



## Consent for Organ Donation — Balancing Conflicting Ethical Obligations

Robert D. Truog, M.D.

Organ transplantation is truly one of the miracles of modern medicine, saving the lives of many patients and improving the quality of life for many more. Given the ever-increasing gap between

the number of organs needed and the supply, clinicians have an ethical obligation to help ensure that the desires of people who want to donate organs are respected. The Department of Health and Human Services took up this challenge in 2003, when it collaborated with leading transplantation organizations to launch the Breakthrough Collaborative, calling on all hospitals to increase their organ-donation rates to 75% or higher.

In addition to facilitating patients' exercising their right to donate organs, however, clinicians have an obligation to ensure that the consent process is informed and voluntary. During the past few years, changes in

the laws, regulations, and guidelines surrounding the procurement of organs for transplantation have created tensions between these two ethical commitments. As one physician recently told the *Washington Post*, "If you promote organ donation too much, people lose sight that it's a dying patient there. It's not just a source of organs. It's a person."<sup>1</sup>

A few examples illustrate the evolution of this tension. In 2006, the Commissioners on Uniform State Laws worked with the transplantation community to amend the Uniform Anatomical Gift Act (UAGA). As originally amended, the act stipulated that physicians must continue the use of life-sustaining treatments for

dying patients until the local organ-procurement organization (OPO) could determine whether the patient's organs were suitable for transplantation, even if the patient had an advance directive in place stating that such treatment was not wanted. When critical care physicians became aware that they could be required to administer life-sustaining treatments against the expressed will of their patients, they voiced their ethical concerns to the commissioners, and in 2007, the UAGA was again amended to emphasize that the attending physician should consult with the patient or surrogate as early as possible to determine and follow the patient's wishes, even if doing so resulted in the loss of potentially transplantable organs.<sup>2</sup>

Although this particular issue seems to have been resolved, further tensions remain. One is the way in which regulations from

the Centers for Medicare and Medicaid Services are being interpreted and implemented. These require hospitals to notify the local OPO “of individuals whose death is imminent or who have died in the hospital” and to ensure that the person who initiates the request to the family is a representative of the OPO or a “designated requestor.” Although it is theoretically possible for hospital clinicians to be trained as designated requestors, in practice this person is almost always an OPO representative.

These representatives therefore have responsibility for obtaining informed consent for organ donation. An ethically valid informed-consent process should consist of a balanced discussion of the available options and counseling to help patients or their families reach the choice that is best for them, including the provision of information about the urgent need for organs and the consolation that many families derive from knowing that their loved one was able to help others. Recently, however, OPOs adopted a strategy known as the “presumptive approach for organ do-

nation.”<sup>3</sup> Under this approach, organ-procurement coordinators are encouraged to introduce themselves to families as members of the “medical team” or as “grief counselors,” without necessarily disclosing that their role is explicitly one of dual advocacy, since — operating under the assumption that organ donation is simply “the right thing to do” — they simultaneously represent the interests of the patient or potential donor and the pool of potential recipients. The table contrasts typical phrases used in the standard approach with those endorsed by OPOs using the presumptive approach, some of which are clearly misleading or even manipulative. These concerns are not just theoretical. As a critical care physician in Chicago observed, “I have seen these guys come in and almost browbeat families into submission to get them to donate organs.”<sup>1</sup>

The presumptive approach clearly undermines many of the core elements of informed consent. An instructive contrast can be drawn between approaches to obtaining consent for participation in medical research, on the one hand, and for organ dona-

tion, on the other. The two activities have much in common: both participation in research and organ donation are altruistic gifts offered primarily for the benefit of others, both may involve some risk or harm to the patient or family, and in both cases, clinicians have an obligation to support the desires of patients. Yet in seeking informed consent for research, we have adopted meticulous safeguards to ensure that the consent is fully informed, voluntary, and free of any manipulation or coercion, whereas in the case of organ donation, we require that families be counseled by people whose agenda and approach are inherently conflicted. This strategy seriously threatens our commitment to the importance of informed consent and undermines fundamental principles that support respect for patients and their families. Although OPO representatives possess a wealth of information that families could find useful in decision making, they should be as committed to an impartial and transparent process as those who seek consent for research.

