

DYING IN THE INTENSIVE CARE UNIT

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The scenario is familiar. The patient, an elderly woman who lives in an assisted living facility, arrives at the hospital emergency room with pneumonia and a history of heart failure. She is intubated on the second day of hospitalization after a respiratory arrest and admitted to the intensive care unit (ICU) in a comatose state. Although she had no advance directives, her family states that she has always been clear about not wanting to be kept alive by extraordinary means if there was little hope of recovery. After 4 days of care in the ICU, the medical team wants to continue aggressive treatment (including a cardiac catheterization), but the nurses and family are united in their insistence that the woman be taken off the ventilator and be kept comfortable.

Is this situation the norm? Nurses and family members questioning aggressive treatment? Physicians eager to treat in the face of a dire prognosis? An elderly patient receiving aggressive diagnostic tests and care when there is little or no chance of recovery? If it is not the norm, this scenario (which is fictional) reflects many conversations we've heard during our combined decades of experience in the ICU. Physicians are often described as "flogging" patients when there is little hope of recovery. Nurses are usually cast as advocates for compassionate care, wanting to discontinue aggressive treatment and focus on symptom management. Certainly, words like "torture" and "suffering" appear to be used more often by nurses than physicians when assessing the effectiveness of intensive care treatment. Family members and patients, as the stereotype plays, are portrayed as united in their desire for palliative care and a peaceful death.

Anyone who has spent time working in critical care knows that, like all stereotypical portrayals, the one described here does not represent the full picture. Yet, like all stereotypes, elements of truth exist. In

many of our patients' lives, care in the ICU will absorb their last months of life. In fact, most individuals will not experience the death that in repeated national surveys they say they want; instead, they will die in the hospital after numerous procedures and treatments. Nurses will provide care that, unfortunately, will exacerbate pain, not eliminate it.

Colliding Cultures

What does dying in the ICU mean from a nurse's perspective? An article in this issue of the *American Journal of Critical Care* focuses on the moral distress that nurses working in one medical ICU experienced.¹ One of the nurse respondents in the study worried about the discomfort that might be inflicted on dying patients as part of treatment: "I'm scared that I'm causing undue pain and suffering and this causes me great distress."^{1(p526)} This particular unit was responsible for a liver transplant program, which further adds complexity to any discussion about aggressive care in the ICU—eg, when patients who receive life-saving treatments then make decisions (such as resuming alcohol or drug abuse) that result in their return to the ICU for another transplant. Other investigators²⁻⁴ have identified the major stressor of ICU nurses as being about conducting unnecessary tests and treatments and prolonging life with heroic measures.

We believe that end-of-life issues in the ICU are among the most serious problems facing the nursing and medical professions today. Unfortunately, the public discourse in this country focuses its attention on ways in which patients and families are caught up in a system of inappropriate physicians' orders and unwanted technologies; it does not focus on the real issue of dying in the ICU.

An Outsider's View

Sharon Kaufman, a medical anthropologist, spent 2 years attending rounds; interviewing nurses, patients, and families; attending ethics meetings; and immersing herself in the ICU culture of 3 different hospitals.

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The product of her intense scrutiny is an amazing book titled *...And a Time to Die: How American Hospitals Shape the End of Life*.⁵ We'd like to send the book to every medical and nursing student and place it in ICU waiting rooms across the country. Based on thousands of hours of observations and interviews, Kaufman makes the following points:

1. No one in the United States dies of old age (in fact, the last year that one could die from "old age" was 1913). People die of discrete diseases, not of becoming old, and this suggests to the public that illness is correctable.

2. The core purpose of hospital medical care is to maintain life. The organization of the institution, particularly the ICU, pushes everyone toward life-saving treatment.

3. The actual unfolding of events that give form to dying in the hospital is much less purposeful and more muddled than the public realizes.

4. Physicians and nurses use unclear terms when talking about the patient's prognosis to family members, which in turn supports increased confusion on the part of the family members who are being asked to make a decision about care options.

5. Families believe that medical technology can save life; they do not distinguish between technological support to maintain bodily functions and to save life. To families, pressure to withdraw medical support can feel like a request to commit murder.

