



# When the ICU Is Not the Answer

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**A** degree of stress, tension and conflict will always be associated with the treatment of most patients near the end of life. Our ethical imperative is to recognize the inherent complexities surrounding the provision of treatment and care under these difficult circumstances.

Washington Hospital in Fremont, Calif., has a strong history of working to improve and assess end-of-life care.<sup>1</sup> During discussions at the hospital's monthly bioethics committee meetings, physician members encouraged development of a policy regarding futile or nonbeneficial treatment, a topic requiring particular sensitivity to the concerns and emotions of patients, families and hospital staff. It was clear, however, that any such policy must be rooted in communicating and connecting effectively.

Communication always represents a major challenge for clinicians,<sup>2</sup> and the challenge is even greater in regard to patients who are near the end of life and placed in the ICU. Not surprisingly, significant ethical issues often arise in supporting these patients, mostly related to disagreements or a lack of understanding among patients, family members and clinical staff.

Most health care professionals realize the ICU is usually an improper set-

ting for a patient who is clearly not on a trajectory to improved health and is, instead, approaching the end of life. However, occasionally there will be some physicians or family members who are convinced that further diagnostic tests and therapeutic interventions will change the clinical outcome. They may see death as the enemy and be unwilling to concede that admission to the ICU, or a prolonged stay there, may only extend life expectancy by a few days without improving the patient's condition or prognosis. Yet good, person-centered care demands an unfaltering focus on improving the quality of end-of-life care that genuinely serves the patient's needs.

It's only to be expected that discussions around such issues can be accompanied by rising tensions. Passionate and eloquent advocates will emphasize that patients must always be the beneficiaries, not the victims, of our remarkable medical technology. They will stress the necessity of using

our limited resources more prudently, both within the institution and within society, particularly given the unsustainable increase in

the nation's health care costs.

No one would disagree with the notion that ICU beds should be available for those who would most benefit by intensive care, and few would argue with such a policy. But policy has the luxury of dealing with statistical and invisible lives that are relatively easy to address in such a broad context. When policy deals with specific individuals — patients and their families — the matter can be very different.

During ethics rounds in the ICU, the authors have found one or more recurring issues that characterize many cases. Among them:

- The patients typically have acute or chronic conditions that now or soon will require dependence on respirators, dialysis, vasopressors, feeding tubes and other comparable support. Frequently such patients no longer have decision-making capacity to direct their own care, and decision-making is provided by the family or a surrogate.

- There is no clear, patient-initi-

ated, advance health care directive documenting their medical goals and preferences.

- The family, usually suffering from profound emotional stress due to the patient's severe condition, becomes distrustful and, at times, angry with staff members, including treating physicians.

- Staff members view a family's insistence that everything be done and that all aggressive measures be pursued as unreasonable or counterproductive.

- Staff and family members have diverse treatment goals and prioritize values differently when evaluating treatment options.

- Staff members are concerned and uncomfortable when asked to provide treatment they feel is not in the patient's best interest, and they experience moral distress in providing what they consider painful and inappropriate treatment.

- Cultural, religious and other important personal issues complicate effective communication.

- The family resists or sabotages what appear to be appropriate transfers to another hospital unit, hospice care, long-term care or other facilities.

- The staff and family have difficulty understanding and appreciating each other's perspectives.

- Physicians worry that if they refuse to provide questionable or non-beneficial medical treatment that the family demands, they will be subject to legal action by the family.

Washington Hospital has a long-established task force focused on improving end-of-life care. The group is composed of representatives from nursing, the medical staff, social service, pharmacy and spiritual care. With support from an ethics consultant, the task force has worked on improving policies, revising standing order forms, initiating educational programs, creating family conference guidelines and promoting completion of advance directives by staff and members of the community.

## **Good, person-centered care demands an unfaltering focus on improving the quality of end-of-life care that genuinely serves the patient's needs.**

The task force members agreed that creating guidelines based on the concept of preventive ethics — which encourages steps be taken to avert ethical conflicts — could be helpful in assisting the staff to deal more effectively with the sorts of issues that recur in the ICU. Such guidelines also could meet such important multiple goals as:

- Enhanced person-centered care
- Perceived improvement of patient outcomes
- Greater understanding by the family of the patient's condition and prognosis
- Better staff understanding of the values and goals that are motivating the family's requests
- Appropriate utilization of the ICU
- Greater likelihood of timely provision of palliative care
- Reduced conflict between physicians/staff and families

Note that a hospital's guidelines to improve communication management of ICU patients obviously should be consistent with the organization's values and culture. The following recommendations, based on Washington Hospital's experience, are intended to help hospitals realize that formulating, following and regularly assessing such guidelines will contribute to better patient care. Moreover, the use of guidelines based on preventive ethics in the ICU should reduce the number and magnitude of issues potentially compromising patients, families and staff members.<sup>3</sup>

1. As early as possible after a patient's ICU admission, assuming the patient is unable to express his or her preferences (and has prepared no advance directive regarding such preferences and a designated surrogate), family members or friends should be asked for information about the patient's values, goals and any previously stated treatment preferences. Potential treatment goals are identified by the patient's principal attending physician in light of this information, and expectations are clarified.

