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Making Treatment Decisions for Oneself: *Weighing the Value*

DAN W. BROCK, JOHN K. PARK, and DAVID WENDLER

Competent adults should be permitted to determine the course of their own lives. We may try to influence them. We may ask them, perhaps even implore them, to change their minds. But in the end, they are in charge of their lives. They get to choose their careers, whether and whom to marry, whether to exercise, and whether to have surgery.¹

The emphasis on respect for patients' autonomy may seem to imply that allowing patients to make their own decisions should always take precedence over other considerations. Given this presumption, there has been almost no discussion in the medical literature or elsewhere about how important this value is and whether it should sometimes be balanced against and give way to other values.² This absence of guidance is especially problematic in cases where respect for patient autonomy conflicts with promoting patients' clinical interests.

Case Presentation

Mrs. M was a forty-four-year-old woman living in North Carolina with her husband, who held her durable power of attorney for health care (DPA). Her immediate family consisted of an adult daughter who did not live with her parents and a sister and mother who lived nearby. In October of 2010, Mrs. M presented to an outside hospital with headache, clumsiness in her left arm (she was right-handed), and an episode of involuntary shaking in her left arm. Magnetic resonance imaging (MRI) revealed a mass in her right parietal lobe. She underwent partial removal of the mass, which was identified as a glioblastoma.

The median survival for individuals with glioblastoma is approximately fifteen months with surgery, radiation, and chemotherapy.³ Because Mrs. M was young and in good physical shape, with a Karnofsky performance score of 100 (which indicates that she was able to perform all of her normal activities, with no impairments), her medical team believed she would probably live for significantly longer than fifteen months, especially if they could achieve radiographic gross total removal of the tumor.⁴

Three weeks after the partial removal of the tumor, Mrs. M traveled to the National Institutes of Health to consider further treatment options. After review of her postoperative MRI, the NIH staff recommended that she have additional surgical removal of the tumor, followed by standard-of-care radiation and chemotherapy. The risks and potential benefits of surgery with conscious sedation, including an approximately 10 percent chance of motor loss ranging from minor weakness lasting a few hours to complete paralysis, were explained to Mrs. M and her husband. Following discussion, which made clear that Mrs. M understood the risks and potential benefits of the surgery, she gave her consent.

Because the tumor was located close to the primary motor cortex and descending fiber tracts, the plan was to do the surgery using conscious sedation so that her motor function

could be continuously assessed during the surgery. By stimulating the motor cortex and fiber tracts to elicit involuntary movements and by assessing whether the patient can voluntarily move, the surgeon can determine whether the cortical and subcortical motor system is functionally intact. If so, the surgeon can continue to remove tumor, with the goal of removing at least 98 percent.

Desaturation and Three Options

During administration of the sedation, Mrs. M had several episodes of desaturation (drops in her blood oxygen levels), and the team felt it would be safer to do the surgery using general anesthesia with intubation. The risks and potential benefits of surgery with general anesthesia were essentially the same as those for conscious sedation, except that the risk of developing a motor deficit increased from approximately 10 to approximately 30 percent. This increased risk was due to the fact that, although involuntary movements resulting from cortical and subcortical motor stimulation could still be assessed, voluntary movements could not be assessed if Mrs. M was under general anesthesia.

Because Mrs. M was already sedated, the team called an emergent bioethics consultation to discuss three options.⁵ The first was to put Mrs. M under general anesthesia and proceed with surgery immediately, using only cortical and subcortical motor stimulation mapping. The team felt that this option was in the patient's best interests on the grounds that it would allow the tumor to be removed and radiation and chemotherapy to be initiated as soon as possible.

The second option was to wait for the sedation to wear off and then solicit Mrs. M's consent to surgery with full anesthesia. Given the demands of other surgeries, this option would involve a delay of approximately a week before the surgery could be performed. The third option involved delaying the surgery for several weeks while Mrs. M underwent pulmonary rehabilitation, with the goal of again attempting to perform surgery using conscious sedation.

Delay of the surgery would increase the chances that the tumor might grow into the motor area, in which case less of it could be removed safely. Delay also might undermine Mrs. M's long-term prognosis by postponing for a time the start of chemotherapy and radiation. Because the rate of tumor growth is unknown and unpredictable, the chances that delay of the surgery would result in a worse outcome for Mrs. M could not be estimated.

