

Virtual Mentor

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Clinical Case

Family Disagreement over Organ Donation

Commentaries by Douglas W. Hanto, MD, PhD; Thomas G. Peters, MD; and Richard J. Howard, MD, and Danielle Cornell, BSN

The sound of Sam's pager suddenly awakens him. A third-year medical student, Sam is in the midst of his trauma surgery rotation. He rushes to the trauma department and learns that his next patient, Justin Lewis, is a 20-year-old male who was in a major automobile accident. Tested en route to the hospital, Justin had a Glasgow coma scale score of 3. As Justin is brought to the trauma room, the paramedics tell the attending physician, Dr Hardy, what they know about the accident. According to the EMTs, Justin fell out of a car that was traveling 70 miles per hour and landed on this head. After an extensive emergency room workup, Justin is declared brain dead. Prior to disconnecting him from the ventilator, the ER staff discovers that he has an organ donor card in his wallet. Familiar with the organ donation procedures, Sam calls the organ procurement agency while Dr Hardy tells Justin's family the news.

An hour later, Mr Sterling, a representative from the organ procurement organization arrives at the hospital and introduces himself to the family. Justin's father tells Mr Sterling that his son definitely wanted to donate his organs, but Justin's mother interjects. She is adamantly opposed to anyone's taking organs out of her son.

Meanwhile, Sam asks Dr Hardy what the plan for the patient is. Dr Hardy says that Justin will remain on mechanical ventilation until a final decision is made regarding donation of his organs.

Commentary 1

by Douglas W. Hanto MD, PhD

When the death of a patient is imminent or has occurred, as in the case of Justin, all hospitals that receive Medicare and Medicaid dollars are required by the Conditions of Participation published by the Centers for Medicare and Medicaid Services to have protocols in place for notifying the local federally designated organ procurement organization (OPO). This notification is mandatory whether the patient has a signed organ donor card or not. In Justin's case, even if the ER staff had not found an organ donor card in his wallet, Sam would have been correct in calling the OPO. The OPO determines the medical suitability of the potential donor and usually sends a trained organ donation coordinator to the hospital to review the patient's records, speak to the family, clarify health-related information, and request permission for organ donation. Some OPOs have specially trained family counselors who request permission for donation from the family. If the family gives permission, the donation coordinator assumes the medical management of the donor, and all medical costs from the time of declared brain death are billed to the OPO, not to the patient's insurance or family.

The refusal of families to grant permission is a major impediment to organ donation. Several factors have been shown to improve family consent rates. First, the request for organ donation should be separate—or “decoupled”—from the declaration of brain death. This allows the family time to understand and accept the concept of brain death. In this case, Justin’s mother may simply need more time to adjust and accept the death of her son. Second, the request for organs should be made by a trained OPO representative along with the hospital staff as a team. It is best that the physician or nurse caring for the patient not discuss organ donation with the family prior to OPO involvement. The hospital staff and OPO donation coordinator can work together to determine the best time to talk to the family. Third, the request should be made in a private and quiet setting. Higher consent rates have been shown to occur when these 3 procedures are followed [1].

Even when a patient has a signed organ donation card, the OPO often seeks family permission to proceed with donation. The Uniform Anatomical Gift Act (1968, revised 1987) established that a signed organ donation card is sufficient to proceed with donation, and it has been confirmed recently that such documents function legally as advance directives. In the United States, however, it is customary for the OPO to request permission from the next-of-kin due to fear of litigation.

Recently, several states have passed legislation establishing “first-person consent” whereby the family cannot override an individual’s documented desire to be an organ donor. Some states have established first-person consent registries for people interested in being deceased organ donors. This is based on the strong belief that the donor’s wishes should be adhered to. It is not dissimilar to a last will and testament that disposes of our personal property and assets after we die. Each year more states are passing first-person consent laws that are strongly supported by the OPOs and the transplant community.

Had Justin died in a state with first-person consent laws, the OPO would have informed the family of his pre-existing declaration to be an organ donor and would not have sought the family’s permission. First-person consent removes a burden from family members because they do not have to come to a decision while attempting to cope with the very stressful situation of the death of a relative. First-person consent also avoids the problem of family members’ disagreement, and it may benefit families later on: more than one-third of families who made a decision themselves and declined to donate the organs subsequently regretted their decision [2].

