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### **Upcoming Issues of *Virtual Mentor***

October: Ethical Decision Making in the Diagnosis and Management of STDs

November: Ethical Issues in Endocrinology

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# Virtual Mentor

Ethics Journal of the American Medical Association  
September 2005, Volume 7, Number 9

## From the Editor

### **Organ Transplantation: A Dream of the Past, a Reality of the Present, an Ethical Challenge for the Future**

Over the last century, organ transplantation, which began as a lofty and far-fetched idea, has been transformed into a real and practicable triumph of modern medicine. The idea behind organ transplantation is simple: replace a failing organ with one that is functional. Despite this simple premise, organ transplants are scientifically complex. From innumerable botched or failed attempts we have reaped unprecedented knowledge and achieved tremendous successes. Two Nobel prizes and much of modern day immunology have been based on knowledge discovered in the effort to make organ transplantation feasible. Now transplant medicine has blossomed to the point where more than 95 percent of patients with kidney transplants survive beyond 1 year, and the majority of the tissue grafts last for the recipient's entire lifetime. Incredibly, 74 lives are saved each day as a result of this medical innovation. Yet, as these scientific innovations have enabled us to perform more complicated procedures, the ethical issues they engender have become more complicated. In this issue of the *Virtual Mentor*, we analyze the ethical dilemmas that surround transplantation.

Currently, the most significant challenge in organ transplantation is small supply and large demand. Seventeen people whose lives could be saved by an organ transplant die every day while waiting [1]. Interestingly, most Americans, when polled, claim that they would like to donate their organs, but in practice, less than 50 percent actually do, and when faced with the decision on behalf of family members many decline to allow donation. This discrepancy is addressed in the medicine and society section of this issue and in 1 of our clinical cases. The case examines the situation in which the mother of a brain-dead patient does not want his organs to be recovered, even though his driver's license registered his desire to be a donor. Some countries have policies under which all people are presumed to be donors unless they document otherwise. In the US, by contrast, people are presumed *not* to be donors unless they document their intentions to donate. Two articles—medicine and society and policy forum—examine the US policy of expressed consent versus the international policy of presumed consent.

Because demand for organs outstrips the supply, organ distribution has become a contentious issue in medical ethics. Through a provocative clinical case, we examine how strict guidelines can impact a patient's status on the transplant list. The op-ed section questions whether the behavior of alcoholics with liver failure should affect their status on the organ transplant list. A second policy forum author suggests that the gap between supply and demand in organs for transplant need not exist, and offers the work of organ donation breakthrough initiatives as evidence.

Looking toward the future of transplantation as science and technology advance, one author discusses the fact that surgeons now possess the ability to transplant a face

from one human being to another, raising numerous difficult questions—medical and ethical. Pushing the boundaries of science is also discussed in an op-ed piece regarding xenotransplantation: the practice of transplanting organs from animals into humans.

Organ transplantation was a dream of the past and is now an important part of modern day medicine. My hope is that this issue of *Virtual Mentor* will bring to light many of the ethical issues surrounding organ transplantation as we continue to make deliberate and responsible scientific progress in this field.

Hari Nadiminti, MD

Dedicated to my parents, Janaki and Venkataramayya.

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1. Organ Procurement and Transplantation Network. Available at: [www.OPTN.org](http://www.OPTN.org). Accessed August 30, 2005.

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# Virtual Mentor

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## Clinical Case

### The “Slip”

Commentaries by Mark D. Fox, MD, PhD, MPH, Arthur L. Caplan, PhD, and Jeffrey S. Crippin, MD

Jenny is a third-year medical student on her internal medicine rotation at the Veterans Administration Hospital. The rotation has been a great learning experience; her patients are generally friendly and grateful for the care they are receiving. One of Jenny’s favorite patients is Mr Hackman, a 53-year-old veteran who has been diagnosed with alcoholic cirrhosis and is currently on the transplant waiting list. Every afternoon Jenny talks with Mr Hackman, and he often shares stories with her about the past. Jenny takes a genuine interest in the stories about his family and supports his attempts at sobriety. During one of their sessions, Mr Hackman revealed that he had taken a drink at a friend’s house 2 months prior. He swore that this was “the only drink I’ve had in the last 2 years.” He pleaded with Jenny not to tell anyone about his transgression because he knew that alcohol abuse could affect his status on the transplant list.

### Commentary 1

by Mark D. Fox, MD, PhD, MPH

This case highlights a crucial aspect of Jenny’s professional development. She should be commended for the rapport she has established with Mr Hackman. He obviously trusts her, as evidenced by his willingness to disclose information that has potentially devastating consequences. The conflict posed by Mr Hackman’s request for confidentiality is heightened by the apparent blurring of personal and professional boundaries. Thus, Jenny’s dilemma must be considered within the context of both personal and professional obligations. Moreover, because of the potential impact on Mr Hackman’s transplant candidacy, Jenny’s actions have broader social implications regarding the allocation of scarce resources.

There is often a naïve presumption of “absolute confidentiality” on the part of both patients and clinicians. In fact, this presumption sometimes leads clinicians to promise more than they can deliver with respect to confidentiality. Clearly there are circumstances in which the risk to the patient (or an identified other) warrants, or even requires, breaching patient confidentiality. One of the developmental tasks for clinical trainees is to divine the limits of confidentiality and to place assurances regarding confidentiality in an appropriate contextual framework.

In this case, Mr Hackman raised the issue of confidentiality only after disclosing potentially incriminating information. Fortunately, Jenny has not painted herself into a corner with any untenable promises. Nevertheless, it is worthwhile to consider the

rationale for expectations of confidentiality, and doing so is necessary for discerning the appropriate course of action for Jenny.

The presumption of confidentiality serves a functional purpose. Clinicians can only provide optimal care when armed with complete information, and patients are more likely to disclose intimate details if they believe the information will be kept in confidence. There is, however, a more fundamental grounding of our commitment to confidentiality: in essence, it is part of a larger pledge to not take advantage of those entrusted to our care. The patient-physician relationship, even when it involves a physician-in-training, is necessarily characterized by a fundamental asymmetry of power. This asymmetry gives rise to a compelling obligation that the physician not use the information in ways that can harm the patient.

Several other aspects of this case are worth further exploration. First, it is not clear that Mr Hackman divulged the information to Jenny in the context of a therapeutic relationship. It appears that their regular conversations may be more social than therapeutic in nature. (This is not meant to suggest that these interactions are not significant or relevant to Jenny's education.) If Jenny were simply his friend rather than on his medical team, Mr Hackman might reasonably expect her to keep his confidence and support him in his efforts to maintain sobriety. Because their relationship is framed primarily by the clinical context, Jenny's obligations are shaped foremost by her professional commitments. Whether Jenny's responsibilities would be different if she were a student on the transplant, rather than the internal medicine, service remains an open question.

Another potentially troubling feature of this case concerns the nature of Jenny's relationship with Mr Hackman, inasmuch as he is identified as one of her "favorite" patients. While it is perfectly natural to feel a particular affinity for, or develop a special connection with, certain patients, we are nevertheless obligated to treat them the same as we do all of our other patients. It would be disconcerting if Jenny felt a greater obligation to preserve Mr Hackman's confidentiality simply because of their personal relationship.

Jenny's ultimate response to this dilemma may rest in part on her understanding of the requirement for abstinence from alcohol for transplant candidates with alcoholic liver disease, regardless of whether she is a part of the transplant program or not. Jenny is under no obligation to relay inconsequential information to other members of the health care team. For example, the fact that Mr Hackman is a Cincinnati Reds fan or prefers chocolate ice cream to vanilla holds no consequence for the anticipated outcome following a transplant. The impact of various psychosocial factors on outcomes following transplantation is admittedly not well-characterized, but a minimum of 6 months of sobriety has become widely accepted as a prerequisite for transplant eligibility.

To some, the sobriety requirement may seem to have a punitive quality—penalizing alcoholics for their role in contributing to their disease. Others may view it as a means of rationing a scarce resource; abstinence serves as a hoop for patients to jump through to be eligible for a transplant. If Jenny were to perceive either of these

rationales as the basis for the abstinence requirement, she may feel justified in honoring Mr Hackman's request for confidentiality.

The requirement for abstinence from alcohol, however, is not rooted in a view of alcoholism as a moral failure. Rather, it reflects the recognition of the chronic nature of the disease, with a high risk of relapse. Although alcohol relapse has not clearly been shown to compromise post-transplant outcomes, there is a substantial risk of recidivism post-transplant and a trend toward decreased survival [1,2]. The rate of relapse cited in various studies ranges from 20-33 percent [1-3]. Abstinence for 6 months or longer has been identified as the best predictor that relapse will not occur [1,3].

