

End-of-life care in trauma

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It is an incredible honor and privilege to serve as your 2014 to 2015 president. The Western Trauma Association (WTA) means a great deal to me. Ron Fischer and Larry Reed invited me to my first meeting in 1991 at Jackson Hole where I presented my first WTA article, which was on mucormycosis.¹ Although our meeting has always been informative—and this year is no exception, it is the friendship that I have made over the years that truly makes this organization unique—my Western Trauma Family!

I would like to recognize and thank a number of people that have been instrumental in making this year possible for me. I met J. Wesley Alexander as a medical student in Cincinnati. It is because of Wes that I entered the ranks of academic surgery.

Working with Tom Stellato at Case Western Reserve during my laboratory year gave me the opportunity to present and further reinforce my decision for academic surgery.

I met Ron Fischer at the American Association for the Surgery of Trauma meeting in Montreal. He and Larry Reed recruited me to Houston and, most importantly, introduced me to the WTA.

Through the WTA, I also met one of my major academic mentors, Dr. Fred Moore. Although he occasionally tried to kill me on the ski slope, he created an incredible clinical laboratory during his many years in Houston, and I was fortunate to be a part of it.

In Sacramento, at UC Davis Medical Center, I had the honor of working with two powerful role models, Dr. Julie Freishlag, who you will meet later this week as she gives the 2015 “Paint the Ceiling Lecture,” and Dr. Diana Farmer, our chairman, who has graciously joined us for my presidential address. I also have a wonderful division, led by Dr. Joe Galante, who is patiently waiting for a WTA membership slot to open, and also includes the WTA secretary, Dr. Dave Shatz. Another colleague, Dr. Skeeter Salcedo is being introduced to his first WTA here in Telluride. I am also very proud of a current resident, Dr. Rachel Russo; a former resident, Dr. Alison Berndtson; and one of my surgical critical care fellows, Dr. Katie Romanowski, who all have presented at this year’s meeting.

I want to recognize my nephews, Colonel Niles Cocanour and Lt Col Spence Cocanour for joining me in Telluride this week and thank them for their service to our country as well as to all who serve and protect our great country. It is a great honor that they took time off from the Air Force to be here.

However, it is my parents that I must truly thank. It is in their memory that I want to dedicate this talk. My dad was born in 1915 and my mom in 1918. Growing up through the great depression, they instilled a strong work ethic in all three of their children. My parents did not have the opportunity to go to college, yet they raised three children who all received advanced degrees. During my high school years, after the death of my grandfather, my father’s mother came to live with us for a part of the year after having had numerous strokes. My mom made it quite clear that if this ever happened to her, she did not want to live this way. The cruel irony is that mom developed Alzheimer’s disease and became incapacitated. Dad cared for her at home with home health care assistance until she died in her sleep in 2001. Having been married for nearly 63 years, dad, I expected, would follow her in death in short order. He said many times that he was ready for death; he had lived a good life, but this was not to be. His reason for getting up and moving was then gone, and since it hurt, he did not move any more than he absolutely had to. It was not a matter of him breaking a hip but when. When it happened, it started the downward spiral that led to his death in a nursing home in 2006. Both mom and dad had numerous conversations with all of us as to what they wanted and did not want at the end of their lives. It is because of their strong stance on end-of-life care that I chose this topic, end-of-life care in trauma.

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Trauma is the epitome of care focused on diagnosis, aggressive resuscitation, and cure. Yet, even with our best efforts, 10% to 20% of trauma patients will die. Both age and a rising Injury Severity Score (ISS) are clearly associated with mortality. As trauma surgeons, we face end-of-life decisions everyday—the patient with the nonsurvivable head injury, the patient with bleeding that cannot be controlled, the patient with multiple-organ failure that has no hope of survival. Patients are often young, without advance directives and whose prognoses are uncertain. Their bereaved families, themselves in crisis, must become surrogate decision makers about limiting life support. Conflict is common around goals of care. Families of critically ill patients have symptoms of traumatic stress disorder both during and after a relative's stay in the intensive care unit (ICU), and trauma may exacerbate this because of its acute, unexpected nature. Many of these deaths are in young patients; after all, trauma has always been considered a disease of the young, but that is changing.