In a case such as this one, where the mother and father disagree about organ donation, the donation coordinator would ask the mother why she was opposed to donation and would try to address her specific concerns. The coordinator would emphasize that her son had expressed a desire to donate and that his gift could save and improve the lives of several seriously ill patients. The coordinator would also try to dispel any myths about organ donation that Justin’s mother might have heard. It is important for her to understand that her son’s body will not be disfigured and that donation will not affect funeral arrangements or viewing of the body. Often times a hospital social worker or pastoral care representative can be called to counsel the family and resolve their disagreement. One of these individuals might have been able to help Justin’s mother agree to donation.

Because of the continued shortage of organs for transplantation, it has been argued that we should go beyond first-person consent and adopt the principle of “presumed consent.”

Presumed consent has been legislated by many European countries with a resulting increase in organ donation rates [3]. Presumed consent is an “opt-out” policy in which everyone is considered an organ donor unless he or she registers opposition. This process contrasts with our current, “opt-in” system, in which the individual or next-of-kin must give explicit consent for organ donation. Individual choice is not removed in either case, but persons opting out have the additional responsibility of documenting their decisions. A recent analysis showed that the opt-out countries had a much higher organ donation rate than opt-in countries [4]. And in an online experiment, responders' decisions about organ donation were dramatically influenced by whether the question was presented as an opt-in or opt-out choice; rates for donation doubled when the default position was opting out and documentation was needed to opt in; that is, to donate.

Once permission has been obtained, the donor is managed medically to maintain optimal organ function [5]. All organs are evaluated for their suitability for transplantation, the donor is screened for infectious diseases (eg, hepatitis, HIV), and blood and tissue types are obtained. The donor information is then entered into the national computer database maintained by UNOS (United Network for Organ Sharing) where it is matched with wait-listed patients. The computer produces a list of the potential recipients for each of the organs ranked by priority as determined by national organ allocation policies. At that point, the donor coordinator calls the transplant centers where prospective recipients are listed to ensure a recipient will be available and waiting for the organ. The organs are then removed in the hospital operating room, often by several surgical teams from different transplant centers in a manner that is respectful of the decedent and his or her family. The young patient in this case could potentially donate his heart, both lungs, liver, pancreas, both kidneys, and small intestine for transplantation, thereby benefiting as many as 8 recipients. He could help many more patients by being a tissue donor (corneas, skin, bone, blood vessels) as well. Many times families report great satisfaction after organ and tissue donation from knowing that so much good can result from so much pain.

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Commentary 2

by Thomas G. Peters, MD

Patient-centered ethical dilemmas often arise in a trauma surgery rotation. For the medical student, a sudden and perplexing ethical dilemma may actually open the door to solving certain clinical problems and issues of family interaction.

In this case, there is no question that the patient, a 20-year-old man who sustained a massive head injury, is dead. With cardiorespiratory function being sustained artificially, the emergency room and trauma surgery staff have appropriately assessed the patient, tested and ruled out any possibility of survival, and determined the hopelessness of the patient care situation. With such a dire determination, however, comes new promise: helping others by way of organ donation. The student is a witness not only to the consequences of severe trauma, but also to the process of consent for organ donation.

The case narrative indicates that the patient, Justin, carried what we presume is a recognized legal organ donor card. Such a document is generally believed to be sufficient to go forward with organ donation. Some states including Florida, Pennsylvania, and Texas, have determined that the organ donor card is an end-of-life document that is afforded as much standing as a will or advance health care directive. Therefore, the issue of consent and legality of organ donation should not be a dilemma considering that a 20-year-old man is past the age of majority—18—in most states.

A dilemma does arise, however, because Justin and his father favor organ donation, but his mother does not. She is adamantly opposed to anyone removing organs from her son, and the story appears to end with the attending physician noting that mechanical ventilation and other support measures will be carried on until an agreement is reached regarding organ donation.

The best-known way to prevent the conflict between the mother and the father is for families to discuss organ donation before any tragedy occurs. Consent disagreements almost never arise when a family has talked about the idea of postmortem organ donation and the intentions of family members are fully understood by all.

It appears, however, that no such discussion took place between Justin and his parents, so the medical staff faces a dilemma: whether or not to maintain mechanical and artificial support, which use critical hospital resources, while the family is further counseled regarding organ donation. In fact, most acute care units have experienced similar circumstances, and giving time to grieving families in the final hours of life, whether organ donation is to occur or not, is not unusual. So, support might be continued for several hours during which resolution of the family conflict would become an important and, perhaps, intense matter.