As stewards of a scarce resource, transplant professionals have an obligation to exercise prudence not only in the selection of candidates for the transplant waiting list but also in the allocation of donor organs to recipients. Optimal allocation of donor organs seeks to balance considerations of medical urgency with the probability of a successful outcome. In addition, because of the limited number of transplantable organs, access and allocation necessarily entail consideration of unknown others. That is, while Mr Hackman may well experience a survival benefit from a transplant (despite his continued alcohol use), there may be other patients, eligible for the same donor organ, who would fare better. This consequence of organ scarcity poses a significant challenge to the Hippocratic ideal of beneficent action on behalf of the patient entrusted to your care. Therefore, Mr Hackman's use of alcohol, albeit allegedly as an isolated indiscretion, is certainly relevant to his suitability for transplantation at this time and needs to be communicated to the transplant team. Moreover, it is often a primary care provider, rather than the transplant staff, who is privy to these details during the waiting period.

While Jenny succeeded in initially establishing rapport with Mr Hackman, she now faces a difficult professional challenge about how best to communicate this information to the transplant team. Ideally, Jenny could help Mr Hackman appreciate the potential impact of his continued use of alcohol on his transplant outcome while playing a pivotal role in providing emotional support when he discloses his indiscretion to the transplant team.

One final consideration relates to the notion of nonabandonment. Regardless of the impact of Mr Hackman's disclosure on his transplant candidacy (he could either be deferred or rejected from the wait list altogether), Jenny has an obligation to provide ongoing care for his chronic condition (within the scope of her clerkship). In the midst of navigating these challenging personal and professional concerns, Jenny must also communicate to Mr Hackman her commitment to participate in his care.

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## **Commentary 2**

by Arthur L. Caplan, PhD

Jenny is facing what seems to be a difficult moral dilemma. On the one hand, she is duty-bound to act as an advocate for Mr Hackman, making sure he receives the best possible medical treatment. In this case, that means she must help ensure that Mr Hackman receives a new liver. On the other hand, she is obligated to be a responsible steward of scarce, life-saving medical resources. If she honestly believes that Mr Hackman will not benefit from access to a donated cadaver liver or lobe of a liver obtained from a living donor, or that there are others who would be better beneficiaries, then she must inform the medical team about her concerns regarding Mr Hackman's alcohol use.

This looks like a genuine professional dilemma. But it may not be. Doing what seems the difficult thing—"snitching" on her patient—may turn out to be the best thing she can do to help him secure the treatment he needs.

What might lead Jenny to believe that her desire to help Mr Hackman must yield to her duty to be a responsible health team member, stewarding the limited supply of livers available for transplant, is Mr Hackman's "confession" that he has had a drink. In many liver transplant programs and perhaps at Jenny's institution, a period of sobriety, usually 6 months, is an absolute requirement for transplant eligibility. Still, despite the fact that Mr Hackman seems to have put himself at a severe disadvantage in the competition to secure a liver, certain facts may make it easier for Jenny to decide how to discharge her conflicting ethical duties.

Having a single drink, sometimes referred to as a "slip" in alcohol abuse programs, is not uncommon. Many people on the road to sobriety slip, as the literature on the treatment of alcoholism quickly reveals [1]. Moreover, views and attitudes about sobriety and alcoholism that prevail among health care professionals are not consistent with what those experienced in the field of drug and alcohol abuse consider efficacious treatment [2]. A single drink is not the end of the line as far as sustained sobriety after a liver transplant goes.

Presumably Jenny can share the information she has about Mr Hackman with a member of the transplant team who is well informed about alcohol abuse and recovery. It is difficult to imagine that a psychiatrist, psychologist, or social worker



affiliated with a liver transplant team would be overly concerned about a report of a single instance of taking a drink on the part of someone on a waiting list.

Jenny can and should tell Mr Hackman she is going to suggest that a more experienced person talk with him about his slip. She can also assure Mr Hackman that a single drink, if that is all that has happened, is not going to lead directly to his being dropped from the transplant list or even weaken his priority in gaining access to a liver.

It may also be of interest to Jenny to know that there is not a lot of data to support the view that a history of alcohol abuse adversely affects the success of liver transplantation. Nor is there much evidence that periods of sobriety—by themselves—are key to the success of liver transplantation. Having a strong social support network has been shown to be the most important factor in achieving success among alcoholics who receive liver transplantation [3]. Mr Hackman has made it clear that he has strong support from friends and family alike. These facts make his chances for doing well with a new liver better than average.

Although Mr Hackman did not tell Jenny about his slip in confidence, he later asked her not to say anything. But any factor that bears on his chances of successfully surviving and flourishing with a liver transplant must be addressed. To act ethically, Jenny must tell Mr Hackman that this is so. Then she needs to inform an appropriate member of the transplant team.

Jenny must also tell Mr Hackman that a single slip is not at all uncommon, that the transplant team will be familiar with this situation, and that one slip should not adversely affect his chances of receiving a transplant. In fact, his willingness to talk about this incident with his doctors and his family shows that he is precisely the sort of candidate that is likely to do well after a surgery. Admitting his mistake with a renewed commitment to sobriety may be just what the transplant team is looking for in prospective patients.

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### Commentary 3

by Jeffrey S. Crippin, MD

To tell or not to tell? That is the dilemma facing Jenny as a member of the team caring for Mr Hackman. Clearly, Jenny has an emotional attachment to Mr Hackman, and this is very common in clinical medicine. But when clinical decisions potentially impact the care of other patients, objectivity must guide the physician's decision.

As you, Jenny, approach this case, you must clarify several issues before deciding what to do. First, what are the medical facts and allocation policies regarding liver transplantation in patients with alcoholic liver disease? What are the survival figures for patients with alcoholic liver disease who receive new livers? What is the rate of alcohol recidivism for transplant recipients like Mr Hackman? Does the admission of alcohol use permanently eliminate Mr Hackman from consideration for a transplant? Will he get a second chance if he is removed from his current spot on the list? What are the implications for other patients on the waiting list if Mr Hackman remains on the list and receives a transplant? Should you withhold this information and “protect” Mr Hackman's chance of getting a transplant? Careful examination of these questions will lead you toward a thoughtful and informed decision.

In the early days of liver transplantation, alcoholic liver disease was the most frequent indicator for liver transplants. Hepatitis C has now become the major indication, but many hepatitis C patients also have histories of alcohol dependence. Survival figures for patients with alcoholic liver disease who have received transplants have been excellent, comparable to the success rates among those who received liver transplants because of non-alcohol-related reasons. In fact, survival rates after transplant for patients with alcoholic liver disease are better than those for patients who received livers because of chronic hepatitis C alone. The major concern in transplant patients with alcoholic liver disease is recidivism—how many patients return to drinking following the transplant. Dr Thomas Starzl, the “father” of liver transplantation in the United States, proposed that a liver transplant was the “ultimate ‘sobering’ experience” [1]. This comment suggests that patients with alcoholic liver disease do not drink following a transplant. Unfortunately, this has not been proven true. Recognizing this, transplant centers now require a period of abstinence before a transplant. This period of abstinence demonstrates 2 important things to the transplant team. First, alcohol abstinence remains the most effective treatment for alcoholic hepatitis, so many patients improve during the period of abstinence and, as a result, their need for a transplant is not as urgent. Second, the period of abstinence shows some degree of commitment by the patient. The longer the pretransplant abstinence lasts, the greater the chance of long-term abstinence. At least 5 years of sobriety is necessary before a reasonable chance of long-term abstinence is present [2]. Due to the severity and complications of their disease, many patients do not have that much time. Yet many centers require at least a 6-month period of sobriety, often with random drug and alcohol screens, before a patient is placed on the waiting list.

Liver transplantation, in general, is plagued by the recurrence of the original disease in the liver allograft. Hepatitis C is the best example of this because Hepatitis C viremia is not eliminated at the time of the transplant, making infection of the allograft inevitable. The cause of recurrence is different in alcoholic liver disease where the disease reappears only if the transplant recipient relapses to alcohol dependence. Multi-centered studies have examined the experience of disease recurrence [3-6], many using patient interviews and recall, eg, "Have you had alcohol since your transplant?" Obviously, this method is dependent on patient recollection and honesty. The studies found that the prevalence of alcohol ingestion increased with the length of time since the transplant, with the rate of recidivism reaching 50 percent after 5 years in some series [3, 4]. Fortunately, the incidence of "problem" drinking, ie, drinking to the point of medical complications, was relatively rare, affecting only 10 percent of patients [6]. Thus, there may actually be some truth to the "ultimate sobering experience" observation by Dr Starzl years ago.