In a perfect world, patients, their families, and their caregivers would all understand that dying is inevitable and that further treatment is futile at some point. Unfortunately, our ICU world is full of examples of healthcare professionals, patients, and/or family members who waffle in their decision about when to move from providing aggressive treatment to accepting the inevitability of death. For example, Kaufman writes about patients who had a written durable power of attorney for health care but who expressed wishes to continue life-prolonging measures once they were in the ICU, even when their condition was terminal and the treatments were unlikely to make a difference in the disease trajectory. She describes cases in which family members required an inordinate amount of time to come to grips with the potential loss of their loved ones, while critical care treatment was being delivered full bore by ambivalent nurses and physicians. Many of the nurses and physicians observed by Kaufman recognized that families needed time to accept that the patient was dying, but felt pressured to "move the families along" in the trajectory to meet hospital goals. Family meetings were held and often no decision was made. Family members were horrified to

discover that they were expected to make the decision about the time of death.

In example after example, Kaufman demonstrates that patients and families are rarely able to make clear decisions about the inevitability of death. Hope creates ambiguity in decision making, which translates into longer ICU stays and inappropriately aggressive treatment. The inevitability of death was accepted only when a series of treatments failed to make a difference in the patient's recovery. When nurses participated in giving those treatments, they experienced emotional distress because their goal was to provide comfort and relieve suffering in the face of a poor prognosis, which was at odds with the team's treatment goal of the moment.

Many of the nurses Kaufman interviewed were aware that certain patients had little or no hope for recovery, with recovery meaning that patients would be able to return to a lifestyle similar to the one they had before hospitalization. If patients survived at all, they would have a much diminished quality of life, depend on others for their physical needs and, at times, depend on mechanical ventilation and parenteral nutrition. Yet, the patients or some family members indicated that they wanted everything to keep their loved one alive. Nurses and doctors, in Kaufman's experience, frequently found themselves caring for patients and their families who had not yet faced the inevitability of death and who believed that medical advances would stave off death indefinitely. Days, weeks, and sometimes months were spent on a heroic and futile intervention pathway because family members, and sometimes patients, were unable to say, "It is time." An intensive care nurse interviewed by Kaufman wrote: "To be truly human, you must experience life bravely, and facing issues of death and dying takes courage."^{5(p205)} If courage fails, aggressive care continues.

The Future

The subject of dying in the ICU has obvious ethical, legal, and political implications. These are not the subject of this editorial. Rather, we want to focus on the human toll of dying on the heroic intervention pathway. We see this toll in studies focusing on the moral distress experienced by intensive care nurses. We see the toll in the conflict between nurses and physicians when there is disagreement about the goals of care. We see the toll in families who are asked to make difficult decisions in the face of unclear or contradictory information from various members of the healthcare team.

We believe that solutions exist to deal with the dilemma of dying in the ICU. The cornerstone of any solution is effective and frequent communication

within the healthcare team. Each individual member of the ICU team—physicians, nurses, social workers, chaplains, care coordinators—shares the responsibility for disseminating information and increasing communication at all levels, especially around end-of-life issues. The dynamic of blaming (eg, nurses blaming physicians, services blaming other services, social workers blaming nurses) for being wedded to aggressive treatment in the face of a dire prognosis creates an undue burden on the family and stress within the team. Frequent and respectful communication among caregivers about the short- and long-term goals of the treatment plan and anticipated patient response is key.

Communication among the healthcare team, the patient, and family is also essential to devising an appropriate plan, especially when the patient fails to improve with heroic measures. Care plans must contain clear criteria for success or failure so that patient response can be reviewed and communicated each day. In one study, an intensive communication intervention between healthcare providers and family members in the ICU led to the continuation of advanced supportive technology for patients with the potential to survive and allowed for the early withdrawal of advanced supportive technology when it was deemed ineffective, leading to a reduced length of stay and lower ICU mortality.⁶ Setting specific treatment goals and reviewing whether those goals have been achieved every day (not every week) will help families adjust their expectations about what can be achieved by care in the ICU.

Palliative care and hospice care (reflected in palliative care services or hospital-based comfort suites) is another alternative to aggressive interventions near the end of life. Innovative nurses and physicians continue to introduce palliative care measures in ICUs that challenge standard practices and cultural imperatives.⁷ Many of these innovations require skillful negotiation

with hospital administrators who, in turn, must battle Medicare or insurance companies for reimbursement.

Finally, speaking to the lay public about the importance of having advance directives and/or identifying a healthcare proxy is critical to making death in the ICU humane. Today, fewer than 30% of Americans have an advance directive.⁸ Although Kaufman pointed out that such directives might not always predict the will of the patient in the ICU, they are undoubtedly helpful to family members. When a decision is made to withdraw life support, family stress is highest in the absence of advance directives, lower when verbal directives have been given, and lowest when written advance directives can guide decisions.⁹ Helping our patients and their families manage expectations around care in the ICU at the end of life and clarify their desires about heroic measures will make the difficult discussions just a little less difficult.

The statements and opinions contained in this editorial are solely those of the Editors.

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