The medical care team must, to the greatest extent possible, remove itself from this conflict resolution process and rely upon the expertise of the organ procurement professionals. It is likely that the procurement coordinator has been in similar situations, has been trained to deal with them, and will be able to adequately resolve most of the issues to the satisfaction of all. This professional should be able to apply techniques of personal communication to persuade the mother that the wishes of her deceased son should be honored.

In the majority of such situations, the procurement coordinator begins by facilitating an empathic discussion among all concerned persons with the aim of reaching a consensus on what the decedent really may have wanted. The presence of an organ donor card itself, while sufficient to preclude the need for family consent to organ removal, does not always silence the objections or satisfy the concerns of those who would prefer that organ donation not occur. Thus, the mother who is objecting might be given time to explore the reasons for her opposition to organ donation before being confronted about her son's wishes. The astute organ procurement coordinator will use techniques of active listening to engage the reluctant—or opposing—person and to allow full expression of his or her thoughts and feelings. It is never enjoyable to talk about recovering organs from a young person who has died unexpectedly. The waves of emotion that must overcome parents are best managed by those trained to listen and respond appropriately in such difficult family circumstances.

Over a period of several hours, the effective procurement coordinator will have established a relationship with the mother and permitted her to work through the early stages of grief and to have her questions regarding organ donation and transplantation answered. It is highly likely that the mother will ultimately come to the understanding that her son's wishes should be honored, even if she opposes organ donation.

It is, of course, possible that the organ procurement specialist is not as talented as one would wish, or that the mother remains adamantly opposed to organ removal no matter what. In such a case, the organ procurement team is beset with a difficult decision: whether or not to go forward with organ recovery since the signed donor card is suitable consent, and, thus, leave the family in conflict. The family would be left in conflict if organs are not recovered anyway, since the father favors organ donation. In the circumstance of unsuccessful counseling, the organ procurement agency would need to examine the procedures and experiences that have allowed for the best outcome of potential donor families and others. In many such situations, organ recovery is accomplished even when objections persist. While the family dilemma goes on, lives of other critically ill persons will be saved by organs recovered from the dead trauma victim.

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Dr Peters' commentary was mistakenly attributed to other authors and posted under their names from September 1 to September 12, 2005. We apologize for the error.

Commentary 3

by Richard J. Howard, MD, and Danielle Cornell, BSN

The death of most people who become deceased organ donors is sudden, unexpected, and frequently tragic. The families of these donors are almost never prepared for this unfortunate situation. In addition to dealing with an unexpected injury or intracerebral accident, the family must come to terms with the fact that their loved one is dead. They may have a difficult time accepting this since the patient has a heartbeat, a measurable blood pressure, produces urine, and has good skin color and other indications that suggest life.

Many individuals (even physicians) do not understand the concept of brain death. And now someone the family has not seen before comes in from something called an organ procurement organization and asks permission to remove the organs of their son or mother or sister for transplantation. The stresses associated with the initial injury, the death, and now the request for organs cannot be underestimated and can be difficult for anyone who has not gone through this process to fully appreciate.

Yet organ donation can salvage a great deal of good from a tragic circumstance. Knowing that their loved one can save and improve the lives of other individuals through organ and tissue donation can be a source of great solace and comfort. The organ donation can become a living memory of and tribute to their relative.

In the example cited here a 20-year-old man, Justin Lewis, died in an automobile accident, and testing showed he was a suitable potential organ and tissue donor. In this particular case, it was discovered that he had signed an organ donor card. The Uniform Anatomical Gift Act (UAGA) of 1968 clearly indicates that a donor card signed in the presence of 2 witnesses is legally binding. The act was adopted by all states within 3 years. Many organ procurement organizations (OPOs), however, do not take advantage of this provision because they are concerned about their relations with the family as well as about potential legal disputes and adverse publicity that could result in a decline in organ donation should they act upon the donor's consent—even though such worries have not proved to be an issue in most places.

States have responded to this concern, and legislation authorizing the donor's intent, called "first-person consent," has now been enacted in 42 states. These laws acknowledge that a documented donation decision (donor card, driver's license, donor registry, etc) that has not been revoked by the donor prior to death, is legally binding and does not require the consent of any other person upon death. Despite this legislation, many OPOs are still reluctant to pursue first-person consent. Fifteen years following the enactment of the UAGA, OPOs in only 4 states reported they were actively practicing first-person consent organ donation recoveries.