Another potential consideration in Jenny's decision is the severity of Mr Hackman's illness. Deceased donor liver allocation is currently based on the severity of the would-be recipient's illness. The model for end-stage liver disease (MELD) uses 3 easily obtainable lab values (serum bilirubin, serum creatinine, and INR) to generate a "score" as a means of predicting a 3-month mortality risk. The higher the MELD score, the higher the risk of death, and the higher the patient's place on the transplant list. Therefore, if Mr Hackman's MELD score is high, he may be "too sick" to survive any additional time on the waiting list. Many centers tell patients that the 6 month "clock" starts over after each use of alcohol, meaning they must remain abstinent another full 6 months before returning to the waiting list. If Mr Hackman has a predicted 80 percent risk mortality in the next 3 months, waiting to get back on the transplant list may not be an option, and Jenny may think she is giving him a death sentence if she reports his "slip" into alcohol consumption. If his MELD score is relatively low, however, coming off the list could allow Mr Hackman to seek additional counseling or treatment that could ultimately lead to a prolonged period of abstinence, both before and after the transplant. Jenny's decision to tell the transplant team might ultimately be better for Mr Hackman if his state of health permits him to survive the consequence.

Jenny must also consider the potential effect of her decision on other patients. Mr Hackman is 1 of over 18 000 patients on the nationwide liver transplant waiting list. If he gets the transplant, someone else does not. This reality often prompts people to ask "whose life is worth more?" This is *not* how transplant teams make decisions regarding the waiting list. Rather, the question that the transplant team must answer is "does any single patient have an acceptable risk of mortality and an acceptable potential for posttransplant survival?" Alcohol recidivism is only 1 of many factors taken into account. Medical comorbidities, previous surgeries, and psychosocial support are equally important and carefully considered.

Finally, Jenny must carefully consider her own emotional attachment to Mr Hackman and his family and take an objective look at her feelings. How long has she known him? Did she just meet him a few days ago at the time of a hospital admission? Does

she think she knows him better than the hepatologist involved in his care over the last 4 years? Is she certain, beyond a shadow of a doubt, that he is telling the truth? Could the one admitted instance be a sign that other episodes have occurred? What triggered the ingestion of alcohol? Was it a stressful situation, indicating that Mr Hackman turns to alcohol in times of crisis? Or was he with a group of old friends and just could not say “no,” indicating that his chance of long-term sobriety may be small?

All of the above must be carefully considered in Jenny’s decision. It is not as simple as it may seem. Yes, Mr Hackman may ultimately die of complications from liver disease. People die of liver disease—an estimated 30 000 Americans annually. Not all patients receive liver transplants—only 5000 per year do. This is the harsh reality of liver transplantation. Thus, Jenny should not allow her emotions to sway her decision. Careful consideration of all the issues, particularly following discussion with the rest of the transplant team, will lead to a decision that will ultimately reap the greatest benefit for all involved.

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# 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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# 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.

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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.

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# Virtual Mentor

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## Journal Discussion

### Constructing the Question: Does *How We Ask* for Organs Determine Whether People Decide to Donate?

by Kelly Carroll

**Johnson EJ, Goldstein DG. Defaults and donation decisions. *Transplantation*. 2004;78:1713-1716.**

#### The Supply-Demand Problem

The statistics in the US are staggering. At the end of 2003, more than 82 000 patients remained on the waiting list for solid organ transplants. In that same year, 7000 people died while waiting, and 13 285 people (6457 deceased and 6828 living) donated organs that resulted in just over 25 000 transplants [1,2].

Clearly, the demand for organs continues to outstrip the supply, and there is no sign of this trend slowing. The number of organ donors has been increasing yearly, but much of that can be attributed to the growing number of living donors, which has surpassed the number of deceased donors since 2001. The number of deaths (based on brain death criteria) that result in eligible organ donors has remained stagnant since 2002 at approximately 12 000 [1].

One can become mired in the statistics of organ donation; the portrait painted by the data frustrates everyone from economists to patients, from politicians to physicians. With data analyses in hand, scholars from a wide array of disciplines have attacked this supply-demand problem vociferously, offering a host of possible solutions, primarily directed toward increasing the supply of organs. Lately, they have switched their attention from the rather unchanging “eligible death” donor pool to living donors and donations after cardiac death, alternatives which have shown clinical success with specific organs but for which the clinical potential is still limited.

Yet, the paramount goal of the transplant community for many years—increasing cadaveric organ donations from eligible donors—remains largely unattainable. In fact, only 49.8 percent of the eligible cadaveric donors become actual donors [1]. Based on 2003 statistics, each cadaveric donor provided, on average, 3 organs for transplantation. So we could reliably predict that, if all (rather than half) of the 12 000 eligible donors became actual donors, cadaveric organ transplants would double from 18 000 (3 organs from 6000 donors) to 36 000—a very substantial increase.

#### Deciding to Donate

A widely cited 1993 Gallup poll of 6127 Americans discovered that 85 percent supported donation and that 69 percent were either very or somewhat likely to want to have their organs donated after their death [3]. A 1999 Pew Research Center survey of

1013 Americans found that 81 percent were in support of donation and that 67 percent were either very or somewhat likely to want their organs donated after their death [4]. These 2 surveys asked the same questions 6 years apart and garnered nearly the same results: support for organ donation was at 81-85 percent, but only two-thirds of those surveyed said they were likely to want their organs donated after their death. More than 25 percent reported that they would most likely *not* want to donate.

Eric Johnson and Daniel Goldstein, professors at Columbia University's Center for the Decision Sciences, offer a unique perspective on how to increase the supply of this life-saving resource: focus on how the decision to donate is framed. Challenging the assumption that Americans, in general, "have reached a decision *not* to donate," the authors argue in their 2004 article, "Defaults and Donation Decisions," that people often construct their preferences based on when and how the question is asked [5]. The authors performed an experimental online survey to test this hypothesis and discover how the framing of the question about willingness to donate organs might influence the result. The authors asked 161 respondents whether they would donate their organs, using 1 of 3 different questions:

1. Participants are told to assume they had just moved to a state where the default was to *not be* an organ donor. Choice: confirm that they did not want to donate or change that status.
2. Participants are told to assume they had just moved to a state where the default was *to be* an organ donor. Choice: confirm that they wanted to donate or change that status.
3. Participants were required to choose whether they wanted to donate or not, with no prior default position. Choice: I want to donate my organs *or* I do not want to donate my organs [5].

Option 1 mirrors the "opt-in" or "explicit-consent" model currently used in the United States. Option 2 represents the "opt-out" or "presumed-consent" model employed by a number of European countries. And one might say that Option 3 resembles the questions from the Gallop and Pew Surveys—a neutral question that requires an active choice.

While the sample set was small, the results of Johnson and Goldstein's experiment sheds valuable light on the apparent gap between the overall opinions of Americans and the actual donor consent rate. Options 2 and 3 resulted in donation consent rates of 82 percent and 79 percent, respectively. In stark contrast, Option 1 yielded only a 42 percent consent rate. The authors use the experimental consent rates coupled with a statistical comparison of consent rates in "opt-in" versus "opt-out" European countries as support for their theory that donation decisions are strongly influenced by whether the default position is donation or nondonation. This is troubling because it suggests that how the question is asked plays a greater role in the respondents' decision than actual preference for or against donation. As the authors put it, "If preferences concerning organ donation [were] strong, defaults should have little or no effect" [5].

Johnson and Goldstein review a number of ways that defaults have been shown to influence individual choices, no matter what the decision at hand: (1) defaults may be seen as a recommendation from policy makers; (2) accepting the default is effortless while making a decision requires effort; (3) defaults represent the status quo, and changing usually involves a trade-off—giving up one thing for another. Regarding the latter point, the authors note that “psychologists have shown that losses loom larger than the equivalent gains” (a phenomenon they call “loss aversion”); and this increased weight given to whatever is forgone makes the default position seem more attractive [5].

