withdrawal, and the measures that can be taken to ensure comfort and relief of suffering. It should be emphasized to families that withdrawal of any therapy is not withdrawal of "care" and that aggressive measures to alleviate suffering will be ongoing. Many family members wish to be present during and after the withdrawal, and allowances should be made for them to do so. If death is likely within minutes, appropriate planning for pastoral care and arrival of crucial family members should be made in advance.

The ventilator can be withdrawn by two methods: direct extubation or terminal weaning.^{20,24} There is little literature to support the use of one method over another, but if the goals are to improve comfort, facilitate communication with family, and avoid prolongation of the dying process, then direct extubation might be preferred. Direct extubation is performed after suctioning, and the patient is placed on humidified oxygen or air for comfort. Medications can be given to minimize oral and pulmonary secretions. Terminal weaning involves rapid weaning of inspired oxygen, tidal volume, and rate followed by extubation, although some describe leaving the endotracheal tube in place to control secretions. Terminal weaning may prolong the dying process and not achieve the goals of comfort or family proximity that extubation does. Before extubation the patient should be medicated with intravenous opiates and benzodiazepines to treat the anticipated dyspnea, discomfort, and anxiety. The necessary level of sedation should be determined before withdrawal of the ventilator based on the goals of care. Does the patient want to be as alert as

possible to talk with family? Then, medication should be titrated to relief of dyspnea but not to complete sedation. Opiates and benzodiazepines should be at the bedside so that frequent assessments and rapid titration can be done judiciously as needed. Other nonpharmacologic modalities to relieve dyspnea such as fans and removal of encumbering clothes and medical equipment can be helpful. There is no role for neuromuscular blockers during or after withdrawal of the ventilator. They provide no relief of pain or anxiety and can, in fact, mask symptoms that need to be treated at the end of life.

PAIN AND SYMPTOM MANAGEMENT

Many people rate fear of unrelieved pain and other symptoms to be their major concern about dying. The American College of Surgeons Committee on Ethics and other professional organizations have made the relief of pain and suffering in dying patients a priority, but review of the current status suggests that in the ICU we have far to go before realizing the lofty goals of these position statements. Recent studies point to disturbing evidence of inadequate palliation of pain and suffering in the intensive care units. In a prospective analysis of ICU patients with cancer, between 55% and 75% patients experienced pain, discomfort, anxiety, sleep disturbance, or unsatisfied hunger or thirst. Depression and dyspnea were present in 40% and 33% of patients, respectively.²⁵ A followup paper from the SUPPORT study revealed an alarming 63% of elderly critically ill patients had difficulty tolerating physical or emotional symptoms before death, according to the memory of the surviving family members. They suffered from severe fatigue and severe pain in considerable numbers.⁴ In another study, anxiety, fear, agony, and panic occurred in nearly half of the patients who were on mechanical ventilation.²⁶

There are ample data to suggest that the current status of pain management for surgical ICU patients is also in need of marked improvement. In level 3 neonatal ICUs in Canada, postoperative pain was managed inadequately in 35% of the neonates who underwent minor surgery, and 12% of the neonates who underwent major surgery, respectively.²⁷ In 221 ICU patients receiving 2,013 total doses of sedatives and analgesics, 90% were ordered on an "as needed" basis, 41% did not have the indications specified, and the doses actually received were significantly less than their maximum allowable

amount.²⁸ In a smaller study of surgical patients, nurses only administered on average 36.5% of the maximum allowable narcotic dose for pain control.²⁹ Among 213 postoperative and trauma surgical patients in a multicenter study, 64% were often in moderate to severe pain.³⁰ High pain intensity and low patient satisfaction correlated with, among others, long waits for analgesic administration and prior expectations of less pain.

The reasons for inadequate pain and symptom management in ICU patients are multifactorial and might be provider- or patient-related. Physicians and nurses can limit the use of potent opioids for fears of addiction, adverse hemodynamic effects such as hypotension, and mental and respiratory depression leading to prolonged ventilatory dependence. In a study of ICU trauma patients, barriers leading to adequate pain management were thought to be from disparity of pain perception between patients and clinicians, lack of patient's request for more analgesia, and physicians' and nurses' concerns about adverse side effects.²⁹ Physicians often cite concerns about hastening death with the administration of opiates or benzodiazepines, particularly in the setting of withdrawal of life support. In fact, the literature suggests that the time to death after withdrawal of the ventilator is the same for patients medicated with high dose opiates (11.2 ± 2.0 mg/hr) and benzodiazepines (9.8 ± 3 mg/hr diazepam equivalent) as for those who were not.³⁰

