

decisionmaking and the danger of a surrogate making paternalistic or possibly harmful decisions.⁷ A shared decision-making model⁸ 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

will take place not within a vacuum but rather in the midst of complicated family dynamics. The effect of these decisions on his family, for whom he presumably cares deeply, is one of many concerns that Ed may have.¹ We hope in this scenario that Ed would feel empowered and allow us to facilitate a conversation with his mother to resolve the matter.

In a much less ideal case, Ed may request that we stop life-sustaining interventions without informing his family. We providers may then be forced to choose between lying to the family and violating the patient's autonomy. Physicians have been shown to occasionally use deception in settings of conflicting moral values, valuing their patients' welfare above truth-telling in isolation.² But the context in which such deception often occurs is toward the patient or toward an unrelated third party, for example, an insurance company. Most authors writing on this subject argue for "a robust conception of fidelity to patients, rooted in the moral urgency of standing by people when they are most vulnerable . . . a duty to champion patients' interests to the limit of what is possible without making false statements or breaching contractual duties."³ Ed's case is different in that deception is not occurring in the usual directions. Although healthcare providers may recognize that dying patients often function in a communal decisionmaking setting during their last days,⁴ and that they have ethical requirements to be "honest in all professional interactions,"⁵ these ethical requirements are *prima facie* requirements and can be overridden by stronger moral claims. In Ed's case, these moral claims include an obligation to respect his wishes to die peacefully and without interference.

A final ethical conundrum arises when Ed loses capacity and his mother attempts to assert her influence as his authorized decisionmaker. She will likely request that aggressive measures be reinstated

and will ensure compliance. It is at this point in Ed's care when the medical team will likely have to explain to his mother that there are certain medical choices that are hers to make and others that are not. Her son had already mapped out a course of care. If unanticipated decisions need to be made, the medical team would seek her guidance, but currently no decisions without prior patient guidance exist.

Option 2: "My Mom"—Deferring Decisionmaking to a Surrogate

If Ed chooses his mother as a surrogate decisionmaker, a different conversation will unfold. In this scenario, we would first confirm how much, if any, he would like to contribute to decisionmaking. That is, does he desire his prior vocalized wishes to be given weight at all in future decisions or does he bestow full surrogacy to his mother without any disclaimer? Assuming he wishes his mother to have full authority, the case becomes an issue of deferred decisionmaking. Patients have been known to defer decisionmaking to their surrogates, especially in times of serious medical illnesses, and even when they have previously expressed preferences. In these situations, the patients express their autonomy through designating another individual to make medical decisions on their behalf. Healthcare providers must not mandate an alternative notion of autonomous decisionmaking by forcing the patient to assert his decisionmaking status over his mother.

Patients often allow their surrogates significant leeway in interpreting their wishes.⁶ In our case, Ed may understand his grim prognosis but feel his mother's emotional well-being outweighs his personal desires to die. As Vig et al. write,

Surrogates are not flawless translators of their loved one's preferences; they are influenced by their own hopes. . . . Patients may be aware of this, are often

concerned about burdening their loved ones, and often grant their surrogates leeway in interpreting their wishes. When appropriate, clinicians should respect surrogates' interpretations of patient values and take steps to decrease surrogate stress during the decision-making process.

We recognize and agree that supporting Ed's mother is important; however, we would also coach her to base her decisions on an explication of the patient's expressed wishes and inferences from his values, goals, and past behavior.

Option 3: "I'm Not Sure"—Working along a Spectrum of Decisionmaking

Given the difficulties of this case, it is most likely that the patient will neither relinquish nor affirm himself as sole decisionmaker when asked to clarify his wishes. We may view this as strife between the family and focus on the differences in content between the interventions Ed tells us he wants and does not want and the treatment course his family dictates. However, as Berger points out, it may be as important to assess the *process* as it is the content.⁷ Understanding the *whys* and *hows* that guide medical decisions are crucial. Patients may want to have some of their preferences explicitly followed (e.g., no feeding tube) but may allow the family to decide in other cases (e.g., continuing antibiotics). Berger suggests that one of several factors that should serve as a measure of good decisionmaking is that decisions made are "consistent with the patient's concerns that surrogates be psycho-emotionally comfortable."⁸

When Ed elects to share decisionmaking with his mother, why does he value her input? As Berger states, "an understanding of the whys can more fully contextualize the patient's preferences, and can facilitate more supportive, responsive, and appropriate use of

medical interventions."⁹ It is also worthwhile to know *how* he would like his mother to make decisions for him. It is widely recognized in the literature that surrogate decisionmakers, often family members, make decisions that are contrary to the decisions that patients may make for themselves.¹⁰ The supposed contradiction in these decisions may not warrant much concern, as patients are often willing to accept the decisions that surrogates make, given that family members will have to live with the decisions.¹¹

According to the traditionally held decisionmaking standards for surrogates, when Ed loses his capacity to make decisions, his mother would be required to follow the following list of standards:

- 1) The patient's previously declared wishes
- 2) A substituted judgment—a standard of surrogate decisionmaking in which decisions are based on the patient's inferred values, preferences, and past decisions as best as the (surrogate) can glean from his or her knowledge of and experience with the patient
- 3) A best-interest decision—a standard of surrogate decisionmaking in which a surrogate chooses what a reasonable person would want in the current situation considering a variety of factors¹²

We believe that the standards of decisionmaking do not always fit neatly into these three categories. Decisions will always require contextual clarity regarding patient wishes, values, and interests, and the standards do not take into account the actual process that surrogates use when making decisions.