Family Meeting

The bioethics consultant met with Mrs. M's husband, sister, and mother. The daughter, though present in the hospital, chose not to participate in the meeting. She seemed overwhelmed by the gravity of her mother's condition. She also seemed upset that someone other than her mother might make decisions about her mother's surgery.

The husband, holding Mrs. M's DPA, and her sister and mother, stated strongly that they were confident, based on numerous conversations with the patient, that she would want to proceed with the surgery immediately, using general anesthesia.⁶ They said that Mrs. M

would be upset by a delay because it would force her to revisit her decision to have more surgery and allow her to worry for at least one more week that her tumor might be growing and the chances of a successful outcome might be dwindling. The surgeon and the surgical resident recalled that Mrs. M had been anxious to complete the surgery as soon as possible.

Respect for Autonomy and Promotion of Interests

Commentators, guidelines, and the law emphasize the importance of respecting patient autonomy, through the process of soliciting informed consent, to such an extent that one might assume it always takes precedence over other values in our lives. In this view, the present case presents no dilemma. Making one's own treatment decisions is so important that the team has only one morally acceptable option: allow the patient to recover from the sedation and make her own decision.

But respect for patient autonomy is not the only value that should guide clinicians. Clinicians also should promote patients' clinical interests. One might grant that this and other values are relevant but argue that there is no way to compare respect for patient autonomy with other values and to determine their relative importance. If this analysis were correct, clinicians could be given no systematic guidance for how to proceed in the face of a conflict between respect for patient autonomy and promotion of patients' clinical interests. Fortunately, this view is mistaken.

Respect for patient autonomy is important because deciding the course of our own lives is an essential part of our overall well-being. Even if someone else could make better decisions for us, we still want to control the course of our own lives and are better off when we do. We may make mistakes, but they are our mistakes. In addition, individuals usually are in the best position to gauge which of the available options is most likely to promote their interests.

Mrs. M was undeniably the best judge of whether it would be better for her to proceed with surgery using general anesthesia or to undertake several weeks of pulmonary rehabilitation therapy before attempting surgery with conscious sedation. The important point, however, is that allowing patients to make their own decisions is not a value that always trumps patients' other interests. Rather, allowing patients to make their own decisions is a central part of promoting their overall well-being.

This analysis suggests that clinicians can and should balance respect for patient autonomy with promoting patients' other interests. To make these determinations, it is important for health care professionals and surrogates to consider whether, in a particular case, the patient's overall well-being would be promoted better by making the decision for her or by allowing her to make her own decision. Two issues are crucial to these determinations.

First, making decisions for a patient can be appropriate when doing so best promotes her overall well-being. However, it is important to recognize that this approach can lead to mistakes and abuse. It can cause clinicians and surrogates to ignore the patient's preferences and interests and make decisions based on their own. Second, the value of deciding the course of one's own life can vary from patient to patient, and the value of making a

particular decision for oneself can vary from decision to decision. In approaching these cases, we should not assume that respect for individual autonomy has a constant value. We should attempt instead to assess to what extent the patient has valued making decisions for herself in general and to what extent she is likely to value making the decision in question for herself.

The Three Options

The first option—proceeding with surgery under general anesthesia—avoided possible further growth of the tumor and allowed chemotherapy and radiation to be started sooner. It also presented an increased risk of serious neurological deficit and required that Mrs. M's surrogate rather than Mrs. M herself make an important decision about the course of her life. One way to have avoided this dilemma would have been to prospectively obtain Mrs. M's consent to general anesthesia, should it become necessary. This case thus underscores the importance of taking steps to avoid ethical dilemmas whenever possible. In the case of surgery, clinicians should discuss the possibility that circumstances might change after the patient has been sedated and assess the patient's preferences regarding potential scenarios. While clinicians cannot consider every possible eventuality with the patient, they can develop a plan for the most likely ones.

Mrs. M's husband, her assigned surrogate, as well as the mother and sister, were confident that she would want the team to pursue the first option. The family supported this approach on the grounds that the other two options would require the patient to undergo the stress of deciding again and the anxiety of having to wait for the surgery. This is obviously relevant to determining which option best promotes the patient's interests and well-being, but it is not determinative.