Applying this psychology to the US opt-in system, changing one’s status to become a donor would be seen, Johnson and Goldstein write, as a “tradeoff between a gain ([the] satisfaction [of donating]) and a loss (the possible negative [body] imagery)” [5]. The authors conclude with 2 important observations unique to organ donation decision making. First, the reason for the difference between the high abstract approval rates of organ donation compared to the actual consent rates is that most Americans have not yet made or acted upon a decision about organ donation. If they had, framing the question in different ways would not elicit such different results. Because this is true, the authors conclude that how the choice is framed—ie, whether the default position is opting in or opting out—will determine the outcome of the decision-making procedure far more dramatically than the offering of incentives—economic or otherwise. Second, the authors believe that the “cognitive cost” present in all decision making is higher in the case of organ donation because constructing a choice in this instance requires people to confront their own death—a scenario most wish to avoid contemplating. The authors cite the “mandated-choice” experiment in Virginia as evidence of people’s reluctance to choose, since more than 24 percent of the people refused to make a decision about organ donation in that experiment [6].

### **Constructing a preference is a process.**

Johnson and Goldstein have added a unique perspective to the organ transplant policy debates in this country through their application of decisional theory. Many in the transplant community believe that a shift in US policy to an opt-out or a modified version of the presumed-consent model is unlikely, but Johnson and Goldstein’s observations can still be helpful without a formal US policy shift. I believe the authors’ more important contribution lies in their relatively unexplored initial premise “that the way in which a request to become a donor is framed will influence the outcome” [5]. A first read of Johnson and Goldstein’s essay may lead one to assume, based upon their experiment, that decisions are instantaneous. One may further suppose that if the default is not woven into a single question, it cannot have the desired effect. But a closer reading of the article reveals that, in fact, the construction of preference is a *process*, and this process is significantly influenced by the way the default choice is framed.

Through an understanding of the current practicalities of cadaveric organ donation—eg, that regardless of whether or not you sign an organ donor card your family members or surrogates have the final decision as to whether to donate your organs—we see that organ donation most frequently occurs after a conversation between one’s

family members and an organ procurement organization (OPO) representative (organ donation expert). Thus, most Americans are not faced with making a real decision about cadaveric donation of their own organs but rather one about cadaveric donation of their loved one's organs. When we consider additionally that most Americans have not yet made a decision about organ donation (let alone about donating a loved one's organs), the importance of the organ donation conversation initiated by the OPO representative becomes even greater. This conversation provides the time and the opportunity to construct preferences in the manner described by Johnson and Goldstein, and the impact of defaults on the donation decision remains the same no matter who serves as the decision maker. What the OPO representative, as an informative expert in organ donation and transplantation, says in this conversation will likely provide the default impact first described by Johnson and Goldstein—that of a policymaker's or expert's suggestion for recommended action. Moreover, the OPO coordinator has the ability to construct the donation conversation from a donation-positive perspective—one that is considerably more authentic than the falsely assumed perspective of neutrality. Using the authors' claim that "donation decisions are often constructed in response to the question," I believe there is great opportunity to work within the current US opt-in policy to shape the donation conversation between potential donors' families and transplant coordinators so that this process leads to more life-saving donations.

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# Virtual Mentor

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## Clinical Pearl

### Approach to the Patient with Alcoholic Liver Disease

by Howard J. Worman, MD

The patient with alcoholic liver disease poses complex medical and ethical challenges. This patient requires not only an understanding of the medical effects of alcohol on the liver but also an appreciation of the psychosocial aspects of alcohol use disorders. Without a doubt, the most critical aspect of treatment for such patients is to help them stop drinking.

### Alcohol Use Disorders

The fourth edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) distinguishes between alcohol dependence and alcohol abuse [1]. Abuse is a destructive pattern of alcohol use, leading to significant social, occupational, or medical impairment [1]. Patients with alcohol dependence demonstrate tolerance (either the need for increased amounts of alcohol to achieve intoxication or diminished effects with use of the same quantity) and withdrawal symptoms, including delirium tremens (DTs) and alcohol withdrawal seizures [1]. Alcohol-dependent persons may also consume alcohol to avoid or relieve withdrawal symptoms. Patients with alcohol use disorders often continue to consume alcohol despite knowing that they suffer from alcohol-related medical problems. This is often true for patients with alcoholic liver disease.

### Effects of Alcohol on the Liver

Alcohol affects many organ systems, most notably the central nervous system and the liver. Excessive alcohol consumption frequently leads to 3 pathological liver disorders, any or all of which can occur singly or simultaneously in the same patient. One type of liver disorder is steatosis, which is the accumulation of fat within hepatocytes, a condition that is reversible if the patient stops drinking. A second condition is hepatitis. Histologically, alcoholic hepatitis is characterized by the ballooning degeneration of hepatocytes, inflammation with neutrophils, and, sometimes, the presence of Mallory bodies, which are abnormal aggregations of intermediate filament and other proteins. Alcoholic hepatitis is also reversible if the patient stops drinking, but it can take months to fully resolve. Cirrhosis is the third type of liver disorder. It is irreversible and is a consequence of long-term excessive alcohol consumption. The anatomic features are widespread nodules combined with fibrosis; alcoholic cirrhosis is almost always micronodular (Laënnec's cirrhosis). Patients with cirrhosis can develop end-stage liver disease with complications such as jaundice, ascites, edema, bleeding esophageal varices, abnormal blood coagulation, hepatic encephalopathy, and coma. Cirrhosis also increases the risk of developing hepatocellular carcinoma. Cirrhosis is currently the tenth leading cause of death in the United States, and alcohol is the cause or a contributing factor in the majority of cases. Despite its high



prevalence, only a minority of heavy alcohol drinkers actually develop this liver disease. Estimates have varied across numerous studies, but it appears that only between 10 and 20 percent of those who consume excessive quantities of alcohol over decades develop cirrhosis [2-4]. It should be noted, however, that environmental factors, such as chronic hepatitis C infection, increase the risk of the development of cirrhosis in an alcoholic. Other factors that may make one more susceptible to cirrhosis are: nutrition, gender (generally, women who drink an equal amount of alcohol are at higher risk than men), and genetic factors, although vulnerable genes or patterns of gene expression have not been identified.

### **Diagnosis and Treatment**

The patient with alcoholic liver disease can present in many different ways. Every internist remembers his or her nights on call as an intern, taking care of a patient with severe alcoholic hepatitis, DTs, and alcohol withdrawal seizures. In these cases, the diagnosis of alcoholic hepatitis is obvious. While many such patients also have cirrhosis, the degree of irreversible liver dysfunction may not be clear until the patient has stopped drinking for several months. Alcoholic hepatitis can cause signs and symptoms of hepatic dysfunction, including jaundice, encephalopathy, and bleeding esophageal varices. Acute treatment of hospitalized patients with alcoholic hepatitis also involves treating the complications of the disease (eg, lactulose for hepatic encephalopathy, antibiotics for infections, and endoscopic procedures for bleeding esophageal varices). More immediate treatment for alcohol use disorders also includes stopping or preventing DTs or seizures (usually with benzodiazepines), nutritional support (eg, with thiamine), and assuring cessation of alcohol intake. When medically stable, patients hospitalized for alcoholic liver disease should be discharged to an inpatient rehabilitation program with plans for subsequent outpatient follow-up and social and psychiatric support. If signs of liver disease remain even after months of abstinence, cirrhosis is likely present. Cirrhosis can sometimes be diagnosed by the clinical picture and radiological or nuclear medicine tests, but a liver biopsy may be necessary to make the definitive diagnosis.

Many subjects with alcoholic liver disease, even cirrhosis, initially present as outpatients and often for other reasons. A majority will not be the typical “skid row” alcoholic but individuals who have managed to hold good jobs and function highly in society. These patients may have none or only a few clinical signs of liver disease. For example, some might have laboratory abnormalities such as elevated serum aminotransferase activities (often aspartate aminotransferase but not always more elevated than alanine aminotransferase), elevated serum bilirubin concentration, thrombocytopenia, hypoalbuminemia, and a prolonged prothrombin time. Intensive questioning about past and current alcohol consumption is critical when taking a history of any subject with liver disease. A liver biopsy may also reveal steatosis, alcoholic hepatitis, or other liver disorders.

Long-term survival of a patient with alcoholic liver disease depends upon his or her commitment to abstinence [5,6]. Liver disease is not the only potentially life-threatening issue in patients with alcohol use disorders, and abstinence will also impact favorably on other medical, social, and psychological problems. Participation in

Alcoholics Anonymous or a similar support network is a vital component of long-term treatment and likely to improve outcomes [7,8]. Family members and friends may also benefit from participation in a support group. Liver transplantation for patients with severe alcohol use disorders and end-stage liver disease is a controversial topic. The generally accepted policy is that alcoholics who are abstinent for 6 months or more are potential candidates for transplantation [9,10]. However, concurrent medical or social problems may prohibit transplantation.