This decisionmaking standard, although theoretically simple, is often an incomplete picture. Berger et al. have placed decisionmaking standards

on a continuum: the standard of the patient's previously expressed wishes leads into that of substituted judgment, and the standard of substituted judgment leads into that of best interests. As we transition along the continuum, we focus less on a patient's values and our interpretation of those values and more on their overall welfare.¹³

Although it appears that the statements made by Ed may be his authentic preference, we believe that often ostensibly clear wishes do require interpretation.¹⁴ Ed has told the medical team that he has "suffered long enough" and "wants to stop all measures" and be allowed to die. In addition, his written directive states that he "accepts all life-sustaining measures." If for the moment we assume that the written directive is Ed's current wishes, it is unclear that this directive really provides any guidance on treatment plans for the patient, and decisionmaking will still require discussions with the mother, his durable power of attorney. The statement that appears on Ed's advance directive reminds us of the adage often used by patients and families in the settings of family meetings who, when prompted by poorly worded questions, request that "everything be done." As Quill et al. pointed out, these requests require clarification.¹⁵ Our experience, similar to that of Quill et al., has been that most requestors for "everything" are not asking for everything with high burden and only small chance of benefit. In addition, when we combine the requests provided in Ed's advance directive with his earlier statements about "suffering long enough," it seems reasonable that he may be asking his surrogate to find those measures that can provide him with a life that does not increase his suffering while at the same time maintains his life. This requires explication of the patient's previously expressed wishes and therefore

lies in between the two standards of decisionmaking.

Given the spectrum along which surrogate decisions lie, and recent work highlighting the importance of family input and relational autonomy,¹⁶ Ed's choice of a shared-decision approach may be appropriate. His desire to withdraw life-sustaining measures may not occur immediately; perhaps seeing his mother at peace about his clinical course is the comfort care he truly desires. Ultimately, as Ed's ability to participate in his decisionmaking waned and his mother's voice grew, we would counsel her to make decisions that reflect and interpret the patient's previously declared preferences. We do not believe that his statements in isolation are sufficient to warrant an order to continue or to discontinue aggressive measures and would rely on her interpretation as his designated surrogate.

Although this case provides a complex entanglement of multiple ethical problems, through good communication we would hope to distill the details into more familiar issues about which the literature may guide us.

Notes

1. Berger JT. Patients' interests in their family members' well-being: An overlooked, fundamental consideration within substituted judgments. *Journal of Clinical Ethics* 2005;16(1):3–10.
2. Novack DH, Detering BJ, Arnold R, Forrow L, Ladinsky M, Pezzullo JC. Physicians' attitudes toward using deception to resolve difficult ethical problems. *JAMA* 1989;261(20): 2980–5.
3. Bloche MG. Fidelity and deceit at the bedside. *JAMA* 2000;283(14):1881–4, at 1884.
4. Ho A. Relational autonomy or undue pressure? Family's role in medical decision-making. *Scandinavian Journal of Caring Science* 2008; 22(1):128–35.
5. American Medical Association. *Principles of Medical Ethics*; 2013; available at <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/principles-medical-ethics.page> (last accessed 26 Sept 2013).
6. See note 4, Ho 2008, at 130.

7. Berger JT. What about process? Limitations in advance directives, care planning, and noncapacitated decision making. *American Journal of Bioethics* 2010;10(4):33–4.
8. See note 7, Berger 2010, at 34.
9. See note 7, Berger 2010, at 33.
10. Rid A, Wendler D. Can we improve treatment decision-making for incapacitated patients? *Hastings Center Report* 2010;40(5):36–45.
11. See note 1, Berger 2005.
12. Jennings B, Wolf SM, Berlinge N. *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life*. 2nd ed. Oxford: Oxford University Press; 2013, at 52.
13. Berger JT, DeRenzo EG, Schwartz J. Surrogate decision making: Reconciling ethical theory and clinical practice. *Annals of Internal Medicine* 2008;149(1):48–53.
14. See note 13, Berger et al. 2008.
15. Quill TE, Arnold R, Back AL. Discussing treatment preferences with patients who want “everything.” *Annals of Internal Medicine* 2009; 151(5):345–9.
16. See note 4, Ho 2008.

doi:10.1017/S0963180113000790

What Actually Happened

After that meeting, the healthcare team and ethics team backed away from trying to ascertain Ed’s wishes, believing they were harming him more than helping him by revisiting the question. He would not explain why he capitulated in his mother’s presence, nor offer any insight as to why his mother was insisting on keeping him alive. He continued to express his wish to die comfortably to his nurses when his mother was not there. The team continued to palliate his symptoms as much as they could, given that his goals of care remained aggressive. They continued to offer to give him comfort care, and to support him (and his parents) in the face of his mother’s disapproval of that goal. He continued to decline comfort care if his mother was going to be informed and declined the offer to appoint another surrogate. Given the history of conflict and distrust, and the fact that she was still Ed’s chosen surrogate decisionmaker, the staff was not comfortable changing goals of care for Ed without informing his mother. No one brought up the document he had signed. His condition worsened slowly.

Some of his nurses noted that Ed’s mother’s conversation suggested that she believed that Ed had not lived a completely upright life. She seemed to disapprove of his motorcycle riding and hinted that the wreck that caused his injuries may have been intentional. They began to wonder if she believed he was being punished for his “lifestyle choices,” though she would not talk much about her feelings.

Three weeks after the fateful meeting, he took a sharp downward turn and showed signs of imminent death. His physician took Ed’s parents aside and explained that their son was dying, that his heart would probably stop within a few hours, and that it was extremely unlikely that the healthcare team would be able to restart his heart when that happened. He suggested a do not resuscitate order and comfort measures, as had many team members over the course of Ed’s hospitalization. This time his mother acquiesced. Ed’s heart rate declined and then stopped, later that day.

Ed’s parents thanked the nurses for their care of Ed over the course of his months-long stay. His mother added, “I think he is at peace now. I believe he has suffered enough.”