As the baby boom generation becomes senior citizens, they are changing the face of health care. Not only are they more active, but they are also joining the ranks of senior citizens in unprecedented numbers. In 2002, the population of 65 years and older was 35.5 million; in 2012, it has increased by 21% to 43.1 million and is projected to increase to 79.7 million in 2040.² Those older than 85 years are projected to increase from 5.9 million in 2012 to 14.1 million in 2040.²

We are seeing more and more of the elderly in our trauma resuscitation rooms. Figure 1 shows the increase in older patients at UC Davis Medical Center from 2007 through 2014. Although it is not a huge increase, those older than 65 years accounted for approximately 12% of trauma patients in 2007 and are now 20%. At approximately 12%, they consumed 25% of trauma-related health care resources. Because of their underlying comorbidities and decreased physiologic reserve, they have higher complication and mortality rates.

It is projected that total US health care expenditures will reach \$5 trillion by 2022 from its current level of \$3 trillion.³ According to the National Institutes of Health, as of 2012, 5% of the most seriously ill Americans accounted for more than 50% of health care spending, with most costs occurring during the last 6 months of a patient's life.⁴ Nearly 30% of all

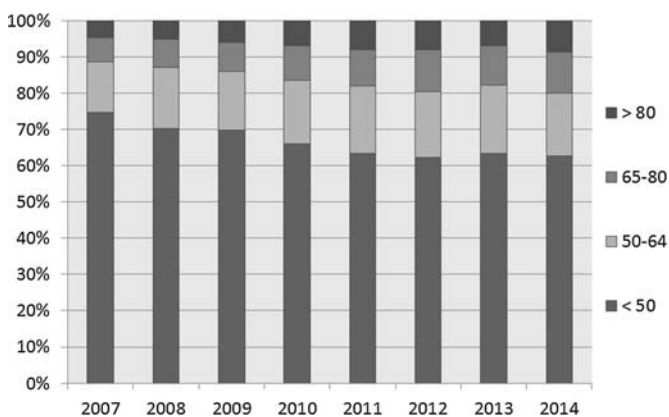


Figure 1. Changing trauma demographics at UC Davis Medical Center.

Medicare spending occurs during the last 6 months of a patient's life.

Trauma expenditures are estimated at 80.8 billion in medical care costs and another \$326 billion in productivity losses.^{5,6} The mean trauma expenditures per person for those older than 65 years was greater than twice the cost for those younger than 65 years. When extrapolating the end-of-life costs with the increase in older trauma patients, the results are truly sobering.

As a consequence of the increase in numbers of elderly trauma patients, more focus is being placed on functional outcomes and the quality of life, not just mortality. It is becoming clear that end-of-life care needs to be addressed for all trauma patients—young and old.

Over the years, I have taken care of numerous patients who have not survived their injuries. Several have been indelibly etched on my memory. An 85-year-old man fell, fracturing his neck, injuring his spinal cord, and arriving in the emergency department as a quadriplegic. He was intubated and admitted to our ICU. His daughter came in the next day and asked that we withdraw care because he would not want to live as a quadriplegic—even if he would have been able to survive the hospitalization. We extubated him, and to our surprise, he was awake enough that they were able to say their goodbyes. Several months later, I received a thank you note from her. She had come in that day, expecting to have to fight to honor what she knew were the decisions that he would want. She told me in her note that she thought that she would have to fight to have care withdrawn, but I had made a very emotionally difficult experience much easier than expected. Another 85-year-old, in fact, she had just turned 85 the day before, was involved in a motor vehicle crash. Her injuries were severe. She did not have a head injury and was awake on her arrival to the emergency department, but she had multiple bilateral rib fractures, bilateral pulmonary contusions, and bilateral hemothoraces. She had a severe pelvic fracture that would require surgery and long-term immobilization. She also had a thoracic aortic injury that would require an open thoracotomy because her femoral vessels were not amenable to an endovascular repair. By the time that the vascular surgeon had seen her and reviewed her films, her family arrived. They knew what her wishes would be in this situation. They had often talked about what was important to her, and they knew that if she was never going to be able to work in her garden or in her kitchen, she would not want to be made to go through what was, at best, a long, arduous hospital course to be followed by a prolonged period in a skilled nursing facility and even more likely death. They asked that we make her comfortable, which we did, and she died a few hours later.

