Ethics Committees and Consultants at Work

To submit a case that has been reviewed by an ethics committee or to submit articles on related topics in clinical ethics, readers are invited to contact section editor Ruchika Mishra at ruchika. mishra@gmail.com.

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The Case

What Are the Patient's Real Wishes?

RUCHIKA MISHRA

Ed is a 45-year-old man admitted to the intensive care unit with sepsis and failure to thrive. He was badly injured in a motorcycle accident two years ago, resulting in multiple medical problems that have left him dependent on a ventilator. The vent makes communication difficult, although Ed can usually make himself understood by mouthing words. He often complains of pain and shortness of breath. His prognosis is very grim.

Ed has been divorced for many years and has no children. He is generally alert and has capacity to make decisions. He has designated his mother as durable power of attorney for healthcare, and she has had to make decisions for him on several occasions since his accident. She appears to be distrustful of the staff and dissatisfied with his care, despite efforts to involve her.

Recently, despite several months of aggressive treatment, both Ed's prognosis and his quality of life have worsened. It is difficult to control his symptoms adequately, especially his feelings of shortness of breath. When alone, Ed repeatedly tells staff members that he wants to stop all measures except the ventilator and be allowed to die comfortably. However, his mother insists on full treatment to keep him alive as long as possible, and in her presence Ed recants his wishes to die. She is dismissive when told about his request for comfort care, and even after being assured that a psychiatrist has assessed her son as having decisional capacity, she says, "Ed isn't in his right mind." Ed seems to truly want to stop life-sustaining treatments but seems to be equally unable to hold onto his wishes under the influence of his mother. Staff members are concerned that if Ed is given comfort care per his request, once his condition declines further, his mother will reverse the goal of care. They are also concerned about the threat of a lawsuit.

Meetings with Ed and his parents are difficult, as repeated exposures to his mother's cajoling seem harmful, and Ed tires easily from the effort of "talking" on the ventilator. His father remains passive, in effect supporting his wife. Opportunities

to limit his parents' visits, change surrogate decisionmakers, or record his wishes in writing have been offered to Ed, but he always declines. Ed and his parents also decline support from the chaplains.

During one emotional family meeting, Ed acknowledged his desire to die to his mother, saying, "I have suffered long enough." Later that afternoon, his parents presented a document to be placed in Ed's chart affirming Ed's wish to accept all life-sustaining measures. It bore Ed's signature.

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Commentary: The Problematic Proxy and the Patient's Best Interests

David Campbell

At first glance, this seems to be a pretty clear-cut case, as the patient has granted his mother durable power of attorney for healthcare decisions, has repeatedly declined offers to change his surrogate decisionmaker and record his wishes to be allowed to die peacefully, and has signed a document stating that he wants to receive all life-sustaining treatment. Therefore, it is tempting to ignore Ed's requests to let him die and instead continue aggressive treatment. This might be stressful for the staff, but at least they will be safe from lawsuits and be fulfilling their ethical duties to their patient. Or will they?

This is in fact an extremely difficult case that immediately raises some troubling questions that must be answered in order to help resolve this impasse so that the patient's autonomy is respected, his surrogate decisionmaker's hopes and fears are addressed, and his care team's ethical and professional duties to care for the patient are fulfilled. First of all, if Ed has been declared to have decisional capacity, why is his mother still his surrogate decisionmaker? Perhaps he lacked capacity in the past or wants her input for difficult medical decisions, yet the fact that he currently has capacity and can communicate his wishes makes his mother's current surrogate role problematic.

Another troubling question is whether Ed truly wants to die. Are his pleas to be left to die authentic, or are they a sign of depression or despair? Perhaps his desire to die is a cry for help in managing his pain and his symptoms. Death is final, so we have to be sure that it is an authentic rational decision, not one made out of desperation or pain. Plus, there is always the chance that Ed changed his mind after the last family meeting and now wants to live.

The medical indicators of this case must also be clear. Is Ed's condition as dire as it appears? Is Ed's mother holding onto false hopes of recovery, or is there a slight chance that Ed's condition could stabilize? How did the attending physician communicate the nature of Ed's condition to him and his mother? Are they hearing different stories from different members of the care team? Is there a sense of trust between Ed's mother and the care team? It is not uncommon for family members of ailing patients to mistrust medical practitioners' prognosis because of hasty predictions of how long a patient has left to live or their chances of recovery. It is therefore important to know why Ed's mother is still insisting on aggressive treatment and whether she truly understands her son's prognosis and the level of suffering he is experiencing.

Finally, there is the question of whether Ed's mother is a suitable surrogate