

A Forbidden Conversation

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This ethics case study centers on striking the right balance between patient and physician autonomy.

Readers are invited to submit cases that have led to ethical questions or conflicts, or those that caused moral distress. The Society of Critical Care Medicine Ethics Committee will solicit analyses authored by qualified ethics consultants with expertise in critical care environments. Through this process, we hope that readers will gain a better appreciation of ethical issues facing critical care clinicians, intensive care unit patients, and families of critically ill and injured patients. We believe that readers will also develop a richer understanding of the role of healthcare ethics consultants and become more comfortable in using local resources.

CASE STUDY

Intensivists are routinely faced with discussions of death and dying while in the intensive care unit (ICU). These conversations are a natural extension of goal-directed care. While cardiovascular function and oxygen delivery are important, equally important are the goals and values of patients relative to their current and future quality of life. However, these discussions can be hampered by the principle of patient autonomy, which ICU clinicians strive to uphold.

Consider the following case:

Mr. Smith, a 35-year-old man originally from Eastern Africa who recently migrated to the United States with his family, had been seen at several emergency departments in an urban metropolitan area. While his initial presenting complaint was a toothache, his medical problems grew exponentially to include, per a cardiology consultation, a “ticking time bomb” in his heart. The patient was informed that he had a heart condition that required surgery, but he was advised to wait for his insurance to clear before scheduling the procedure. He was given a prescription for pain medication and discharged. Later that day, while waiting in line to get his prescription filled, he fell to the ground. He was rushed to a nearby hospital, where it was concluded that he had had a massive stroke directly related to his cardiac condition. The patient was transferred to an ICU at a neighboring hospital and was determined to have irreversible brain damage. His prognosis was very poor, and his status worsened precipitously over the next several hours. The physicians brought in his family to discuss possible withdrawal of life-sustaining therapies and a shift of focus to comfort care interventions only.

The patient’s wife was his surrogate decision maker, but she refused to discuss end-of-life logistics as they pertained to her husband. She brought in others for support, including older men in the patient’s extended family and religious leaders. The wife refused to enter into any dialogue with the clinicians, instead leaving the discussion up to the male relatives and the religious

leadership. As it happened, the other family members were willing to discuss the patient's medical status; however, like the patient's wife, they refused to talk about end-of-life decisions—the topic the physicians felt was most important at the time. Further complicating matters, the wife never verbally expressed a desire to renounce decision making on behalf of her husband, so the clinical team continued to regard her as the legal surrogate. The ethics department was asked to assist in clarifying the appropriate decision maker, and to facilitate a family meeting to address goals of care and end-of-life decision making.

So, what action should the clinicians ultimately take?

“Physician autonomy” is a new interpretation of the well-known, much-maligned concept of paternalism. The medical community has emphatically eschewed the idea that physicians should tell patients what is good for them. Paternalism grew to signify the practice of medicine without regard to individual patient needs and goals. However, the concept of medicine as a menu of choices from which an autonomous patient independently picks options is just as demeaning and just as dangerous. Physicians are empowered by their training to do what is medically best for patients; patients endorse this empowerment by literally—or figuratively—asking for help with their medical problems. This can mean limiting care to what is appropriate, despite a wide array of technically possible therapies.

At times, the interplay of physician and patient autonomy produces a collaborative environment where feasible goals are identified by all concerned parties. Other times patients or their families are uncommunicative or disagree with physicians about goals of care. In these instances, physicians are often left to make difficult choices in the face of silence or opposition. These situations occur regularly in the ICU, where the complexity of medical decision making can be overwhelming.

The ethics team facilitated and participated in a meeting with the family, the religious leaders and the clinical team. During this meeting, a relative of the patient (who happened to work for the hospital) informed all involved that discussions around death, dying or the withdrawal of life-supporting medical interventions were expressly forbidden by the patient's and family's religion. Now fully understanding the situation, the ethics team advised the clinical team that the ethically acceptable course of action was for the clinicians to make a decision and inform the family that comfort care interventions were the only ones that would be initiated. The team made a plan to proceed with the withdrawal of life-sustaining therapies. The family maintained a defiance to the plan throughout this process, but gathered to say goodbye and ultimately yielded to the new plan of care. The patient died shortly thereafter. By shouldering the decision to stop life-sustaining—yet medically futile—care, the clinical team allowed the family to move through their grieving process without violating their religious principles.