There has been a shift during the 30 plus years that I have been in medicine. We have gone from almost never withdrawing care, using all of our available technologies, even with knowing that the likelihood of survival was nil, to being much more likely to withhold and withdraw life support technology. Advance directives have much greater emphasis.

Both of the patients that I described had talked with their families about what was important to them and what they were willing to go through. They exemplify the influence of advance directives.

The Patient Self-Determination Act enacted in December 1991⁷ required that health care providers, predominantly hospitals, nursing homes, and home health agencies give patients information about their rights to make advance directives. Advance directives provide an opportunity to improve the tenor of care during the inescapable end-of-life process. The Institute of Medicine in its report “Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life” concluded that “a patient-centered, family-oriented approach to care near the end of life should be a national priority and that compassionate, affordable, and effective care for these patients is an achievable goal.”⁸ However, unfortunately, only approximately 25% to 30% of Americans have executed advance directives. The exception is the hometown of one of Western Trauma’s former presidents, Dr. Tom Cogbill, La Crosse, Wisconsin. In La Crosse, 96% of those who die have signed an advance directive.^{9,10} They achieved this through communication—they talked about it. In the 1990s, local medical leaders headed a systematic campaign to get medical personnel and patients to discuss end-of-life wishes. Now called *Respecting Choices Advance Care Planning*, the original idea was to create an end-of-life plan for these patients while they could still make conscious decisions. Within 2 years, advance directives in La Crosse rose from 2% to 45%. By 1995, 85% who died had advance directives, and by 2009, that number had risen to 96%. Innovation in end-of-life care requires highly personalized local solutions with the patient and the family at the center of the process. The advance directive form cannot just be handed to a patient or family and expect that it will automatically be completed; it is a psychological and familial journey that requires the engagement of the patient and their most trusted and loved family and friends. The discussion, not the list of choices of what they want, is what matters most.

Most end-of-life discussions center around the patient with either chronic illness or cancer. These patients’ course toward death is slower, often with ups and downs. Patients and their families have more time to acknowledge the disease and the alterations in health and daily activities that come with illness. Trauma is abrupt. A fully functioning person and his or her family are suddenly, without warning, thrown into the medical maw. There is no time to choose a physician, let alone develop a relationship with one, before injury occurs. The patient is at the mercy of the call schedule. Surgical culture pushes this further. We are engrained from medical school that surgeons cure no matter the burden or cost. We measure success not by quality of life but by morbidity and mortality. Death is considered a failure, and we associate palliative care with giving up.

Palliative care is not only for those at the end of life. Palliative care is an also approach that improves the quality of life of patients and their families when facing life-threatening illness, through the prevention, assessment, and treatment of pain and other physical, psychosocial, and spiritual problems.

