

Trauma Care and Palliative Care: Time to Integrate the Two?

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The phrase “palliative care in trauma” might seem an oxymoron if we think of the traditional definitions of palliative care and trauma care. Palliative care as defined by the World Health Organization is “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.” The principles of palliative care encompass excellent communication, pain and symptom management, goals of care, bereavement, and spiritual support, usually for patients who are at the end of life. Conversely, trauma surgery is focused on acute care of the critically injured, where decisions and care are provided to rapidly cure the patient and prolong life, often no matter the cost in suffering and resources. If the patient dies it is often suddenly, in the emergency room or the operating room, leaving little room for the traditional notions of palliative care as we know it.

Recent developments in society and medicine have highlighted the importance of end-of-life care and the gap between how we wish to die and how many of us do die. These developments have spread to surgery as well, with increased attention to palliative and end-of-life care in the practice and study of surgery, as demonstrated by the recent publications in this journal and others. But this trend brings with it inherent conflict in values, both for society at large and within medicine. Nowhere is this more apparent than on the trauma service. On one hand, the public increasingly values death with dignity, free of life-prolonging machines, but it also values high-technology trauma and critical care, with its potential for cure and dramatic life-saving maneuvers. Death from trauma is a tragic event, often afflicting young and previously healthy people. It is rarely peaceful or dignified. This conflict is further played out in the current practice of trauma care. The role of end-of-life care in trauma

surgery remains ill defined, and is often something to offer only when all other options have failed. *The American College of Surgeons Committee on Trauma Optimal Resource Manual* defines an ideal trauma system to “include all the components identified with optimal trauma care, such as prevention, access, acute hospital care, rehabilitation, and research activities.”¹ Palliative or end-of-life care has not been considered an essential feature of the trauma system and, if provided, is often relegated to other services or providers, often in the last minutes or hours of the patient’s life when care is deemed futile. Trauma surgeons and other specialists have little expertise and training in the skills of palliative care, such as communication, and pain and symptom management. If all of this is so, then how can palliative care be integrated into trauma care and, more importantly, should it?

Several trends in healthcare in general and trauma care in particular suggest that palliative care can and should be integrated into trauma. First, despite all efforts, 10% to 15% of trauma patients who make it to the hospital will die from their injuries. An additional percentage of survivors will be disabled or functionally impaired. Clearly, because end-of-life care is increasingly valued, appropriate management of death must become part of the daily workings of a trauma service. Second, demographics suggest that the population is aging; this is reflected in the demographics of trauma admissions. The elderly are increasingly represented on the trauma service, with the oldest old a fast growing group suffering from injury. Outcomes studies clearly demonstrate increased mortality for the elderly trauma patient, both in the hospital and after discharge, compared with younger adults or age-matched elderly who have not been injured.^{2,3} This group is more likely to have chronic life-threatening illness, advance directives, and preferences for end-of-life care that may involve limitation of life-supporting technologies.⁴ As the situation of elderly trauma patients becomes more frequent, quality end-of-life care becomes a more important part of trauma care. Finally, the evolution of trauma care itself portends a

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greater focus on quality of life and functional outcomes as important endpoints along with survival. Several studies suggest that if greater attention is paid to interventions in the acute hospital setting to improve parameters such as psychosocial support and symptom management, longterm functional outcomes and quality of life may be improved.^{5,6} The case can be made that palliative care is as important for survivors of trauma as it is for the dying. Because death or disability are inevitable outcomes for a significant percentage of trauma patients, comprehensive trauma care must expand to include compassionate, appropriate palliative care alongside the expert curative care already provided.

Although the case can be made for incorporating good palliative care into trauma care, how to do so and for which patients is neither obvious nor easy to accomplish. The nature of traumatic injury, its natural history and trajectory to death, and the psychosocial issues surrounding it for survivors and families, are unique and different from those of other diseases, necessitating a different approach to palliative care, the skills required, and its time frame. In addition, trauma systems and the culture of trauma as a surgical specialty often create subtle barriers to providing good end-of-life care. The remainder of this article describes two cases that illustrate the need to provide palliative care for trauma patients, the challenges to doing so, and some potential solutions.