ANALYSIS

This case illustrates several complex ethical concepts that are often faced by critical care clinicians. Standards of decision making, patient and physician autonomy, and futility are all important considerations. Underpinning the entire case is the need to honor patient, family and clinician values.

The first issue of importance in this case is choosing the standard of decision making. The preferred standard is substituted judgment, by which the family surrogate decision maker would make decisions for the patient based on knowledge of what the patient would choose.⁽¹⁾ In this case, the patient's wife declined to discuss end-of-life issues, deferring to male family members and religious leaders who, it was ultimately revealed, similarly refused to discuss these matters due to religious prohibitions. In the absence of a decision from the wife, the best interest standard was employed. The best interest standard requires that all aspects of the patient's interest be considered to determine the greatest benefit.⁽¹⁾ In this case, the team determined that withdrawal of aggressive treatment was in the patient's best interest. At issue is whether the wife actually provided enough information to make a substituted judgment. She did not merely refuse to engage in conversations about death, dying or withdrawal of treatment but “maintained a defiance to the plan throughout this process, but gathered to say goodbye and ultimately yielded to the new plan of care.” This could indicate a choice to continue with the current treatment.

The second issue relates to autonomy. Patient autonomy is cited as a goal of the process of decision making. Principlism is a moral decision-making approach that promotes a system of ethics that considers autonomy, beneficence, nonmaleficence, and justice. It is thought that principlism is congruent with all major religions and beliefs. When principlism is employed as the basis for an ethical decision, autonomy is not the only principle to be considered. Beneficence, nonmaleficence and justice are just as important.⁽²⁾ These other principles may have influenced the clinicians' decision to withdraw treatment. The case also cites "physician autonomy," differentiated from "paternalism," as supporting the expert decision of the physician when the family cannot make a decision. A physician should not be trapped by a system overly driven by respect for patient autonomy (i.e., patient autonomy should not run rampant over good medical practice), but this concept may be better reserved for situations in which a patient or family is requesting medically inappropriate treatment. In this case, the family objected to the plan to withdraw treatment that had already been instituted by the physicians involved, but the family did not specifically request additional aggressive treatments.

The final issue concerns the idea of futility. The classic bioethical definition of futility requires that three criteria be met: 1) there is a (mutually agreed upon) goal that requires a decision; 2) there is a proposed action to meet that goal; and 3) there is virtual certainty that the action will fail.⁽³⁾ Many bioethics scholars object to arguments based on futility when the true source of conflict is related to values. In this case, there was no mutually defined goal, as the family refused to engage in conversations about end-of-life logistics. The medical team did not clearly state their goal for the patient but implied that an acceptable outcome could not be achieved when the stated reason for bringing the family in was "to discuss possible withdrawal of life-sustaining therapies and a shift of focus to comfort care interventions only." Though the ongoing interventions were not futile from a physiological perspective, they were potentially inappropriate if they could not achieve the goals of care. The fact that the patient's and family's goals of care had not been determined added to the difficulty of the medical decision.

This case illustrates the complexity of end-of-life decision making in critical care and highlights problems that occur when discussing such decisions. The medical team sought an ethics consultation and made decisions it felt to be in the patient's best interest. Retrospectively, several suggestions can be made. Additional conversation with the religious leaders alone might have provided insight into how best to respect the family's beliefs while determining the best interest of the patient. Consideration could have been given to continuing current treatment but not escalating care. The patient's condition was deteriorating. A plan of no escalation may have respected the patient's and family's religious beliefs better than moving forward with withdrawal, particularly since the family did not agree to the withdrawal plan. The family refused to discuss death, dying or withdrawal of treatment but was willing to discuss the patient's medical status. As such, the family may have been willing to discuss the patient's values, preferences and goals for life. *What does the patient value most in life? What, in the patient's estimation, makes life worth living?* The team could have posed these questions to the family, and the responses might have proved instructive and efficacious as the team determined whether withdrawal and comfort care were in the patient's best interest. The final outcome may have been the same, but the decision would have been based more on respect for the patient's values as opposed to physician autonomy alone.

References:

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2. Beauchamp TL, Childress JF, eds. Principles of Biomedical Ethics. 7th ed. New York, NY: Oxford University Press; 2013.
3. Trotter G. Mediating disputes about medical futility. *Camb Q Healthc Ethics*. 1999;8(4):527-537.