Providers can perceive conflict between different goals of critical care; high doses of opioids can provide excellent pain relief, but providers fear that important symptoms that require monitoring might be masked. Even the seemingly straightforward palliative goal of sedation can conflict with other patient care goals, such as reduction of length of stay. In a study of 128 adult patients on mechanical ventilation,³¹ intravenous infusion of sedative agent was interrupted on a daily basis in the study group until they were awake or uncomfortable. Compared with the control group, whose sedative infusion was interrupted only at the discretion of the intensivists, the study group had decreased duration of mechanical ventilation and ICU length of stay. Despite the limitations of the study, the data raise a possibility that the goals of palliative care can oppose the goals of clinical efficiency. Considering that pain and stress are known to cause adverse physiologic effects,³² leading to worse clinical outcomes, one might argue that optimal sedation and pain relief will probably provide better overall outcomes in the end.

Patient-related barriers to effective pain and symptom management are equally complex. Patients in critical care settings are often incapable of expressing their discomfort because of altered mental status or intubation. Accurate assessment of the patient's pain can be difficult in these settings. Critical care surgeons and nursing staff must maintain a high index of suspicion for significant pain experienced by the patient. A variety of assessment tools have been developed specifically for critically ill patients using both verbal and nonverbal means of communication with the patient.^{33,34} Intensity of pain should be assessed on a numeric scale, and nonverbal patients should also be assessed for behaviors such as grimacing, splinting, restlessness, stiffness, and alterations in vital signs with movement, turning, etc.³³ Medication should be titrated to these scales and assessments repeated in a sequential fashion for efficacy. It is imperative that critical care providers familiarize themselves with the assessment tools, monitor for pain, and intervene repeatedly for optimal relief of suffering.

Once pain is assessed the appropriate use of analgesics in the ICU is critical for treatment. Foley details the key principles of effective pain management as follows.³⁵ First, the choice of analgesics must be based on the type, the site, and the cause of the specific pain experienced by the patient. Second, the analgesic effect should be maximized by switching the drugs as necessary, observing equianalgesic doses. Third, various routes of administration should be weighed to fit the patient's needs: oral, rectal, transmucosal, subcutaneous, transcutaneous, intravenous, epidural, intrathecal, and intraventricular. Fourth, a dose titration protocol must be used to deliver adequate amounts of analgesia to a desired effect. Rescue doses should be administered for breakthrough pain in addition to the baseline dosing schedule. The baseline dose of opioids should be increased by an amount that reflects the additional rescue dose requirements. Fifth, surgeons must understand the concepts of tolerance and physical dependence to avoid undertreatment while opioid requirement escalates, and to prevent acute withdrawal symptoms while opioid use is being weaned and stopped.

Adjuvant agents should be used when appropriate to enhance analgesia and control side effects. Traditional nonsteroidal antiinflammatory drugs and new Cox-2 inhibitors are two such examples that are readily available. Other adjuvant agents for symptom control include antiemetics for nausea, benzodiazepines for anxiety, neuro-

leptics such as haloperidol for delirium, and antidepressants (eg, amitriptyline) and anticonvulsants (eg, gabapentin), among others, for neuropathic pain.³⁵ Dyspnea, a "curse" for the dying, can be caused by a combination of factors, and the treatment must take a multi-pronged approach. In addition to treating the underlying pulmonary process and providing conventional ventilatory support measures, low-dose morphine and benzodiazepines have been shown to be effective in reducing physical and psychological stress to improve breathing in patients with terminal dyspnea.³⁶

Education of all staff is a key element for optimal pain and symptom management. Critical care residents, fellows, nurses, and attendings must be trained specifically in the area of pain management for ICU patients, a subject that has accumulated a considerable body of knowledge over the past two decades. A quality improvement process in the SICA at UCLA reduced from 35% to 21% the incidence of pain score of greater than 2 (out of 5) at the end of the ICU stay. The initiative involved, among many steps, establishment of guidelines for acute pain management, assessment of pain scores, and education of the staff.³⁷ By providing the staff with the tools for pain assessment, documentation, and intervention based on a guideline, improvement of pain control was achieved with some degree of success. In another study involving 787 postsurgical patients, staff education led to decreased incidence of patient-related barriers to adequate pain management.³⁸

EMOTIONAL AND BEREAVEMENT SUPPORT

Because the majority of patients dying in the ICU are comatose, much of the emotional and spiritual suffering around the end of life is felt by the family. The goals of a peaceful death and meaningful closure can only be achieved by the next of kin, not the patient himself. Successful palliative care in the ICU must support the family and facilitate these goals. It should include a multidisciplinary team of social workers, pastoral care, palliative care practitioners, and bereavement counselors. The physician should be versed in the available resources at the institution to support the family. Despite these consultants, the physicians and nurses caring for the patient must play a pivotal role in supporting the family. They are the providers most knowledgeable about the patient's condition, what to expect, and the natural history of the patient's disease process. Communication between the physician and the family is essential for

end-of-life decision making, education about what to expect during the dying process, and reassurance that comfort care will be provided.

