

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.

---

doi:10.1017/S0963180113000777

## **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

decisionmaker and whether she is making decisions based on Ed's wishes and his best interests or on her opinion regarding what is best for her son. She is being paternalistic and might actually be coercing her son into decisions that are not truly his own. It is also important to investigate whether she might be in a conflict of interest in her role as Ed's surrogate decisionmaker and if there are any deep psychological or financial issues that could be affecting her decision to push for aggressive treatment.

### **The Role and Responsibilities of the Surrogate**

A surrogate decisionmaker has certain ethical duties in order to make important medical decisions for another person. If the patient lacks capacity, the surrogate must exercise a substituted judgment standard in which the patient's expressed wishes are carried out. If the patient's wishes are unclear or unknown, a best interests standard based on more objective values such as quality of life should guide the surrogate.<sup>1</sup> However, there is always the danger that the surrogate will make decisions based on her subjective idea of the patient's best interests. Studies support the claim that surrogates, and in particular family members, often make decisions based on their own values and interests and not those of the patient.<sup>2</sup> Even thoughtful, well-intentioned surrogates base their decisions on what they believe are shared interests and values and have difficulty making accurate substitute decisions,<sup>3</sup> while feelings of guilt can cloud their ability to refuse life-sustaining treatment.<sup>4</sup> Therefore, it is important to have the surrogate provide reasons and justifications for her decision and that she be made aware of her duty as a surrogate as well as any possible biases or conflicts that might affect her judgment.

It is also important to note that not only surrogates have responsibilities and duties to acknowledge and respect the patient's wishes. The medical team has an ethical obligation to continually assess the surrogate's decisions and her ability to both respect the patient's wishes and act in his best interests. The care team must assess the surrogate's capacity to make informed decisions as well as the surrogate's relationship with the patient.<sup>5</sup> They must ensure that the surrogate is not being overly paternalistic or dismissive of the patient's wishes or substituting her desires for the patient's wishes. In this case, Ed's mother is clearly not fulfilling her ethical responsibilities as a surrogate decisionmaker, as she is not respecting his wishes and seems to be coercing him. Therefore her suitability as a surrogate should be challenged.

### **Possible Strategies and Solutions**

The attending physician can play an important role in helping a surrogate decisionmaker come to terms with the terminal nature of his or her loved one's illness and his or her loved one's desire to end his or her suffering by forgoing aggressive treatment in favor of comfort care measures. A recent study of critical care physicians managing disagreements with surrogate decisionmakers over treatment options for incapacitated patients revealed that nuanced communication strategies that helped foster a sense of trust and shared values and objectives could help both parties reach mutually acceptable compromises. Providing adequate time for the surrogate to accept the patient's prognosis as well as detailed education on the treatment options and best possible outcomes and the role and duties of a surrogate decisionmaker were also helpful.<sup>6</sup>

Collective or shared decisionmaking could also help act as a curb against the possible arbitrary nature of surrogate

decisionmaking and the danger of a surrogate making paternalistic or possibly harmful decisions.<sup>7</sup> A shared decision-making model<sup>8</sup> that involves members of the care team, members of an ethics committee, and other members of the patient's family or the patient's friends, as well as the surrogate, would help in this case. There is a good chance that Ed's mother is in denial and is still suffering immense grief over her son's predicament and needs both time and support to help her address the reality of his condition. Through a shared decision-making model, her burden of making decisions on Ed's behalf could be lessened, and she could become more open to acknowledging her son's desire to die peacefully and come to be at peace with this decision, knowing that she did not give up on her son. As with most ethical dilemmas, compassion, trust, patience, and good communication strategies can go a long way to helping resolve seemingly intractable disagreements.

## Notes

1. Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*. 2nd ed. New York: MacMillan; 1986, at 82.
2. Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: A systematic review. *Archives of Internal Medicine* 2006;166:493–7; Fagerlin A, Danks J, Ditto PH, Houts RM, Sucker WD. Projection in surrogate decisions about life-sustaining medical treatments. *Health Psychology* 2001; 20:166–75.
3. Vig EK, Taylor JS, Starks H, Hopely EK, Fryer-Edwards K. Beyond substituted judgment: How surrogates navigate end-of-life decision-making. *Journal of the American Geriatrics Society* 2006;54:1688–93.
4. Fritch J, Petronio S, Helft PR, Torke A. Making decisions for hospitalized older adults: Ethical factors considered by family surrogates. *Journal of Clinical Ethics* 2013;24:125–34.
5. Rhodes R, Holzman I. The not unreasonable standard for assessment of surrogates and surrogate decisions. *Theoretical Medicine and Bioethics* 2004;25:367–86.
6. Brush DR, Brown CE, Caleb AG. Critical care physicians' approaches to negotiating with surrogate decision makers: A qualitative study. *Critical Care Medicine* 2012;40:1080–7.
7. Baeroe K. Patient autonomy, assessment of competence and surrogate decision-making: A call for reasonableness in deciding for others. *Bioethics* 2010;24:87–95.
8. Brock DW. The ideal of shared decision making between physicians and patients. *Kennedy Institute of Ethics Journal* 1991;1:28–47.

doi:10.1017/S0963180113000789

## Commentary: A Case of Too Much Maternalism

Maura George and  
Jason Lesandrini

This case appears at first to be a kaleidoscope of ethical issues, with multiple potential decisionmakers expressing conflicting opinions about the course of action. However, by resolving one problem, the issues align into more discreet dilemmas, each well described in the literature. Those involved in clinical ethics will recognize these commonly encountered, though not necessarily straightforward, cases. The ethics of the case begin with the patient's response to a simple but substantial question: Who do you think should make medical decisions for you right now?

### Option 1: "Listen to Me"—Respecting Autonomy and Advocating for Patients

If Ed asserts his place as his own decisionmaker, we can proceed with his true wishes, first by readdressing his goals of care and elucidating his written directive. Let us assume his true wishes are in fact to transition from aggressive to comfort care, as he previously stated, and this most current declaration nullifies the previously written directive. We would next ask him how he would like us to interact with his mother and family, recognizing that these actions