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# Virtual Mentor

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## Health Law

### National Organ Allocation Policy: The Final Rule

by Lara Duda

More than 5 years after its controversial introduction, the Final Rule continues to guide the nation's policy on cadaveric organ allocation. The Department of Health and Human Services (DHHS) issued the Final Rule in March 2000 to replace local and regional organ allocation systems with 1 national distribution protocol. This caused much debate among states, especially those that had been successful in their endeavors to increase organ donations. One of the primary concerns of the regulation's opponents was the fear that it would require local and regional centers to offer organs to patients nationwide without giving preference to local potential recipients. Over the years, however, this fear subsided as it became apparent that regional and local transplant organizations retained enough autonomy to continue giving priority to local patients. Another objection was that the Final Rule gave DHHS—and not the medical community—control of the organ allocation policy, with the DHHS Secretary having the ultimate authority. Objections to DHHS control waned because physicians and transplant specialists both continue to play important roles in organ allocation oversight.

### Background

The United States Congress passed the Uniform Anatomical Gift Act in 1968 in an effort to have a national organ transplantation policy. By 1980, every state and the District of Columbia had adopted some form of the act, and in 1984 Congress passed the National Organ Transplant Act (NOTA) to streamline the organ distribution process. One of the primary purposes of NOTA was to establish the Organ Procurement and Transplantation Network (OPTN), a system that both maintains the names of individuals who need transplants and, when organs become available, matches organs with appropriate patients.

In 1986, the Health Resources and Services Administration, a division of DHHS, contracted with the United Network for Organ Sharing (UNOS) to maintain the OPTN. Today, UNOS continues to administer the OPTN to ensure the “effectiveness, efficiency and equity of organ sharing in the national system of organ allocation,” as well as to increase “the supply of donated organs available for transplantation” [1]. UNOS has set about achieving these goals by organizing the country into 11 geographic regions, which are further divided into local organ procurement organization service areas.

### The Organ Donation Process after Donor Death

The organ donation process begins for the potential donor when a hospital physician caring for a patient concludes the patient will not survive. When determining death,

states abide by the Uniform Determination of Death Act of 1980, which is endorsed by the American Medical Association and provides that a patient who has “sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead” [2]. Many states have provisions that amend this general definition.

Once the physician declares the patient’s impending death, the hospital informs a local organ procurement organization (OPO) of the possible organ donation. Upon death of the patient, usually because of irreversible functions of the brain, an OPO representative secures permission from the patient’s family and performs a medical evaluation of the potential organ. The OPO then accesses the UNOS computer to match the donor’s characteristics to those of a patient awaiting an organ [3]. For each organ recovered from the donor, the computer generates a separate list that ranks potential recipients using factors such as tissue match, blood type, length of time on the waiting list, immune status, and the distance between the potential recipient and the donor [3]. Donation procedures for all solid organs except for kidneys take the potential recipient’s degree of medical urgency into consideration. Once a match becomes apparent, the OPO representative contacts the transplant team of the first patient on each list.

### **The Organ Allocation System**

Organs and tissue eligible for donation include the heart, kidneys, lungs, pancreas, liver, intestines, corneas, skin, tendons, bone, and heart valves. While the specific donation procedure for each organ differs slightly, the current organ allocation system favors placing organs with local patients. If the organ cannot be matched to a patient in the local area, it is next offered to patients within the UNOS multi-state region in which the organ donor resides. If the organ fails to be matched regionally, it will then be offered to patients nationwide.

### **The Final Rule**

Before 2000 organs donated in the United States were distributed locally or regionally, meaning that an organ might have gone to a patient inside a region who needed it less urgently than a patient outside the region. This resulted in a discrepancy between the availability of organs in states with larger donor banks and those with smaller donor banks. Because of the inconsistency of organ availability among states, as well as the increasingly limited supply of organs nationwide, there was growing support for a change in the organ allocation system.

In 1998, DHHS Secretary Donna Shalala issued the original Final Rule designed to distribute organs more equitably by replacing the local allocation system with a national one. A number of states, however, worried that if organs donated by their residents were given to out-of-state recipients, willingness to donate would decrease [4]. In an effort to curb this effect, some states passed laws that limited the transfer of organs out of state, to, for example, situations in which a suitable match could not be found in state.

Although scheduled for October 1999, implementation of the original Final Rule was delayed by the Omnibus Act and, later, by the Ticket to Work and Work Incentives Improvement Act of 1999 that postponed the original rule's effective date to March 2000. During this time, DHHS invited the public to submit comments about the rule. On March 16, 2000, DHHS announced an amended Final Rule that reflected public input by including clarifications of many of the criticized provisions of the original regulation. Nevertheless, the State of Wisconsin, University of Wisconsin Hospitals and Clinics Authority, Froedtert Memorial Lutheran Hospital, Oregon Health Sciences University, and the State of New Jersey brought a suit in federal court seeking injunctive relief from the Final Rule. The court dismissed the case in November 2000, holding that a state may not bring an action against the federal government. The plaintiffs chose not to appeal the case because of their low probability of succeeding.

### **Current Policy**

The amended Final Rule, still in effect today, directs the OPTN to create policies based on sound medical judgment and to avoid futile transplantations [5]. Specifically, the amended Final Rule provides that "organs should be distributed over as broad a geographic area as feasible" and considers the urgency of a recipient patient's need for an organ transplantation [6]. In effect, states may still give preference to local and regional organ recipients; however, if a match is not made, the amended rule directs states to offer the organ to patients nationwide.

Under the amended rule, the DHHS Secretary may approve or veto any allocation policies developed by the OPTN, although to date this has not happened. As the administrator of the OPTN, UNOS develops policies by a consensus of organ transplant and procurement professionals, patients, and donor families. UNOS is also responsible for ensuring these policies are followed by, for example, auditing and monitoring all transplant centers and organ procurement organizations in the United States.

### **Ethics Perspective**

In general, the AMA *Code of Medical Ethics (Code)* accords with the Final Rule. The *Code* states that organs should be considered a national, rather than a local or regional, resource. That is, geographical priorities in the allocation of organs should be prohibited except when the transportation of organs would threaten their suitability for transplantation. Moreover, the *Code* emphasizes 5 ethically appropriate criteria for the allocation of any limited medical resource. These criteria include likelihood of benefit, urgency of need, change in quality of life, duration of benefit, and the amount of resources required for successful treatment [7]. Finally, the *Code* states that patients should not be placed on the waiting lists of multiple local transplant centers but rather on a single waiting list for each type of organ. For more about the "spirit" of the *Code* regarding organ donation and transplantation, see "[The Living Code](#)."

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# Virtual Mentor

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## Policy Forum

### **The Waiting List for Organs Is Not Necessary**

by John B. Chessare, MD

On average, 17 Americans die every day waiting for a life-saving organ [1]. Other Americans die of catastrophic injury or illness who would be good candidates for donation, but, often because of ignorance of the opportunity or poor systems of care, they take their organs with them to the grave. There are over 80 000 Americans now on the waiting list for organs, and they are hopeful that time will not run out on them.

Our federal government, through the auspices of the Division of Transplantation of the Health Resources and Services Administration (HRSA) of the Department of Health and Human Services, has begun an initiative that can now offer these patients more hope. HRSA began a breakthrough collaborative in September of 2003 after then-Secretary of Health and Human Services Tommy Thompson believed that action was needed to save more of the lives on the list. Although the number of donors was growing at a rate of about 2-3 percent per year, the number of those waiting for a transplanted organ was growing at a faster rate.

Leaders at HRSA called on large hospitals (where most potential donors could be found) and organ procurement organizations (OPOs) to work together to improve the donation rate. The national average of donation by eligible donors in 2003 was about 48 percent, and Thompson issued a bold challenge to increase the rate of donation to 75 percent. To help reach this goal HRSA teamed up with the Institute for Healthcare Improvement (IHI), an organization known for its use of quality improvement techniques and rapid cycle change. HRSA staff went to the IHI's Breakthrough College and learned their technique for change.

HRSA then convened a group of national experts in donation and quality improvement from hospitals and OPOs to implement the IHI techniques and recommendations. The results in the first year were so exciting that a second collaborative kicked off in September of 2004. A total of 200 teams worked for a 20-month period with the official collaboratives ending in May of 2005. The results have shown that in the first 12 months the national rate of donations was up 12 percent [1]. In the 20 months that the programs were running 1400 more lives were saved than would have been under traditional methods of procurement [1].