Palliative care in sudden traumatic death

A young man is brought by ambulance to the emergency room after a single transcranial gunshot wound to the head. He has been intubated in the field and arrives with a Glasgow Coma Scale of 3. He shows no evidence of spontaneous movement and pupils are fixed and dilated, but he has spontaneous respirations. His blood pressure is 90 systolic. Resuscitation is initiated with IV fluids and ventilator support. During this time the family arrives in the waiting room. They are his mother, grandmother, two teenage brothers, his girlfriend, and their 4-year-old son. Although brain death is imminent, the patient has signs of life, and consideration is made for ongoing resuscitation, despite the poor prognosis. Within the next few minutes the patient has a cardiac arrest and cannot be resuscitated. He is pronounced dead after only 15 minutes in the emergency room. The clerk comes in and informs you that the family is very anxious in the waiting room and someone needs to talk to them.

Clinical details often differ, but the majority of trauma deaths in the hospital occur within hours of onset of injury. Management of these sudden deaths and their aftermath are often ignored in trauma systems and palliative care services alike. The bereavement needs of the family and postmortem rituals are not emphasized, and the skills necessary to address them are not considered part of clinical trauma care for physicians despite the fact that such deaths are routine and physicians usually are called on to deliver bad news and support families. After only 15 minutes in the hospital there seems to be little room for palliative or end-of-life care. The physicians and nurses have no relationship to the patient or the family; there are no difficult decisions to be made about withdrawal and withholding of life support, and there are no symptoms to be managed. How then is palliative care even relevant in this setting? In reality, management of the death once it has occurred is as important as life-saving care. Although alleviation of the patient's suffering is not particularly relevant in this clinical case, alleviation of the family's suffering becomes the important goal. Compassionate communication and support for the family is paramount. How this is done has long-lasting effects for grief and bereavement.⁷ Several studies now show the positive impact of hospital bereavement services on survivors' mental health and function, and on other issues such as consent to organ donation.^{8,9} There has been little formal attention to this aspect of trauma management. Bereavement support personnel or palliative care professionals are not standard members of a trauma center staff. This type of support is often provided informally by other personnel, despite the fact that evidence suggests that specific parameters for family presence at resuscitation, death notification, breaking bad news, and the ability to see the loved one's body after death are vital to the bereavement of family members.^{7,8,10,11} Studies also suggest that bereavement outcomes of families of patients who die unexpectedly, as frequently occurs from trauma, are worse than those whose loved ones' death was expected from chronic illness.^{12,13} The case described presents several opportunities for interventions that should be used. Before the patient suffers cardiac arrest, the family should be offered the opportunity to see and touch him. Studies have shown that survivors who witnessed resuscitative efforts in the emergency room while accompanied by a staff member had no traumatic effects from the experience.^{14,15} In one study, 94% of family members who were present reported it as helpful.¹⁶ In another study