The presumptive approach is

Key Elements of the Standard Approach and the Presumptive Approach to Counseling Potential Organ Donors.*	
The Standard Approach	The Presumptive Approach
“This is Mary. She works with families like yours who have lost a loved one. Would it be possible for her to speak with you for a moment?”	“Mary is a member of our team. . . . She is going to speak with you and answer any questions you might have.”
“I’m here to provide you with information about organ donation.”	“I’m here to provide you the opportunity to donate your loved one’s organs.”
“Some families choose the option of donating their loved one’s organs. I am here to help you make the decision that is best for you and your family.”	“You and your husband now have the opportunity to make your son a hero through the gift of organ donation.”
“We will support whatever choice you make.”	“Most people, if given the chance to save a life, will do it.”
“If you decide to donate. . . .”	“When you decide to donate. . . .”
“Would you like me to give you some time before you make your final decision?”	“If you do not have any more questions, I will now guide you through this process.”

\* Quotations are from Zink and Wertlieb.<sup>3</sup>

of particular concern in light of the reaffirmation in the amended UAGA of the importance of acting on the first-person consent of patients, as expressed through organ-donor registries, regardless of the wishes of the patient's family.<sup>2</sup> On first impression, this makes good sense: families should not be able to veto the wishes of patients. But some have voiced concern that a patient's general indication of a willingness to donate (e.g., a checked box on a driver's license) could be interpreted as indicating a desire to donate through newer procedures that were not envisioned by the patient at the time the intent was expressed. For example, as of July 2007, all transplantation hospitals are required by the United Network for Organ Sharing to develop and follow protocols that facilitate organ donation after cardiac death.<sup>4</sup> Unlike organ donation after brain death, in which patients are declared dead before organ-procurement procedures begin, some protocols for donation after cardiac death involve the exposure of dying patients to resuscitation efforts, placement of central venous catheters, the administration of heparin and vasodilators, and withdrawal of life support under

sterile conditions in the operating room. Although consent from the next of kin is required for any antemortem procedures, under the presumptive approach, families may feel pressured to give consent by OPO representatives who choose to assume that the patient's general willingness to be an organ donor indicates a willingness to undergo these additional procedures before death, which may not be the case. As one ethicist has noted, "Most people who agree to be organ donors think about it in terms of what will happen to their body after they die. This [approach] has implications for what they do to you before you die."<sup>5</sup>

Both clinicians and OPOs therefore face conflicting ethical obligations. The growing transplant waiting lists obligate us to strive to increase the supply of transplantable organs. But our commitments to respecting the rights of our patients and their families require that consent be obtained by people who are, in turn, committed to being fully transparent, fair, and evenhanded. When we are faced with competing ethical obligations, our challenge is to find a balance that will preserve our most essential ethical principles. Over the past

few years, the pendulum has swung too far in the direction of procuring organs at the expense of commitments that are fundamental to the patient-physician relationship. If uncorrected, this trend could substantially erode the public's trust in the transplantation enterprise, to the ultimate detriment of people who desire to make these remarkable gifts as well as those who are desperately in need of them.

A letter to the editor from Luskin and colleagues at the New England Organ Bank appears on page 1297.

No potential conflict of interest relevant to this article was reported.

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## Taking Your Child's Breath Away — The Extension of Asthma's Global Reach

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On a clear summer day, as Michael runs through the fields playing with his friends, the view from his farm is spectacular. You can look past the hills where his family grows olives and raises sheep to the

Mediterranean Sea. Last winter, however, the picture was far less tranquil for the 4-year-old and his family. In their small cottage that is heated by burning olive pits left over from the olive-oil press, with his mother cook-

ing over an open fire and his father smoking two to three packs of cigarettes a day, Michael developed frequent colds, a chronic cough that worsened considerably at night, and shortness of breath when he played.