The collaboratives were successful because they took motivated people seeking a common goal, taught them proven ideas and practices, and allowed them to test these changes within their organizations. HRSA is now embarking on a transplant collaborative to increase the yield of organs per donor. In combination with the donation collaborative, workers in the field no longer believe that the waiting list



needs to exist in its current form and are looking forward to the day in the not too distant future when there will be an organ available for every American who needs it.

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# Virtual Mentor

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## Policy Forum

### Presumed vs Expressed Consent in the US and Internationally

by Sheldon Zink, PhD, Rachel Zeehandelaar, and Stacey Wertlieb, MBe

The shortage of organs available for transplant has been a serious and unchanging worldwide problem since such surgeries were first made feasible and safe several decades ago. Nations around the world have relied on different strategies to try to alleviate this problem with varying levels of success.

The United States' system for organ procurement operates under a model of expressed consent. This means that an individual will *not* be an organ donor unless he or she explicitly states otherwise. The desire to be a donor is typically noted on a driver's license, in an advance directive, or by a surrogate with decision-making responsibility. While maintaining the autonomy of potential donors, the expressed-consent model has not been shown to be effective in increasing the supply of organs to a level anywhere near that of the demand.

In contrast, some countries have relied on a method of *presumed* (rather than *expressed*) consent for organ procurement. This model takes the opposite assumption for granted—individuals are presumed to want to donate their organs upon brain death unless they have expressly objected to doing so. Every country has a slightly different policy, but in all forms of the model consent can be presumed only when individuals are properly informed of the policy and given the opportunity to opt out of donating [1]. A short review of the policies employed by different countries follows.

#### International Presumed Consent Policies

With 33.5 out of every 1 million residents having organs that are in a condition that allows them to be transplanted after death, Spain has the world's highest rate of actual donation [2]. Spain's presumed-consent law was passed in 1979 and requires the prospective donor to be declared dead on neurological criteria ("brain dead") by 3 physicians [3]. Once death has been declared, any individual who has not formally registered an opposition is considered a potential donor. This system, combined with a societal respect for organ donors, has contributed to Spain's successful organ procurement program [4]. Moreover, the presumed-consent policy in Spain is cost-effective, saving the National Health Service more than 200 000 euros in medical costs for each kidney transplant preformed on a patient on dialysis [2].

A similar presumed-consent law was passed in Belgium in 1986 and implemented in 1987 [3,5]. If an individual does not want to donate, he or she is required to register the objection with the Central Health Authority. Prospective donors can change their decision at any time [6]. While physicians in Belgium are under no obligation to ask

the prospective donor's family for permission to recover the organs, or even to inform them of their intention to do so, if a family member explicitly opposes organ recovery, the physician cannot proceed [6]. Consent is presumed not only for Belgian citizens, but for anyone who has lived in the country for 6 months or more [6]. After widespread educational efforts and almost 20 years' experience since the policy was implemented, less than 2 percent of the Belgian population has registered an objection to organ donation [5].

Other countries with presumed-consent policies include Austria, France, Columbia, Norway, Italy, and Singapore. In Austria, the rate of donation quadrupled within 8 years of a presumed-consent policy's being introduced [3, 6]. Under Austrian legislation, organs can be recovered irrespective of relatives' objections [7]. Today, the procurement rate in Austria is twice as high as those in the United States and most of Europe, with the number of kidney transplants performed nearly equal to the number of people awaiting donor kidneys [4].

Other policies for organ donation include the Caillavet Law of France passed in December 1976, which allows a third party to state whether the potential donor had objections, even if the donor himself had not registered them [4]. A Columbian law states: "There shall be a legal presumption of donation if a person during his lifetime has refrained from exercising his right to object to the removal from his body of anatomical organs or parts during his death [8]." In Norway, organs may be removed after the relatives have been informed of the intention to remove them, and only the immediate next-of-kin can halt procurement by withholding consent [7]. Contrastingly, in Italy, despite presumed-consent laws, organs may only be removed once it has been determined that the donor's relatives do not object [7]. Lastly, in Singapore a presumed-consent law has been in effect since 1987 [9]. All residents receive a letter when they reach the age of 18 that states they are presumed to consent to organ donation unless they explicitly object to it. The only exceptions to this policy are Muslims, who are automatically considered objectors unless they opt in [9]. Countries with presumed consent have generally seen higher rates of organ donation than countries with expressed consent such as the United States. In fact, when Denmark switched from presumed to expressed consent in 1986, donation rates fell by 50 percent [3].

It is interesting to note that most countries that have presumed-consent laws also have national health care or a system that combines some universal health care with some private care. In the United States, the government pays for transplants of kidneys but not of other organs. In a country with private health care, only those with insurance would be eligible (or able to afford) other transplants, whereas in countries where consent is presumed and health care is universal, all citizens are eligible to receive these transplants.

### **International Expressed-Consent Policies**

The United States and Denmark are not the only countries to operate under a model of expressed consent; the United Kingdom, Canada, and Brazil, for example, do also. A Gallup poll found that 70 percent of the US respondents said they wanted to donate

their organs; however, the proportion that are registered to do so is significantly lower [10]. Similarly, in the UK, only 15 percent of the public formally join the National Health Service Organ Donation Register [11], despite public opinion polls that suggest an increasing support for a change to presumed consent. The British Medical Association believes this shift is “not only feasible in this climate, but is also the right and morally appropriate thing to do” [11].

Brazil adopted a presumed-consent policy in 1997, but it was quickly repealed, and the country returned to a policy of expressed consent after the Brazilian Medical Association and the Federal Council of Medicine criticized the law and claimed that “most doctors were unwilling to remove the organs without family consent, even if the law demanded them to do so” [4].

If presumed consent has been more successful than expressed consent worldwide, why haven't all countries made the transition in organ procurement policies? Should the United States switch to a model of presumed consent, and if so, would it work here? There are strong arguments on both sides of the ethical question.

### **Ethical Arguments**

A primary objection of those who oppose implementing a presumed-consent policy in the United States is a claim of the loss of patient autonomy. Many physicians and bioethicists believe that it is wrong to invade someone's body without that person's consent [12] and that “absolute respect for the will of the deceased” is necessary [6]. Furthermore, Kennedy et al argue that the state is already too involved in our lives, and “further incursion into our affairs by assuming possession of our body parts... would be a step too far” [7]. The authors also wonder whether implementation of a presumed-consent law would cause such social unease that people would turn away from organ transplantation entirely, although this has not come to pass in other countries [7].

Some objectors to presumed consent employ a Constitutional argument to support their stance, stating that such a law would violate the 5th Amendment prohibition on taking private property without due process and just compensation [13]. Objectors also mention the possibility of “false positives”; that is, presuming someone consented when in actuality he or she did not want to donate, had not read the necessary materials, did not know the relevant facts, or was otherwise unable to participate in the debate over organ donation [14].

On the other side of the argument are those who believe the United States should adopt a system of presumed consent for organ procurement. They respond to the argument over a loss of autonomy by countering that a presumed-consent model actually provides more autonomy than expressed consent because it allows the donor, not his or her family members, to make the final decision [3]. They maintain that asking a family for a loved one's organs at a time of intense grief is cruel and unnecessary and that, by presuming consent, the family's anxiety over this decision is alleviated [14,15].

Supporters of presumed consent also employ a utilitarian argument as support for implementing such a policy. Meredith Watson claims that presumed consent provides the greatest good for the greatest number of people by harming no one and benefiting many [16]. She adds that the burden of communicating and registering preference should fall on those who object to donating, not those who support it, because the goal of transplantation is one that is socially desirable [16]. Dr Michael Gill believes that this would also increase accuracy, inasmuch as objectors are more likely to register their opposition than supporters are to sign up as donors. Following this argument, there would be fewer mistakes in interpreting a potential donor's wishes [12]. To conclude this line of reasoning, Gill suggests that all mistakes in interpreting a donor's preferences have the same moral worth; it is no worse, Gill says, to assume that someone wants to donate, take his or her organs, and then find out that he or she objected than to wrongly assume that someone did not wish to donate and therefore forgo potential organs [12]. In response to this claim, objectors to a presumed-consent model argue that these 2 types of mistakes do not have the same moral worth; mistaken removals are inherently worse than mistaken nonremovals [12].