done in Britain, family members who were present at resuscitations demonstrated lower levels of anxiety, depression, posttraumatic avoidance behavior, and “intrusive imagery,” such as flashbacks of the event, than did those in a control group of relatives who did not attend the resuscitation.¹⁷ The bereavement support professional should ask the immediate family members if they want to see the patient, explain all that they will see, and tell them that they may go in only for a very short time. They should be brought into the room two at a time and not left unattended. They should be invited to kiss or touch the patient and then escorted back to the family room.¹¹ This process allows the family to witness the heroic attempts to save the patient’s life and also begins to prepare them for the eventual death. Not all resuscitations are amenable to family presence, and not all families want to be present. Guidelines for when and who should attend are not clearly defined, although it is clear that a bereavement support person who is not caring for the patient must be free to accompany the family, provide support, and interpret events. Sudden, unexpected death is a significant factor in complicated mourning.¹² Schut and colleagues¹⁸ systemically studied posttraumatic stress disorder and bereavement. They found this disorder to be frequent among bereaved individuals and often correlated with the perceived inadequacy of the goodbye said to the deceased. This study concluded that creating opportunities for “saying farewell” might be an important component that can facilitate recovery. If palliative care is the active total care of patients and families with respect to physical, psychologic, and spiritual suffering, then palliative care must include bereavement interventions beginning in the emergency room and following the family to the trauma intensive care unit and beyond. After the pronouncement of death in the above case, the family must be told in a clear, caring manner by a professional skilled in this task. Jurkovich and others¹⁹ studied 58 families whose loved one died after a short stay in the emergency room or intensive care unit. They concluded that the manner in which families are told of the death has a lifelong impact on the survivors. The behaviors and personnel that families found most helpful were a caring attitude and a well-informed, sympathetic caregiver who gives a clear message and is able to answer questions. Special attention should be paid to bereaved children, because often there is confusion about what information and support are appropriate for different age levels. In this case, for example, the patient’s 4-year-old son will be exposed to strong displays of emo-

tion. His needs must be addressed by professionals in a developmentally appropriate fashion. A child’s understanding of the concept of death is related to emotional and cognitive development. Young children cannot comprehend the irreversibility of death and need frequent reminders of the reality that the dead person is not going to return.²⁰ Simple, clear information about the young child’s reaction to the sudden death of his father should be given to his primary caregiver. Printed information that is easily understandable should be given to them to take home. Iverson¹¹ has published a simple but thorough list of adult behaviors that are helpful to young children. It is essential that the child be told the truth in words he can understand. To do otherwise not only delays his understanding of what has occurred but can also lead to distrust of adults. Real words should be used to describe what has happened such as: “your dad was shot in the head and the doctors worked really hard to try to fix him, but his body just stopped working and he died.” Children take their cues from their adult caregivers, so this little boy will be watching their behavior very carefully. He needs to be assured that his mother is okay and that she will not abandon him. There are no published studies that support a young child’s participation during the resuscitation, but there is support for his attendance at the funeral rituals.^{20,21} When children are told in advance about what to expect and are given the opportunity to attend the funeral ritual, most elect to do so. As described above, management of sudden death and its aftermath in the trauma setting is primarily focused on communication and bereavement support for the survivors. Because a high proportion of trauma deaths occur suddenly, attention to these services and skills are critical for trauma-care providers. Although the majority of trauma deaths occur in this fashion, in the emergency room or operating room, another 20% to 30% of the injured will die after a prolonged ICU stay, often amidst uncertainty of prognosis and goals of care. Here, end-of-life care is more complicated, as illustrated by the following case.

Death in the trauma ICU

A 55-year-old man is brought to the emergency room after a motor vehicle crash. He has a Glasgow Coma Scale of 12 and is hypoxic on 100% oxygen by mask and is intubated immediately. His injuries include traumatic brain injury with multiple contusions and subarachnoid hemorrhage, pulmonary contusion, rib fractures, and pelvic fractures. His course is complicated by

respiratory failure, renal failure, and prolonged coma. His family states that the patient would not want to remain ventilator dependent or live in a nursing home, but if there were a good chance for meaningful recovery he would want full support and surgery. The patient's Injury Severity Score is 41 and his probability of survival is 49%. It is difficult to convey the uncertainty of the prognosis to the family and advise them on the treatment options, but after a family meeting, a time-limited trial of therapy including continuous venovenous hemofiltration is instituted and the patient improves. He undergoes pelvic surgery and his renal failure resolves, he is off dialysis, and his infections are successfully treated but he remains comatose and ventilator dependent. The family again raises the issue of withdrawal of the ventilator, because the patient's wishes were not to have his life prolonged by artificial means if he could not return to his previous quality of life.