Anne Mosenthal is a trauma surgeon and a boarded palliative care physician. She found that when a structured interdisciplinary model for palliative care was integrated into standard ICU care, the rates of mortality, do-not-resuscitate (DNR) orders, and withdrawal of life support were unchanged,

but DNR and withdrawal of life support occurred earlier in the hospital course, and as a consequence, ICU length of stay was decreased in those who died.¹¹

The clinical intervention consisted of a six-step pathway for all patients admitted to the surgical ICU. Each step was based on time from admission, not on prognosis. The family and the patient were considered the unit of care. Care was directed at pain and symptom management and shared decision making even if death was an unlikely outcome. These six steps are as follows:

1. Bereavement and psychosocial support within 24 hours of admission to the ICU. This was provided by either palliative care counselors or pastoral care. This intervention established support for families who are often in crisis, and it lays the groundwork for communication with physicians and nurses.
2. Interdisciplinary palliative care assessment within 24 hours of admission. This includes assessment for pain and symptoms, psychosocial and bereavement needs of family, identification of surrogate decision makers, advance directives, spiritual needs, and assessment of likely outcome and prognosis.
3. Family meeting with physician and nurse within 72 hours of admission to the surgical ICU. Evidence suggests that early communication with families in the ICU decreases conflict around end-of-life care and avoids prolongation of the dying process.
4. Comprehensive palliative care plan by 72 hours. This plan encompasses pain and symptom management, goals of care, psychosocial support for the family, and shared decision making. If appropriate, discussion of DNR or withdrawal of life support would have occurred at this time.
5. Implementation of a palliative care standing order set for patients who are identified as imminently dying. If goals of care move to a comfort care approach, this order set is used.
6. Integration of palliative care performance measures into morbidity and mortality as well as peer review.

As you can tell from this framework, communication is one of the most important tools in caring for critically ill patients. It is also one of the hardest. Surgeons are not trained in communication skills. Susan Block, who is the chair of psychosocial oncology and palliative care at Dana Farber Cancer Institute and Brigham and Women’s Hospital, regards the family meeting as a procedure that takes no less skill than performing an operation.¹² As surgeons, like most physicians, we view the primary purpose of a discussion with a patient or family as a way to lay out the facts and options, but Block views this as a mistake. “A large part of the task is helping people negotiate the overwhelming anxiety—anxiety about death, anxiety about suffering, anxiety about loved ones, anxiety about finances. There are many worries and real terrors. No one conversation can address them all. Arriving at an acceptance of one’s mortality and a clear understanding of the limits and the possibilities of medicine is a process, not an epiphany.”

So how do we talk with patients about end-of-life care? Figure 2 is from Zara Cooper’s article on pitfalls in communication¹³ and illustrates the surgeon, patient, surrogate, and systemic factors that contribute to communication breakdown.

