

Virtual Mentor

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Clinical Case

Patient-Initiated Request for Donation Information

Commentaries by Arthur J. Matas, MD; Timothy F. Murphy, PhD; and
Elizabeth A. Davies, MD, and Mitchell L. Henry, MD

John is on his family practice rotation and working at an outpatient clinic. One day he sees Ms Smith for a routine medical exam. She has been a patient of the clinic for 7 years, has always been compliant with recommendations, and has no significant past medical history. While reviewing Ms Smith's history with her, John asks if she has any specific questions or concerns. Ms Smith states that she recently saw an ad about organ donation and wanted to know more about becoming a donor. John becomes excited about this question because he knows that there is a shortage of organ donors, and he sees this as an opportunity to educate Ms Smith about this altruistic act. At 30 years old and in good health, Ms Smith is probably an eligible donor, John thinks. As the conversation progresses, Ms Smith asks John if he has "ever seen organs being removed for donation" and John states that he, personally, has not seen this, but knows that the utmost care is taken to procure the organs. Ms Smith then discloses that she is worried that if she becomes a donor her organs may be taken before she is dead. John assures Ms Smith that this would not happen and that many tests are performed to make sure the patient is dead before organs are recovered. After answering all her questions, John informs Ms Smith that she can fill out the necessary paper work for organ donation in the office. Just as he is about to excuse himself to get her the necessary documentation, Ms Smith states that she is not entirely convinced about being an organ donor. "I'm still unsure—I still need some time to think about it." John is clearly disappointed because he knows how important organ donation is but does not want to pressure Ms Smith into making a decision.

Commentary 1

by Arthur J. Matas, MD

There are currently more than 60 000 people on the waiting list for kidney transplants in the US, and in many parts of the country average waiting time for a kidney is more than 5 years. More than 7 percent of wait-listed patients die annually before receiving transplants. As a consequence, there is ongoing discussion about how to increase the number of available organs.

Ethical issues are of primary importance in discussions about enrolling new donors. In the case presented here, a third-year medical student is enthusiastic about trying to persuade a patient to sign organ donor forms. The patient, Ms Smith, has many questions and is unsure about whether or not she wants to become a donor. I was asked how I would address this as a clinician and how I would navigate between giving the patient information and coercing her into becoming a donor.

Simply stated, there is no room for coercion in medicine. This is both a legal and a moral point. Coercion is defined as “persuasion (of an unwilling person) to do something by use of force or threats” [1]. The courts have ruled that a competent person can refuse a life-saving procedure (ie, cannot be coerced into having it). This has been demonstrated by Jehovah’s Witnesses’ refusing life-saving blood transfusions. Another concern in this case is that the student (or any other enthusiastic believer) might exploit or manipulate Ms Smith’s vulnerability as a patient by suggesting, for example, that she might get better medical care if she were a potential donor.

What do I believe the third-year medical student should do under these circumstances? There are numerous possibilities; here are some of them:

1. He could offer to spend more time with Ms Smith, either at this or a follow-up visit, to discuss her concerns;
2. He could ask Ms Smith if she would like to discuss her reservations with the attending physician;
3. He could give her the telephone number for the local Organ Procurement Organization (OPO) so she could get more information about the organ donation process.

What if, after numerous discussions and a review of available literature, Ms Smith is still unsure if she wants to donate? Organ donation is a wonderful act which has been termed “the gift of life.” An organ donor (or donor family) has the opportunity to prolong and improve the quality of many lives. But no one should be “talked into” signing organ donor forms (or any other informed consent document). If Ms Smith is still unsatisfied after discussing her concerns with the people who can answer her questions, the medical student should curb his enthusiasm.

Reference

1. *The New Oxford American Dictionary*. New York: Oxford University Press; 2001.

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Commentary 2

by Timothy F. Murphy, PhD

United States transplantation policy rests on the cornerstone of individual consent. With the exception of taking corneas, people (or their surrogate decision makers) must agree to donate their organs and tissues for transplantation, whether that donation takes place before or after death. This approach has never been successful in fulfilling the ever-increasing need for organs and tissues in this country. More than 80 000 people are listed for transplants at present, and most discussions of transplantation do not fail to mention this yawning need. Even as more donors come forward, more

people become eligible for transplantation, widening the gap between need and availability even farther.

One of the key ethical obligations in any system based on consent is the protection of autonomous decision making. For this reason, federal regulations require prior review and approval of virtually all the pharmaceutical research that goes on in this country. Yet there are no parallel regulations with respect to transplant donations. In some states, people may indicate on their drivers' licenses whether or not they wish to be donors after death and no one ever evaluates the rationale for their decision. By contrast, transplant programs do carry out evaluations of living donors—people who want to donate a kidney, a part of their liver, or even part of their bowel to someone known (or even unknown) to them. In this kind of donation, people may expose themselves to real pain and risks for poorly formed reasons, and every transplant program has an obligation to protect against the uninformed assumption of such risk.

Ultimately, of course, people are under no obligation to donate their tissues or organs. As social policy, we have decided that it is better to forgo organs and tissues than to require their donation through compulsory or opt-out systems. It may exasperate some health care workers, but people are under no obligation to accept the arguments that health care workers think are compelling reasons to donate. Sometimes volunteers come forward for reasons of their own; persuasion brings others to the decision. There are various and increasing levels of ethical concern with the methods used to help people reach their decisions: engagement (what's needed to get people's attention), information (what's needed to advise them about the procedures and consequences), undue influence (contextual pressures that dispose someone to a particular answer), and coercion (using structural advantages or power to compel decisions).