### **Conclusion**

It seems unlikely that the United States will make the transition to a system of presumed consent for organ procurement in the near future. State bills proposing presumed consent were defeated in Maryland and Pennsylvania [8], and fear of litigation would put a serious damper on its feasibility. In 2002, however, Delaware law specified that if a person had clearly indicated his or her wish to be an organ donor the "family cannot thwart that desire after death" [17]. Kentucky, Virginia, West Virginia, Indiana, Oklahoma, South Dakota, and Tennessee have also "taken action to ensure that the expressed wishes of organ donors are carried out" [17]. Autonomy remains a priority in American medicine today along with the right of the competent patient to make all of his or her own medical decisions. Based on the proportion of people who say they are willing to donate their organs and those who actually register to do so, it seems that the organ shortage problem stems in part from a failure to obtain permission to recover organs [15]. This critical problem requires our attention.

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# Virtual Mentor

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## Medicine and Society

### To Donate or Not: Is That the Question?

by Justin List, MAR

A 1993 Gallup Poll found that 85 percent of surveyed participants supported the donation of organs for transplantation [1]. When asked how likely they were to donate their organs upon death, 69 percent of those surveyed said that they were either “somewhat likely” or “very likely” to donate. Ninety-three percent answered that, if asked at the time of death, they would be willing to donate a family member’s organs. One might think that, given the 296 million people living in the United States, these reported percentages would translate into high rates of donation and a relatively short time on an organ waiting list. But this is not the case. As of June 3, 2005, there were 88 165 candidates on the wait list for organ transplantation [2].

The demand for organs continues to increase, and the supply consistently falls short of meeting that demand. Many reasons are given for this gap. For one, many potential donors have not documented their wishes, and family members often decline to donate the organs of their loved one when presented with the option. Some potential donors have deferred donation decisions altogether because of the stress induced by reflection on death and loss [3]. Fears of organ theft, a black market for organs, and physician dereliction of a potential donor in a life-threatening situation may also play into the cultural ethos of organ donation in the US.

The US currently has an opt-in system of informed consent for organ donation operated, in part and most popularly, through the Department of Motor Vehicles (DMV). When obtaining a driver’s license, individuals can indicate that they would like to be donors and select what organs that they would like to donate. Since not all potential donors visit a DMV, information is available—usually upon patient request—at doctor offices and hospitals. Many DMV-declared donors have not discussed their desire to donate with family members, and, even though the license declaration is a legal document, families often override their loved ones’ donation decisions. Physicians and organ procurement organizations (OPOs) do not currently have nationwide legal protections to uphold the wishes of the potential donor against the dissent of a family member [4].

If a majority of Americans indicate that they would donate but actual organ donation rates are lower than would be expected, it follows that increasing the number of documented donors and creating a system that honors donor wishes are crucial challenges confronting OPOs and society at large. Many novel approaches to increasing donation have been proposed in academic and policy literature. To ameliorate the shortage in an innovative way, many authors seek to effectively address common cultural attitudes in America—societal and individual—that impact the

donation decision making process. At the policy implementation level, the problems associated with organ donation are far from solved, prompting many to look to the experiences that other countries have had with organ donation.

Some European and Latin American countries have implemented a presumed-consent model of organ procurement wherein donation is the default policy. Individuals can opt out of this system but it requires that one actively do so. Many of the countries that practice presumed consent, such as Austria and Hungary, have very low opt-out rates, nearing 0 percent of the population [2]. Adoption of presumed-consent policy has been proposed by some groups in the US, but many policymakers and others argue that ingrained US values that favor individual choice over government intervention render presumed consent an inviable option. It should be noted that many of the European countries with presumed-consent policies also have histories of governmental authority over cadavers and autopsies that the US does not. US laws mandate that remains become the responsibility of the next of kin for burial or cremation, a practice not present in some countries [5].

Presumed-consent systems do not completely rectify the problem of organ shortages, but they have dramatically reduced waiting lists in many of the countries where they have been enforced, most notably in Spain [6]. Nonetheless, it is likely that differences in cultural attitudes and political structure mean that the US will need a system that is different from presumed consent to increase organ procurement. Current academic literature contains an abundance of alternatives ranging from awarding “points” for opting in [7] to changing current policies so that they honor patients’ individual donor preferences better.

A mandated-choice model is currently viewed as a potential alternative method for increasing organ supply because its structure reflects the American disposition for choice. Forcing one to choose whether to become documented as either a donor or nondonor is the central feature of this model, which has been promoted as preserving individual choice and increasing the organ supply. Variations of the mandated-choice model might be explored, but pilot studies in Virginia and Texas were not very encouraging—many OPOs and other interested parties who have evaluated the pilot studies found the model less than successful. A sizable proportion of participants—24 percent in Virginia—simply refused to make a decision [8].

About the Virginia experience some researchers concluded, “These data support the hypothesis that many persons who are not opposed to donation still want to leave their family the ‘right to refusal’ and are therefore unwilling to commit to a binding pro-donation decision beforehand” [8]. Some have proposed that when a person fails to make a choice regarding organ donation the default “choice” is in favor of donation. Such a default policy would probably be a contentious facet of a mandated-choice model. Although in theory a mandated-choice policy may best balance individual autonomy with efforts to increase organ supply, as some have argued [9], it has been shown to be fraught with policy difficulties in the experimental models used thus far.



Presumptive consent is a newer idea that is, in essence, a framework for talking with patients and patient's families rather than a donation policy. Presumptive consent is predicated upon 2 ideas—that organ donation is the “right thing to do” and that, given the opportunity to save a life, most people would want to do it [10]. One way that the transplant coordinator can subtly and less directly encourage donation is through value-positive language about organ donation rather than the standard use of value-neutral language. A simple example of positive value, presumptive language is, “When you decide to donate...” compared to, “If you decide to donate...” in the standard model. This approach is seen by some as an easy solution to the organ shortage since it does not require a major external policy overhaul. While it may increase and encourage organ donation, using value-laden language raises ethical questions about coercion—however soft—and trust in the medical encounter.

OPOs, medical professionals, and patients are, by and large, frustrated with the current organ procurement system in the US. In discussing alternative allocation strategies, other factors must be taken into account including personal choice, family relationships, legal protections, and the documentation of decisions. Underneath these factors lies a deeper challenge for advocates of organ donation: better understanding of the intricate psychological facets of human decision making, the influence of language, and deliberate reflections on mortality. The American experience may entail cultural trends unique to its citizens that require specific attention for the purposes of policy making, but, in reality, all organ donor recruitment efforts are likely to require more focus on these complex relationships in order to best understand how to motivate sustained organ donation and awareness.

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# Virtual Mentor

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## Medicine and Society

### Advertising for Organs

by Aviva Goldberg, MD

Advertising works. McDonalds, Coca Cola, and Nike know that their commercial success relies on their ability to tell people about a product and make them want to buy it. Nonprofit organizations also realize that public appeals are required to forward their cause—thus the advent of telethons and campaigns. Not surprisingly, individuals have also turned to advertising for personal causes, be it on the Internet or through traditional media sources, to get what they need.

In the last year, several organ transplant candidates have launched campaigns to procure organs from living or deceased donors. These campaigns for “directed donations” have raised concerns from the medical community, lawmakers, and the public. The collision of autonomy and justice principles caused by this practice has forced us to re-examine our values and the legislation controlling the organ allocation process. While there are several important reasons to consider organ advertisements, a careful analysis reveals that the practice raises serious ethical problems. Medical societies should continue to discourage these appeals [1, 2], and legislation must outlaw the practice.

In August 2004, Todd Krampitz, a newlywed suffering from liver cancer, received an organ from a deceased out-of-state donor after Krampitz’s family posted a billboard asking for a directed donation [3]. In the wake of Krampitz’s successful campaign, several other candidates have launched Internet or media appeals or have advertised for living donors through websites like [matchingdonors.com](http://matchingdonors.com). Recently, Shari Kurzrok, a 31-year-old PR executive who urgently needed a liver transplant, became the target of a multimedia campaign which included an ad in the Sunday *New York Times*, a website, and a blitz of advertising from her college alumni organization. Ms Kurzrok eventually obtained a liver through the standard transplant waiting list.

To determine whether these campaigns are ethical, it is important to understand how the current organ allocation system operates in the US. Organ donations from deceased donors are managed by the United Network for Organ Sharing (UNOS). UNOS is a private, nonprofit organization under contract with the Health Resources and Services Administration of the US Department of Health and Human Services to administer the Organ Procurement and Transplantation Network (OPTN). The OPTN was established by US Congress under the National Organ Transplant Act (NOTA) [4], in part due to concerns regarding unfair organ distribution [5]. Transplant centers and organ procurement organizations must comply with NOTA guidelines and regulations in order to receive Medicare and Medicaid funding [6]. UNOS has a mandate to distribute organs based on a “combination of medical factors

such as degree of illness, blood type and size of the organ needed, and medical/ethical circumstances such as a patient's waiting time and the relative distance between the organ donor and recipient" [7]. While UNOS policy states that "no consideration in allocation is given to gender, race, citizenship, or social factors such as wealth or celebrity status" [7], the OPTN regulation that has prevailed since March 2000 (called the Final Rule) allows families donating a deceased loved one's organs to circumvent the list by directing the donation to a *named* individual of their choice [8].