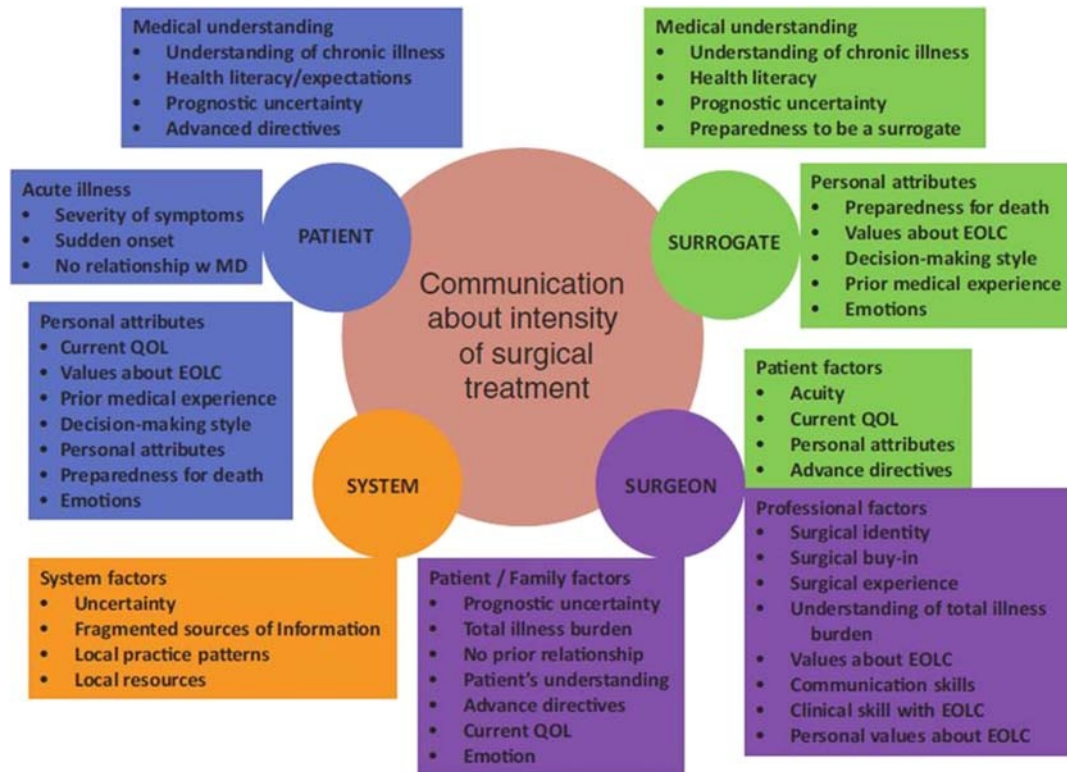


Figure 2. Diagrammatic representation of the surgeon, patient, surrogate, and systemic factors that contribute to communication breakdown. Adapted from Cooper et al.¹³

Some of the barriers that we as surgeons face are our time constraints, inadequate communication training, and a belief that patients do not want to talk about death and dying, when in reality it is probably us that do not want to talk about it. When we are in crisis situations—probably most nights on call—we are less likely to have the time and resources to undertake difficult and time-consuming discussions about end-of-life care. We are also at a loss because we are often uncertain of the prognosis; we generally tend to overestimate the prognosis and focus on a curative approach. Because of our lack of training in talking about death or providing a palliative approach to care, we are less likely to respond to emotional cues from patients. Instead, as a defense, we focus on medical details, offer reassurance, or focus on problem solving and avoidance.

There are multiple patient variables that affect end-of-life care. Race, religiosity, functional ability, and availability of family support all affect the intensity of treatment at the end of life. How patients and their families understand their prognosis influences the intensity of care that they will receive. For example, we have a very large Hmong population in Sacramento. Their culture brings many different values to end-of-life considerations and care.

Surrogates are often unprepared to use substituted judgment. Their understanding of the illness, their preparedness to be a surrogate, their own values about end-of-life care, and their emotions all bring variables that affect their approach to end-of-life care. They will often err on doing more.

There are system factors that include uncertainty about the prognosis. The fragmented sources of information—especially in trauma where multiple specialists, including trauma surgeons, neurosurgeons, or orthopedic surgeons, may all be providing information in different ways to the patient

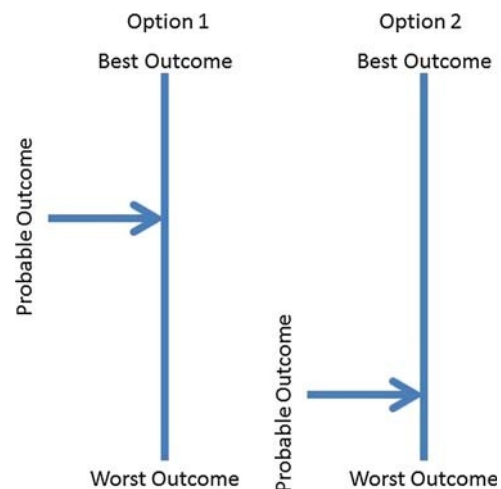


Figure 3. Schematic for describing options of care for a patient with the physician interpreting where the patient's outcome is most likely to occur.

and family. The local resources that may or may not be present and the local practice patterns can all affect end-of-life care.