There is a need to consider how likely it is that the surrogate's views about what the patient would want accurately reflect the patient's own preferences. In this regard, it is important to be aware that empirical studies find that surrogates' predictions regarding which treatment course their charges prefer often are mistaken.⁷ Even a surrogate and family who are confident that they understand a patient's wishes may be mistaken. A surrogate may unconsciously substitute his own preferences for those of the patient.

To take this concern into account, clinicians should not simply assess how confident a surrogate is that a particular decision reflects the patient's wishes. They should also explore the basis for a surrogate's views about what decision the patient would make. Did the surrogate have an explicit discussion with the patient? What was discussed, and what did the patient say? In the case of Mrs M, the family reported that their understanding of what she would want was based on extensive discussions with her.

Clinicians should not assume that, when there is compelling evidence regarding what decision the patient would make, making the decision for the patient is just as good as obtaining her consent. There is important and additional value in being the one who decides which treatment course one undergoes. This seems especially important in cases, including the present case, where reasonable individuals might disagree about how to proceed. It is

crucial to recognize patients' right to make important decisions for themselves. This value is lost if the first option is pursued.

To take this concern into account, clinicians should evaluate to what extent their patients value making their own decisions. In the present case, it was not known how important it was to Mrs. M to make her own decisions and to what extent she was willing to have her husband and family make decisions, including this decision, for her. This aspect of the case underscores the importance of expanding discussion of a patient's advance directive beyond treatment preferences to include discussion and documentation of the patient's preferences about how she wants decisions to be made if she becomes incapacitated. Does the patient strongly prefer to make her own decisions, or is the patient willing to allow the surrogate to make decisions for the patient when there are strong reasons to do so? In addition, in a case like Mrs. M's, where reasonable persons can disagree about how to proceed, an ethics consult can be a helpful safeguard.

This analysis suggests that option two—letting the sedation wear off and then soliciting Mrs. M's consent—is preferable; it would have ensured that Mrs. M made the choice and eliminated the possibility of mistakes or abuse. This seems especially germane in the present case given that it was the clinicians who induced the patient's inability to make decisions in the first place. Clearly, we should be very reluctant to medically incapacitate patients and then make decisions based on what we regard as best for them.

The Outcome

Based on the permission of the surrogate, as well as the agreement of the sister, mother, and team, the decision was made to proceed with surgery under full anesthesia, using cortical and subcortical motor stimulation mapping. The bioethics consultant offered to talk with Mrs. M's daughter since she did not participate in the consultation meeting. Mrs. M had a gross total resection of her tumor without any new neurological deficits and then underwent radiation and chemotherapy. She had no signs of tumor recurrence two years later.

After Mrs. M recovered from surgery, the surgeon explained to her that there had been significant discussion about whether to proceed with the surgery using general anesthesia or to allow her to recover from the sedation and make her own decision. She looked at the surgeon and responded with a smile: "I would have killed you if you had woken me up and waited to do the surgery later."

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References

1. Faden, RR.; Beauchamp, TL. A History and Theory of Informed Consent. Oxford: Oxford University Press; 1986.
2. Buchanan, AE.; Brock, DW. Deciding for Others: The Ethics of Surrogate Decision Making. Cambridge: Cambridge University Press; 1989.
3. Stupp R, et al. Radiotherapy Plus Concomitant and Adjuvant Temozolomide for Glioblastoma. New England Journal of Medicine. 2005; 352:987–96. [PubMed: 15758009]
4. Lacroix M, et al. A Multivariate Analysis of 416 Patients with Glioblastoma Multiforme: Prognosis, Extent of Resection, and Survival. Journal of Neurosurgery. 2001; 95:190–98. [PubMed: 11780887]
5. Brock DW. Trumping Advance Directives. Hastings Center Report. 1991; 21(5):S5–S6. [PubMed: 1743940]
6. Brock DW. What Is the Moral Basis of the Authority of Family Members to Act as Surrogates for Incompetent Patients? Journal of Clinical Ethics. 1992; 3:121–23. [PubMed: 11643063]
7. Ditto PH, et al. Advance Directives as Acts of Communication: A Randomized Controlled Trial. Archives of Internal Medicine. 2001; 16:421–30. [PubMed: 11176768] Shalowitz DI, Garrett-Mayer E, Wendler D. The Accuracy of Surrogate Decision Makers: A Systematic Review. Archives of Internal Medicine. 2006; 166:493–97. [PubMed: 16534034]