In the case at hand, Ms Smith, like many Americans, will not come to a decision about donating organs on the basis of a single conversation. Her decision will take time, no matter what she finally chooses to do. She has brought up the issue, making it fair for the medical student to answer her questions. After the conversation she remains guarded, which means she may not yet have all the information she wants in order to come to a decision. Or she may not yet trust the answers. No health care worker talking to her need worry about undue influence and coercion as long as her questions guide and structure the conversation. One way to avoid these ethical dilemmas—and to build trust—is to work toward answers together. In this case, Ms Smith asks the medical student if he has ever seen organs taken for transplantation. He says he has not, but he assures Ms Smith that the procedure is done with the “utmost care.” Maybe he knows this, maybe he doesn't. Either way, it has the ring of a stock answer. He might have done better to say: “Let me find out exactly what's involved and get that information to you.” A pamphlet and a conversation about brain death might help resolve Ms Smith's worries about the actual donation process. A conversation that is a mutual exploration and that builds trust will go a long way toward dissolving worries about undue influence and coercion in organ donation.

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Commentary 3

by Elizabeth A. Davies, MD, and Mitchell L. Henry, MD

This scenario in which Ms Smith consults her doctor's office about becoming an organ donor is realistic. A recent survey asked southeast Ohio residents, "Where would you prefer to get information about organ donation," and nearly 82 percent of the respondents indicated the family doctor or health care provider [1].

Organ and tissue donation can occur under 1 of 3 conditions: (1) death as determined by neurologic criteria (also known as "brain death"), (2) death as determined by cardiac criteria, and (3) living donation. The American College of Surgery's *Code of Professional Conduct*, published in 2003, delineated the primacy of patient welfare. The surgeon is primarily responsible for communicating "the therapeutic options in a fashion that is both comprehensive and comprehensible, and in a manner that is inclusive of the patient's values and belief systems [2]." The American Medical Association's *Code of Medical Ethics* recognizes the physician's "responsibility to participate in activities contributing to the improvement of the community" as well as the need to "support access to medical care for all people [3]." In order to manage the ethical demands made by these organizations, physicians must balance respect for individual patient autonomy with concern for all of society.

Each of the methods for organ and tissue donation has a distinctive informed consent process. In 2004, nearly half of all donors in the United States were living donors. Nearly 95 percent of these donated a kidney; just over 300 donated liver segments; 28 donated portions of lung, and 6 donated portions of intestine. Most living donors are family members or friends of the recipient, although altruistic donation is on the rise. Living donation entails significant medical risks, including those associated with general anesthesia and surgery, and the potential for long-term complications. Benefits for the donor include the recipient's improved quantity and quality of life and the sense of well-being engendered by personal generosity.

The choice to make a living donation must be a fully informed one and must include a medical evaluation. A potential living donor must go through an extensive process of education about the procedure, risks and possible complications, long-term outcomes, and possible alternatives, such as deciding not to donate. The medical evaluation is conducted by an independent physician who is the donor advocate and not part of the transplant surgical team. If the donor advocate is not satisfied with the medical evaluation and preparedness of the potential donor, he or she can unilaterally prevent the donation from proceeding. The psychological assessment of the potential altruistic donor is a subject of its own, generally addressed by the transplant center.

A proven way to increase organ donation from patients who die of brain injury is by "decoupling" the team that is caring for the brain-injured potential donor from the transplant team. The transplant team must have no part in declaring the death of the

donor or receiving consent from the family for the donation. The local organ procurement agency, with support from local hospital personnel, provides information and obtains consent for donation. These individuals take great care to offer the possibility of donation without pressuring or coercing family members. Most states now make it possible for people to choose to become organ donors and record the choice on their drivers' licenses. This official document becomes a legal statement of that individual's wish to donate should that become possible. The act of "opting-in" to be a donor is a cogent way to communicate to family members and loved ones that the choice was made during a thoughtful, lucid moment. If the individual changes his or her mind, the decision can be rescinded at any time.

Death by cardiac criteria offers 2 opportunities for organ and tissue donation. In the most common scenario, the patient dies at home or in the hospital following cardiopulmonary arrest. Under these circumstances tissue donation may then follow. The second scenario—donation after cardiac death (DCD)—refers to donation by patients with severe brain injury—but not brain death—from whom the family has decided to withdraw support. Here, the option of donation is addressed independent of, and occurs after, the decision to withdraw support is made. Support is withdrawn in a controlled fashion in either the operating room or ICU, allowing the recovery of organs for transplantation. Tissue donation may also follow. In 2003, DCD accounted for 4 percent of deceased donors and 2 percent of all organ donors in the US [4]. Prior to the development of death by neurologic criteria, all donated organs in the United States were recovered in this fashion.

Finally, death by neurologic criteria requires the irreversible cessation of all brain function. Common etiologies for cessation of brain function include stroke, intracranial hemorrhage, trauma, and prolonged hypoxia. Following declaration of death by neurologic criteria, donation of up to 8 organs and a variety of tissue is possible. Mrs Smith's concern that her organs might be recovered prior to death is an oft-repeated misconception. Providing patients with printed material, websites, and access to the local organ procurement may alleviate fears—both spoken and unspoken.

References

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3. American Medical Association. Principles of medical ethics. *Code of Medical Ethics*. Available at: <http://www.ama-assn.org/ama/pub/category/2512.html>. Accessed August 1, 2005.
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