Is the patient at the end of his life? What is his expected quality of life and function, and are they acceptable to the patient? Can appropriate palliative care make it any better? What is the prognosis both for his traumatic brain injury and his respiratory failure? What would the patient want? How does the family's bereavement and understanding in a crisis affect their decisions around the end of life? This case illustrates the challenges and barriers to providing end-of-life care for trauma patients who survive their initial injury; these challenges are different because of the natural history of traumatic disease itself and the unique experience of bereaved families who must be surrogate decision makers. In addition, the culture of cure and rescue that defines the trauma service and trauma surgeons can make transition to palliative care and goals difficult. Clearly, the now well-described palliative care principles in the intensive care unit—good communication and bereavement support, transition in goals of care, pain and symptom management, and withdrawal and withholding of life support—are critical for caring for these patients.²²⁻²⁴ But the challenges posed by the nature of trauma necessitate subtle yet different approaches to end-of-life care and the interventions needed to improve it. How each of these factors affects palliative care in trauma is examined below. First, once the patient has survived his initial injury there is considerable uncertainty about the ultimate outcome. Many patients succumb to multiple organ failure and sepsis, with a long trajectory to death; others with a similar injury pattern and organ failure will recover and survive to discharge. This has been considered a major

obstacle to providing end-of-life care for trauma patients because, in the face of uncertain prognosis, both societal values and healthcare practice lead us to err on the side of doing “everything” rather than on the side of doing “too little.” Prognostic scoring systems abound in trauma, and patients can be stratified by Injury Severity Score, TRISS, Glasgow Coma Score, and Multiple Organ Dysfunction Score. In theory these are helpful, but in practice, for the individual patient, they are not. As in the case above, the probability of survival (TRISS) at 50% provides little guidance for decisions regarding withholding or withdrawal of life support. Studies have better established prognosis and disease trajectory for other diagnoses in the ICU, such as bone marrow transplant and AIDS, which have informed appropriate end-of-life care management for these patients.^{25,26} Although these principles can be applied to trauma patients dying in the ICU, the question of how, when, and for which patients remains a barrier. The presence of severe multiple organ failure in a trauma patient does not necessarily portend death, as it may in a bone marrow transplant patient. It seems unlikely that prognostication will improve sufficiently to affect end-of-life decision making in critically ill trauma patients. The SUPPORT (Study to Understand Prognosis and Preference for Outcomes and Risk of Treatment) study suggests that even when increased information on prognosis is provided to physicians, there is little change in end-of-life care with respect to DNR orders or withholding or withdrawal of therapy: 50% of critically ill patients were still on life support and in pain within 3 days of death.²⁷ Although studies have shown that the majority of patients dying in an ICU have life support withdrawn or withheld before death,²⁸ there is wide variability based on type of ICU and provider.^{29,30} How and when these decisions are made for critically ill trauma patients have been poorly studied. The presence of severe traumatic brain injury seems to be associated with withholding or withdrawing of life support in some studies,^{31,32} with decisions made based on a perceived poor prognosis by physicians for survival or persistent vegetative state.³² Elderly age rather than injury or illness severity seems to be the most consistent patient variable in changing to a palliative type of care in the trauma intensive care unit.^{31,33,34} The physician caring for the patient and the perception of prognosis is possibly a more important determinant of end-of-life decisions.³³ When offered a case scenario similar to the one above at a symposium on withholding and withdrawing of life support at the American College of Sur-

