ETHICAL PERSPECTIVES IN NEUROLOGY

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The practice of neurology presents a series of ethical challenges for the clinician. These rarely have simple or straightforward solutions, but require careful consideration by the neurologist. This section of CONTINUUM, written by colleagues with particular interest in the area of bioethics, provides a case vignette that raises one or more ethical questions related to the subject area of this issue. The discussion that follows should help the reader understand and resolve the ethical dilemma.

NOTE: This is based on an actual case. Details have been changed so that the patient is unidentifiable.

An 18-year-old right-handed teenager is brought by his parents to the epilepsy center for surgical evaluation. He has had epilepsy, mild developmental delay, and learning disorder since infancy. He had delayed onset of crawling at 11 months, walking at 19 months, and talking at 24 months. He had febrile seizures that resolved by age 3 and focal-onset seizures at age 5 that were variably controlled throughout his life but are now intractable and significantly impact his quality of life. He has had problems in school with math but stayed at grade level for reading. He remained in mainstream classes with the help of tutors and graduated from high school. He has otherwise been healthy. He lives with his parents.

A family friend had successful epilepsy surgery, and the young man’s parents, who have been very involved in his treatment throughout his life, brought in their son for evaluation of epilepsy surgery. He willingly participated in the extensive evaluation, including an MRI, video EEG recording, a PET scan, and a neuropsychological evaluation. The patient has reached the age of majority, and even though his parents do not have guardianship, they have been present at all physician visits.

At epilepsy conference he was determined to be an ideal candidate for right temporal resective surgery. When the findings and recommendations were presented to him and his parents, he unexpectedly asserted, “No one can make me have this surgery.” His parents insist that he should have the surgery, and the epilepsy team believes that surgery is in his best interests.

COMMENT

Respect for autonomy is a concept that is well established in ethics and the law. The law presumes that children are not competent to make decisions and exercise their autonomy and that their parents have the authority and responsibility to make medical decisions that are in the child’s best interests. The law also presumes that persons above the age of majority (in this case, 18 years) are competent to make decisions for themselves and are free to exercise their autonomy by accepting or declining treatments recommended by
their physicians. When a child reaches the age of majority, the law, therefore, creates an abrupt change in the locus of decision-making authority from the parent to the child. This can be a very difficult transition to negotiate when children with chronic medical disorders, whose parents have been responsible for all medical decisions, reach the age of majority and can refuse treatments that their parents and physicians want them to have.

The case raises several ethical questions. Can the patient refuse surgery? Do his parents have any authority to make him have the surgery, or can they obtain it by becoming his guardians? Is it ethically permissible for the epileptologist and the surgeon to try to persuade the patient to have the surgery he is refusing?

**DISCUSSION**

The patient’s assertion that “no one can make me have this surgery” is a clear and unambiguous statement. Physicians may not treat patients who have clearly refused treatment. To do so would be considered battery under many statutes. In the case of invasive procedures, the only time that physicians may treat a patient without consent is when the patient is unable to give consent (eg, unconsciousness) and delay in treatment would likely result in serious harm or death, known as implied consent for emergency treatment.

While it is clear that the patient is within his legal rights to refuse surgery, it is not clear that his decision is in his own best interests. An ethical analysis would consider whether the patient’s refusal was informed, and, more specifically, whether he possessed decision-making capacity. His cognitive and decision-making abilities are almost certainly impacted by his frequent seizures and the medications used to treat them and theoretically are influenced by his developmental delay. Considering that he was in mainstream classes and graduated from high school, however, it is likely that he possesses decision-making capacity. In fact, as long as he can explain in his own words the treatment options before him (surgery versus continued medical treatment), the consequences of each option, and his own choice, then he would be considered to have decision-making capacity.

While it could be argued that his last-minute refusal of surgery suggests instability of his decisions, especially since he willingly participated in the presurgical evaluation, the counterargument is that the decision to have surgery is separate from the decision to be evaluated for surgery and has a very different risk-benefit profile. Put another way, the decision to be evaluated for surgery does not obligate a patient to undergo the surgery if it is recommended.

The patient’s parents have been making medical decisions for him all of his life and want him to have the epilepsy surgery. If their son were 12 years old instead of 18, they would be able to make him have the surgery against his wishes. Now that he is 18 years old, they no longer have this authority. They fear that in exercising his own autonomy to refuse surgery now, he may be limiting his autonomy in the future. They want the best for their son and feel that the surgery would give him a chance to be free of his seizures. Freedom from seizures may confer greater independence in the long term, whereas with continued seizures, his prospects for functioning independently will be highly restricted in that he will remain dependent on his parents not only for his medical care and medications, but also for his basic needs.

His parents have considered obtaining guardianship based on his medical condition and his poor judgment, as indicated by his refusal of the surgery. By obtaining...
guardianship and requiring him to have surgery, they believe they could help to ensure his long-term independence. In order to obtain guardianship, however, they would have to petition a court of law and attempt to demonstrate that their son lacks competence. Their son would be entitled to speak on his own behalf and would be able to have independent legal counsel. Were guardianship granted to the parents, they would then have to persuade the court that the risk to their son is so imminent and the benefit of surgery outweighs the risks to such an extent that the court should order their son to have surgery against his wishes. While courts order involuntary treatment of patients with anorexia nervosa (Watson et al, 2000) and serious psychiatric disorders, they rarely order involuntary treatment in circumstances such as those in this case. Thus, it is unlikely that the parents can obtain guardianship.

Autonomy is not absolute, and the law sometimes restricts it, especially if harm could occur to other individuals or property. In epilepsy, examples include revocation of driving privileges and restriction from operating an aircraft. In these cases, there is a significant risk to other people and property as well the patient’s safety and property.

What can the epileptologist and the neurosurgeon do in this circumstance? Are they restricted to simply honoring his wish? No. While they must respect the patient’s choice, they may also work with his parents to try to persuade him to change his mind. The patient may have reasons to refuse that he has not been able to articulate and that his parents and physicians do not yet understand. Fortunately, there is time to work with him to reconsider his choice and to continue to support him by respecting his choice.

One solution would be for the patient to meet with the physicians independently of his parents. This would show respect for him and his autonomy. He would be free to ask his own questions and hear what his physicians have to say in response. In addition, he would have the opportunity to express concerns that he may not be willing to discuss with his parents present. He similarly could be invited to discuss his concerns with the entire epilepsy team, independent of his parents.

He could be given an opportunity to attend a support group that includes patients who have had epilepsy surgery and patients who are considering it. This would afford him the opportunity to learn from peers who have faced the same decision and chose to have the surgery. These support groups offer a nonthreatening venue for many patients to express their feelings and concerns that they may not be able to express to family members or physicians.

He could spend individual time in consultation with the epilepsy social worker to help him develop his own sense of autonomy and independence within the scope of his abilities. Even if he has decided to have surgery, he may benefit from the opportunity to discuss possible outcomes and plans for the future.

CONCLUSION

When children with chronic medical conditions reach the age of majority, they receive the right to make their own medical decisions, which should be respected as autonomous choices. Ideally, their physicians and parents should begin to prepare them for this new responsibility before they reach the age of majority. When young patients make choices that are considered to be unwise, it is advisable to respect them and work with them to understand the rationale and reasons for their choices. Doing so respects them as persons and gives their physicians and parents the best opportunity to try to persuade them to change their minds.
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REFERENCES AND SUGGESTED READING


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