Over the years, we have gone through several models of providing information to patients.¹⁴ The doctor-knows-best model or paternalistic model has the physician telling the patient only what the physician wants them to know and what they should do. This has largely gone away. The informative model provides treatment alternatives and expects the patient or surrogate to choose. Unfortunately, this may make the patient and family feel solely responsible for the decision that is made. The interpretive model has come to be called shared decision making and is the preferred method for decision making, especially in the ICU.¹⁵ It is especially useful when the outcome is uncertain and where the patient's values determine the best choice. Figure 3 shows a schematic of a best case/worst case for each option, with the physician interpreting where the patient's outcome is most likely to occur for each option given the injuries and the patient's underlying comorbidities. However, as part of this approach, it is critical that it includes the following: clarifying the patient's understanding of the injuries, the prognosis and expectations for recovery, identifying the patient's priorities and goals, determining health states that the patient would find unacceptable, and affirming the physician's commitment to the patient's well-being.

Atul Gawande¹⁶ recently published *Being Mortal*. He has made many pertinent observations on our relationships with patients at the end of their lives, our families, and our attitudes toward aging and death. It should be a required reading for anyone, but especially surgeons who care for patients who are critically ill or may die.

As physicians and surgeons, we are trained that medicine exists to fight death and disease. As trauma surgeons, we train and study to prevent, repair, and save injured patients. We treat death as an enemy, something that must be defeated at all cost, but death is not a failure. Death is normal. It is the natural order of things. Sherwin Nuland¹⁷ in *How We Die* lamented that the necessity of nature's final victory was expected and accepted in generations before our own. Doctors were far more willing to recognize the signs of defeat and far less arrogant about denying them. Gawande^{16(p187)} offered the analogy that in a war that you cannot win, you do not want a General Custer who fights to the point of total annihilation. You want a General Robert E. Lee who knows how to fight strategically, fighting for the territory that can be won and surrendering when it cannot. You want someone who understands that the damage is greatest when you fight to the bitter end.

Gawande notes that our reluctance to honestly examine the experience of aging and dying has increased the harm we inflict on people and has denied them the basic comforts they most need. How often have we been told by patient's families "to do everything," but in my opinion, just because we can do a procedure or add another pressor does not necessarily make it appropriate or right to do so. We need to examine the benefit versus the discomfort and keep in consideration the overall outcome. As a medical student, I remember the first time that I did CPR [cardiopulmonary resuscitation] during a code. The crunch of the ribs in the elderly frail patient who died

after this "heroic" attempt to save her life is something that I have never forgotten. A study of patients enrolled in hospice versus those that were given maximum therapy found that those in hospice lived longer and with less pain than those that opted for maximum treatment.¹⁸ Gawande^{16(p178)} notes that "our decision making in medicine has failed so spectacularly that we have reached the point of actively inflicting harm on patients rather than confronting the subject of mortality. If end of life discussions were an experimental drug, the FDA would approve it."

Medical science has given us remarkable power to push against the limits of the constraints of our biology. Yet, just because we can do a procedure or give another drug does not make it right or appropriate to do so.

Here are the thoughts that I would like to leave you with today.

- Our changing trauma demographics are emphasizing the need for better end-of-life care in trauma.
- Palliation is not just for those who are actively dying. Palliative care is an approach that improves the quality of life of patients and their families facing life-threatening illness. As surgeons, we need to embrace these qualities for all of our patients.
- Treat the family meeting as a skill, just as you would an operation. Make the time, sit down, and use a shared decision model.
- Critical components of the shared decision model include not only information on the medical condition but also
 - clarifying the patient's understanding of the injuries, the prognosis, and expectations for recovery;
 - identifying the patients priorities and goals;
 - determining health states that the patient would find unacceptable; and
 - affirming your commitment to the patient's well-being.
- Read *Being Mortal*

I would again like to thank all of the WTA members for allowing me to be your president.

Thank you.

DISCLOSURE

The author declares no conflict of interest.

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