geons Clinical Congress, surgeon opinion varied about end-of-life decisions for the patient, demonstrating how provider bias and attitude affects end-of-life care. But when the patient's age was changed, they changed their decisions, with many more likely to withdraw support if the patient were 80 than if the patient were young.³⁵ In the face of prognostic uncertainty about survival, two fundamental shifts in care must be accomplished in order to ensure palliative care for trauma patients when needed. First, it is important to redefine outcomes beyond life and death. Quality of life and functional outcomes are important to patients and families, and, as in the case above, a poor quality of life may be a worse outcome than death. Although more data on quality of life and functional outcome following injury have come forth, the acute injury and preexisting illness factors that can predict these outcomes remain indistinct. Although admission Glasgow Coma Score is useful for predicting mortality from traumatic brain injury, it has proved a poor predictor for functional outcomes in survivors. Preferences and goals of care should be elicited from patients (usually families as surrogates) regarding what outcomes are acceptable and what procedures or burdens they would endure to reach those goals. In the face of uncertainty sometimes a range of outcomes must be communicated to the family so that they can begin to consider choices. Likely outcomes are perhaps the most important factor influencing patient and family proxy decisions for withholding and withdrawal of life support.³⁶ Many patients have strong preferences regarding withdrawal of therapy, for example, if persistent coma or vegetative state is likely, but many others do not.³⁷ Assumptions by physicians that a poor quality of life or elderly age universally means people prefer withholding of therapy are unfounded. Second, if it is unclear who is dying, then it is important to incorporate palliative care early in the patient's course (communication of possible outcomes, bereavement support, symptom management) so that when the outcome becomes clearer, families and physicians are ready for a transition in goals of care from curative to palliative. Communication between physicians and families and nurses and families is a vital component of both palliative care and trauma care. Studies suggest that good communication can affect outcomes in many areas, and patients and families rate it as highly important in their perception of quality of care.^{38,39} It is also increasingly clear that the quality of communication around end of life can affect decisions regarding DNR and withdrawal of life support, and

that, in turn, physician attitudes about death and dying will affect that communication.^{39,40} Little is known about communication between trauma physicians and families, and its impact on end-of-life decisions, perceptions of outcomes, and preferences. As illustrated by the case, another feature that makes palliative care difficult in trauma is that traumatic injury is sudden, and the patient is often young and previously healthy. By virtue of the fact that injury is traumatic or even violent, it creates stress and crisis conditions for families. Grief is more likely to be complicated if the death or illness occurred unexpectedly. The bereavement and psychosocial needs are different from families of patients dying from chronic illness. Families may be unwilling or unready to accept death as a possible outcome, profoundly affecting end-of-life decision making for surrogates and leading to conflict with healthcare providers. Studies have shown that if patients perceive the prognosis to be poor, they prefer palliative care rather than life-prolonging therapy, but many are either unable or not ready to perceive an accurate prognosis.⁴¹ Qualitative data from the SUPPORT study also suggest that readiness to accept death of a loved one is a prerequisite to accepting palliative care.³⁹ The acute nature of traumatic injury may have an associated prolonged course to readiness; further research into this process is necessary so that appropriate, trauma-specific support interventions can be addressed to ensure appropriate end-of-life care. Early psychosocial and bereavement support, as well as communication with physicians and nurses, has clearly been shown to improve later end-of-life decision making and reduce conflict. Again, in the trauma setting, this support should be offered to all patients and families, regardless of prognosis; data suggest it not only facilitates end-of-life care but may improve overall quality of care in the intensive care unit.^{42,43} Lastly, the culture of cure on the trauma service does not traditionally allow room for palliative care as part of the mission of comprehensive trauma care. Death is regarded as a failure and can be met with shame by surgeons.⁴⁴ It is universally a bad outcome, defined by morbidity and mortality conference, and not by the patient's preferences or goals. Palliative care is seen as something to do when there is nothing else to do. Surgeons, just like patients and families, might not be ready or accepting of death for the patient. Studies suggest that the closer relationship a physician has with a dying patient, the more optimistic he is about the prognosis.⁴⁵ Although there are little data on whether the surgeon-patient relationship is affected