Good communication skills and knowledge about the acute grief response are requisites for the physician who cares for dying patients. Studies on breaking bad news have shown that the manner in which death or poor outcome is relayed to the family can have life-long ramifications for their bereavement.³⁹ A survey of surviving family of trauma patients noted that the caring attitude of the newsgiver, the clarity of the message, and the opportunity to ask questions were most important to them.⁴⁰ The range of possible outcomes should be communicated to the family clearly, uncertainty should be discussed openly, and the family should be prepared for the most and least likely events and the need for future decision making.

Support for families is best achieved if they are at the bedside. A peaceful death, surrounded by family, is the main goal of palliative care for many. The presence of family in the ICU, while controversial in the past, is now standard in many hospitals, with unrestricted visiting hours. Several studies have demonstrated that the presence of family does not adversely affect the care of the patient or the course of disease, and, in fact, can improve it.⁴¹ Physicians and nurses can be stressed by their presence and support for the staff can be important. The role of palliative care specialists such as counselors, nurse practitioners, and social workers is critical here both to educate and support ICU staff. Some have proposed that families can and should be present during cardiopulmonary resuscitation, particularly when the dying are children. Fears that if the family witnesses CPR they might be traumatized or misinterpret interventions seems to be unfounded; conversely, some can be grateful for the opportunity to be with their loved ones in their last moments.⁴² During the last moments of life, any interventions or monitoring devices should be removed as much as possible so that the family can touch, hold, or even bathe the patient. Even mundane things as EKG leads, intravenous fluid catheters, and oxygen masks can be in the way.

After the death of the patient, bereavement support and spiritual support should be provided. Palliative care specialists, bereavement counselors, pastoral caregivers, or social workers with expertise in bereavement and grief counseling should be part of the critical care team to provide this support. Different cultures have different

rituals for preparation of the body or prayer. Families might need important time with the body, to bathe the body, or might believe that the body should not be left alone. Photographs of the body or a lock of hair can be important for bereavement. Again, bereavement specialists who have expertise in these issues are helpful to facilitate simple rituals in the ICU. Families need advice and guidance on the practical aspects of death such as autopsy, movement of the body, burial, and legal issues. Information regarding longterm support groups and bereavement therapy is helpful; often families think of questions days after the death and they should be provided with a phone number if followup support is needed. The belief that discussion about the death later or contact with the health care providers is traumatic or emotionally harmful to the family appears unfounded. Literature suggests that families welcome these discussions.

In summary, if we return to the case of Mary, only retrospectively can one see her ICU stay as the end of her life. Neither Mary nor her family or physicians knew for certain until the last day of her life that her care had become “end-of-life-care,” although throughout the 6 weeks, that possibility loomed large. As in so many cases in the ICU, critical care became palliative care, but this transition was neither abrupt nor obvious.

In the setting of uncertain prognosis, marked by devastating complications interspersed by periods of hopeful recovery, the transition of goals of care occurs equivocally over time. But the intent for palliation must remain proactive and aggressive throughout. Palliative care in the ICU is more than the judicious practice of withdrawal of life support at the end. Pain and physical symptoms must be managed diligently throughout the ICU course. Communication with the family should be maintained to discuss therapeutic options and immediate and longterm goals for care, including the decision for withdrawal of support when appropriate and the provision of bereavement support when necessary. In many ways, “intensive care” encompasses both curative and palliative care. Surgeons who care for the critically ill, should apply the *Principles Guiding Care at the End of Life* to all care, both curative and palliative, in the ICU.

Appendix

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Invited Commentary

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I feel honored to have been asked to comment on this excellent article, "Palliative Care in the Surgical Intensive Care Unit." The article is especially informative in bringing together all the recent interest and research in this area. In this era of evidence-based medicine, I found that the authors provide a wonderful reference for those who are not sure how to "jump in." Because I "grew up" with the development of Surgical Intensive Care and had to learn about palliative care on-the-job, I thought I might record my associations in the order that they occurred as I read the manuscript. For me, these associations represent what I learned from my patients and their families over the years. I hope that they can provide