In the case of this 20-year-old designated donor, our organ procurement organization, would have modified its approach to the family. The staff would have notified the parents that their son had clearly showed his intent to be a donor by so designating on his driver's license and that we planned to honor his wishes. Even if both parents disagree with organ donation, the signed organ donor card is sufficient permission for the OPO to recover organs for transplantation. We have had only a few differences of opinion with the donor's legal next of kin in honoring first-person consent.

The case of Justin Lewis would not be unmanageable for an OPO that is actively pursuing first-person consent cases. The OPO staff must discuss organ donation and what it entails with the family and answer their questions in a supportive, non-confrontational, non-threatening manner. We have found that much of the objection to organ donation is due to lack of accurate information. For instance, some individuals believe that if organ or tissue donation occurs, there can be no viewing of the body afterwards. Some will agree to organ donation once they realize that a viewing can still take place and that no incisions will be made on the head or neck.

Parental or next-of-kin refusal often has less to do with the concept of organ donation than with control or authority for decision making for their injured and now dead relative. Building a relationship with the family by asking questions about what type of person their relative was can assist in establishing communication related to the patient; the importance of this relationship cannot be overstated. Having a sympathetic OPO coordinator or designated requester who is willing to take time with the family, hear their concerns, and answer questions frequently means the difference between obtaining permission and being met with refusal. Asking the parents if they understood what the physician told them about brain death also provides an opportunity for educating and trust-building.

Even if the OPO staff or other designated requestors aren't negotiating with family members to obtain consent, they should still speak to the next-of-kin in a quiet room that is softly lit and has enough chairs so that no person is left standing. The number of people in the room should be limited to 1 or 2 family members. The more people who are in the room, the more likely someone will object to donation. It is important for the requestor staff to state that the adult decedent willingly made a choice to give the "gift of life" upon his or her death, and that the purpose of the meeting is to answer any questions they may have about the procedure and to ask some questions about the medical history of the donor.

Although the law is on the side of the designated donor, it is critical to procurement organizations, transplant centers, and recipients that the OPO make a concerted effort to establish a cooperative relationship with the family. Legal and public conflicts that could result in fewer donors must be avoided. Willing participation from the family will also enable the procurement coordinator to obtain a thorough medical and social history, and will allow him or her to explain the procedure fully, confirm that donation will not interfere with the funeral, clarify that the OPO will assume hospital costs related to the donation, and convey much other information.

Perhaps the most compelling reason to establish a positive relationship with the family of a potential donor is the benefit it offers to the future of organ donation. Working cooperatively with the donor family will result in a positive continued relationship. The surviving family members of a donor are known as donor families, and, in our mission to increase awareness of the need for more organ donors, donor families remain an unparalleled resource for promoting the message.

When an OPO makes the choice to recover organs from a designated donor against the family's wishes, an ethical balancing act may ensue. Some would argue that the wishes of the surviving family members should be given primary consideration; that procuring organs from a deceased patient in opposition to the family's desire will add to their grief, especially in the case of parents. But others will dispute that the surviving family members deserve primary consideration, arguing that the patient's wishes to be an organ donor upon death must be honored. Is it ethical for the OPO to walk away from a patient and not honor the documented decision he or she made while alive? Is it defensible to decide not to attempt to place and procure organs for transplant because the family doesn't agree with the decision the adult patient made during life? Finally, is it right to ignore the patient's request because he can no longer speak for himself?

Would we deny living patients' the right to decline blood products, to see their religious representative, or to decline cardiopulmonary resuscitation? The answer, simply, is no. People who make the decision to become donors during their lives have a right to have that decision carried out upon their death. It is not ethical for an OPO to refuse to recover organs only because the donor can no longer speak for himself or herself. We believe the wishes of someone who signs a donor card should be respected even if the family disagrees. And yet we realize there may be unique circumstances where pursuing first- person consent might not be in the best interest of the family or of the transplantation community. Every potential donor situation has unique aspects. While some OPOs err on the side of the designated donor, there is no 1 formula that will always guarantee a good outcome.

There are also times when a disagreement about donation cannot be resolved among family members (and where the donor has not indicated his wishes while alive). If a resolution is not attainable despite the best efforts of the OPO coordinator, it may be appropriate for the OPO to withdraw and make no further efforts to get those who object to donation to change their minds. In these situations the family usually comes to a consensus and refuses permission for donation. If, for example, the family stated that the patient, in the presence of his mother, girlfriend, or other family member, verbally revoked his decision to become a donor, the OPO would have to withdraw all attempts of obtaining consent for donation.

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