in the same way, one can speculate that while caring for a critically ill trauma patient, prognostic uncertainty may lead to a delay in end-of-life care. This culture of cure on the trauma service has also historically undervalued the palliative principles of pain and symptom management for the injured, although there is evidence that this is changing. The myth continues that life-saving care and symptom relief cannot be provided simultaneously, because of the bias that relief of physical suffering such as pain can have adverse physiologic consequences or mask important diagnostic findings. Concerns about pain medication worsening shock, hypotension, or respiratory failure, have been shown to prevent adequate pain management in the trauma setting,⁴⁶ despite the fact that there is little substantive evidence that analgesics have a clinically significant adverse effect.⁴⁷ Recent literature has disproved the notion that morphine will obscure diagnosis in patients with abdominal pain.⁴⁸ Historically, standard burn treatment has included pain relief as an essential part of therapy, and this is beginning to extend to other trauma care as well. Several studies in burn centers have demonstrated that inadequate acute pain management can lead to posttraumatic stress disorder or poor quality of life later.⁴⁹ Attention to pain and symptom relief in the intensive care unit and elsewhere may reduce acute stress and posttraumatic stress disorder among survivors, and there is little reason to wait past the resuscitation phase of care to attend to this suffering. As we learn further about quality-of-life outcomes after injury, the principles of palliative care, such as relief of physical pain, will become increasingly important for the survivors and the dying.

Redefining palliative care in trauma

To compassionately and appropriately care for these trauma patients, we need to expand our notion of trauma care to include alleviation of suffering alongside curative care, both for patient and family, and expand our notion of palliative care to include the care of the patient who dies suddenly and often violently from trauma, as well as for the family. The sudden death of the young man by gunshot wound and the lingering ICU course of multiple organ failure both illustrate difficult, yet common situations in trauma care when management of death is so important. To address these difficulties one must redefine preconceived notions of palliative care and trauma care. First, palliative care must be redefined to include care for families of victims of sudden

death. Here bereavement support and attention to the communication of bad news and after-death rituals are critical. These interventions should be standard in emergency rooms, hospitals, and trauma centers, and the literature supports this concept.

Although palliative care for the ICU trauma patient is similar in principle to that of other critically ill patients, it also requires a fundamental shift in philosophy. Although life and death are seen as dichotomous, palliative care and curative care should be viewed as two parallel therapies that are not mutually exclusive. If it is unclear who is dying or who will have a poor functional outcome, it is important that curative and palliative care be offered simultaneously, starting early in the patient's hospital course, so that if a transition in goals of care is needed, it can be done seamlessly. Leaving palliative care to the last few days of life in the ICU, when futility becomes apparent, will prolong suffering unnecessarily. On the other hand, premature withdrawal or withholding of therapy when it is not consistent with a patient's goals or preferences is not appropriate either. Palliative care in the trauma ICU should include early bereavement and psychosocial support for families, early and consistent communication about likely outcomes, patient wishes, therapeutic choices, and appropriate symptom management.

It is critical as well that these services be integrated into the workings of the ICU and trauma service. Trauma providers in general and surgeons in particular have had little formal training in the principles and skills of palliative care. Historically there has been little focus on these issues in the trauma literature, although this is changing. Education of providers, performance improvement, and peer review should incorporate the principles of palliative care as they apply to trauma patients, or it will continue to be either optional care or care tacked on at the end of "usual" care. One can make the case that fundamental knowledge and skills in communication, giving bad news, grief and bereavement, DNR discussions, and the ethics of withdrawal and withholding support are essential components of trauma practice. Not only must providers know when to use these skills so the transition in goals of care, from cure and life saving to comfort and palliation can occur, but trauma systems must evolve to support these transitions with guidelines and trained personnel. As more attention is focused on these issues in clinical and outcomes research, what con-

stitutes appropriate and quality palliative care in trauma will become more apparent.

Appendix

Executive Group, Surgical Palliative Care Task Force,
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Geoffrey Parker Dunn, MD, FACS, Erie, PA, Series
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