2. If an advance directive has identified who will be the surrogate decision-maker, that person should be informed of his or her responsibility to make decisions that the patient would make if the patient had the capacity to do so — that is called substituted judgment. In the absence of information about the patient's preferences, the surrogate's responsibility is to make decisions that would be in the patient's best interest, taking into account whatever they may know about the patient's values.

3. If the patient has not identified a surrogate decision-maker, state laws vary regarding which family member, if any, has priority. Surrogates who seem motivated by their own interest, financial or otherwise, or by what they would want if they were the patient, should be encouraged to consider instead what the patient would want. (Separate but related policies should exist regarding unrepresented patients who have no known family members or friends.)

4. Special attention should be focused on how to speak with families. The message should be as clear and concise as possible. Discussion regarding the provision or withdrawal of treatment should be provided in language understood by family and friends; they must understand that "treatment" and "care" are two different concepts and the terms are not interchangeable. Thus, statements mentioning "withdrawal of care" are indefensible and inappropriate. In these situations, the importance of being extra sensi-



tive to the power of words cannot be overemphasized.<sup>4</sup>

5. A primary physician leader should be identified as the main communicator with family members and friends. Consulting clinicians should generally be discouraged from providing updates, deferring instead to the physician leader whose responsibility it is to synthesize the information and to provide a fuller context for any medical updates. The possibility that an individual specialist may give a positive statement about the patient's kidneys, lungs or heart, for example, can produce unrealistic optimism when taken out of context.<sup>5</sup>

6. When transferring the patient to a medical/surgical unit or to a skilled nursing facility, surrogate decision-makers should be given advance notice of the clinical rationale for the move. Similarly, writing a do-not-resuscitate or allow-natural-death order, as well as the role of palliative care and hospice services, should be discussed when it is timely to do so. Although a decision may result in withholding or withdrawing treatment, family members and friends must be assured that under no circumstances will *care* ever be withheld or withdrawn.

7. One or two family members should be identified as the primary family spokespersons. Phone calls or bedside questions from other family members on treatment goals or details of the patient's condition should be referred to the primary family spokesperson. This approach will reduce misunderstanding and potential confusion by the family and reinforce a consistent message.

8. Regular family conferences should be scheduled to provide updates and to review goals for care. The nursing staff, chaplain, social worker, case manager and others may be involved in these conferences, but they should be conducted by the acknowledged physician leader.

9. Family conference guidelines should be established to assure optimal outcomes, to document goals, to

set objectives for the next meeting and to allow time for family members to raise questions, express any concerns and to promote their understanding of the patient's current condition and prognosis. Clinicians and patient families experience time differently. Having treated many patients over a number of years, clinicians predictably will be much more knowledgeable and prepared to make challenging decisions relatively quickly. Family members invariably need more time to process and make decisions, and clinicians should respect that need.

10. Staff should be sensitive to cultural, religious and other issues affecting the family's perception of patient care. When possible, a staff or community representative with the same cultural, religious and ethnic background should be involved to facilitate understanding.

11. A timely request for an ethics consultation should always be considered in the event of continuing concerns. Ideally, principal caregivers, family members and a broadly representative ethics committee should participate.

12. Hospital risk management should be consulted if the family perceives that an iatrogenic incident or a problem allegedly caused by the staff has affected the patient's condition and prognosis.

## **Family members and friends must be assured that under no circumstances will care ever be withheld or withdrawn.**

An important part of the process is to design how to monitor use of the guidelines and to evaluate their effectiveness. Too many policies and guidelines are implemented in response to external requirements — and are viewed intuitively as having value —

but they lack appropriate baseline measures and methods of collecting data and comparing results. Therefore, it is impossible to verify that goals have been accomplished or whether guidelines need to be revised.

We must remember that patients, families and staff members are all challenged by the difficulties associated with making hard decisions. At least some of the difficulties can be reduced by not inappropriately placing patients in the ICU and by minimizing the length of stay of ICU patients who will not benefit from having been placed there. By collaborating on the development and implementation of practical guidelines to improve communications, we should be much more effective in providing not only genuine person-centered, quality care but also a more supportive working environment.

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### **NOTES**

1. Paul B. Hofmann, "Family Evaluation of End-of-Life Care — An Essential Perspective," *Health Progress* 90, no. 3 (2009): 65-68.
2. Cindy L. Munro and Richard H. Savel, "Communicating and Connecting with Patients and Their Families," *American Journal of Critical Care* 22, no. 1 (2013): 4-6.
3. Elizabeth Gingell Epstein, "Preventive Ethics in the Intensive Care Unit," *AACN Advanced Critical Care* 23, no. 2 (2012): 217-224.
4. Paul B. Hofmann, "A Better Conversation about End-of-life Care," *Hospitals and Health Networks Daily*, Sept. 12, 2012.
5. Robert R. Stavert and Jason P. Lott, "The Bystander Effect in Medical Care," *New England Journal of Medicine* 368, no. 1 (2013): 8-9. Also see Paul B. Hofmann and Lawrence J. Schneiderman, "Physicians Should Not Always Pursue a Good 'Clinical' Outcome," *Hastings Center Report*, 37, no. 3 (2007), inside back cover.

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