Donations from living donors are not regulated in the same manner. Individual transplant centers may adopt their own rules for accepting living donors but must ensure that donors are physically healthy and choose to donate after receiving full disclosure of possible risks and consequences of donation. NOTA prohibits the purchasing of organs, either from living or deceased donors [4].

The directed-donation exception in the Final Rule has been used in several situations where a friend or close family member of a person waiting for transplant dies unexpectedly. More recently, however, transplant candidates have attempted to use this rule to ask strangers to donate a loved one's organ, not to the general waiting list, but to them in particular. It is the perception that these media campaigns unfairly circumvent the traditional system that creates the controversy.

Those who argue in support of media appeals cite the autonomy rights of potential donors and recipients. They champion the prerogative of the intended organ recipient to procure an organ in any legal manner possible and "the right" of the donor to give the "gift of life" to the recipient of his or her choosing. As a society, we encourage potential transplant recipients to persuade their families and friends to become organ donors, and we applaud those individuals who choose to donate to a loved one, never questioning their right to designate a recipient. How, then, can we condemn media appeals and their respondents who make the same choices?

Justice issues oppose these strong autonomy claims when we consider the effect of media appeals on the larger community. We offer family members and close friends the choice of donating to a loved one because of the special bond that these intimate relationships create; some ethicists even argue that there is a *prima facie* obligation for family members to donate [9]. The same obligations and privileges do not extend to strangers because intimate bonds do not exist between them. When gifts are exchanged outside of close relationships, the impact on other members of the community must be taken into account. Expanding the call for organs into the larger community obligates the solicitor to consider the impact of that appeal. A media appeal casts a wide net, beyond the normal human bonds of close relationships. A campaign that seeks to further the cause of 1 individual by reaching into a large community when many are similarly suffering seems unjust.

Proponents of media appeals offer several reasons besides respect for autonomy to support this practice. Some argue that allowing donors to choose recipients may overcome some current barriers to donation [10]. For example, researchers have noted reluctance among minorities to donate because they perceive inequities in the system

[11,12]. Permitting minority donors to direct donations to minority recipients could theoretically improve donation rates. Advocates of media appeals also believe that personal stories of illness and impending death garner donations that would otherwise not be offered. And, they say, public appeals raise awareness of organ donation in general, which may increase the donor pool for all [13].

Of course, it is helpful to put a face on the suffering of those on the organ waiting list, and research has shown that providing information about organ recipients—even anonymously—has a positive effect on willingness to donate [14]. The idea of using a “poster child” to represent a cause is employed in many fundraising campaigns, and most reasonable people understand that donations to charity are contributions to help those *like* the publicized representative, not necessarily that actual individual. The face presented in the directed donations media campaigns is often not all that “representative”: it typically belongs to someone white, educated, photogenic, and with access to substantial resources. Minority members and the poor continue to be overrepresented on transplant waiting lists, but their stories are not being told through these campaigns.

Claims that high-profile, directed donations increase the donor pool make theoretical sense, but the evidence to support them is far from clear. Over 1000 potential donors signed up with [matchingdonors.com](#) after the first media directed transplant, and several more matches have been brokered [15]. On the other hand, a survey of the American public found that 93 percent of Americans willing to donate to a stranger would do so even if they could not choose their recipient [16]. In the same survey, those initially reluctant to donate were asked whether the opportunity of directed donation would affect their decision. Twenty-three percent of respondents said that this policy would make them more likely to donate, but almost as many (17 percent) said they would be *less* likely to donate if this were the rule. The claim that organs obtained through media campaigns helps to increase donations has simply not been proven.

Even if it were true that media appeals raise donation rates, this would not, in and of itself, justify the practice. Many strategies for increasing donor numbers have been rejected by Americans, including the sale of organs [4] and the use of organs from anencephalic infants [17] or executed prisoners [18]. As a society, we believe certain goals, in this case the preservation of an equitable system, can sometimes trump the interest in preserving a particular life.

Furthermore, media appeals offer no guarantee of accuracy; intentional misrepresentation or incomplete information given by potential recipients may persuade donors who will later feel betrayed. For example, many people listed on the [matchingdonors.com](#) website emphasize the fact that they are parents or grandparents, presumably because they hope this will help them attract a donor. Less favorable characteristics, like a history of drug use, are seldom, if ever, mentioned. It is understandable from the recipient’s perspective—each wants to put forward the best possible image in order to increase chances of a donation. The potential donors in this situation, however, must choose their recipients on the basis of incomplete—and

sometimes inaccurate—information. If unfavorable characteristics are somehow revealed after the transplant, the donor may feel deceived, and these stories, if they find their way back into the media, may erode public trust of the overall transplant process.

Unregulated media-brokered matching also puts recipients at risk. Donors are given access to personal information about recipients that is not generally accessible. When organ transplantation takes place through OPTN, the medical community's emphasis on patient confidentiality aims to protect the sick person's dignity. Expecting recipients to expose their medical and personal histories on the Internet in a desperate plea for a limited resource goes against this important element of respect for persons and produces an inappropriate "Queen-for-a-Day" atmosphere.

Besides the multitude of ethical concerns brought up by the idea of Internet solicitation, one suspects that the entire process will be limited by our short media-wise attention spans and therefore not become a practical long-term strategy. Ms Kurzrok's story, while it certainly seems as compelling as that of Mr Krampitz, received much less media coverage. Although there may be other explanations, public interest may be waning as transplant pleas become more commonplace.

What, then, is the solution? Should we prohibit all transplant candidates from discussing their situations? It is neither ethical nor legal to prohibit patients from telling their stories in private venues. Public solicitation may not, however, deserve the same protection or respect. Even if we cannot silence the call for organs, we can refuse to heed it. Transplant centers can refuse to perform transplants brokered through Internet appeals or other forms of advertising. As ethicist Lanie Freidman Ross suggests, media outlets can pledge to refuse to cover such stories, thereby lessening their impact [5].

It is important not to fault the patients or their families for the problems associated with media appeals. These families are using legal means to do what any one of us would try to do in a similar situation—save the life of someone we love. The responsibility to see that transplant candidates are treated justly lies with the transplant community, not with the candidates. We must remain committed to *all* the waiting transplant candidates, not just those with the ability to campaign for their lives. We should refuse to participate in such campaigns and urge lawmakers to close the legal loopholes that allow them. At the same time, we need to develop strategies that will increase overall organ donation and address existing disparities in the UNOS system.

Media campaigns are an unfair practice that undermines the values of distributive justice that the OPTN was created to champion. Autonomy and utility arguments cannot defend the practice successfully because they are outweighed by the potential harm to the larger community of recipients, to donors, and to society. By supporting a change in the laws that govern the list, we can prevent the deterioration of the system and ensure equitable distribution of organs.

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# **Virtual Mentor**

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## **Medicine and Society**

### **The Ethics of Face Transplantation**

by Molly Mark

It is well known that several surgical teams in the US and Europe currently have the ability to perform full face transplants on humans. Development and implementation of the surgery, however, has been on hold for several years now due to the many complex ethical and medical questions surrounding the procedure. Potential candidates for face transplants include survivors of debilitating diseases, such as mouth cancer, and burn victims, whose faces have been so deformed that their quality of life is severely diminished.

The primary medical concern associated with the procedure is the patient's ability to tolerate the aggressive immunosuppressant therapy necessary to overcome the physical rejection associated with transplantation of an organ. Despite the fact that immunosuppressants themselves can cause life-threatening conditions like cancer and kidney failure, the face transplantation patient would need to take these expensive medications for the rest of his or her life.

This need gives rise to an ethical question associated with the selection of face transplant candidates: should their ability to pay for these medications be a factor in their selection? The issue of money may seem trivial when talking about a scientific breakthrough of this magnitude, but if a patient stops taking the prescribed immunosuppressants the result is likely to be fatal, as it was for one of the very first successful hand transplant patients. While in that particular case, there was no evidence of the patient's inability to pay for the immunosuppressants, the fact remains that if a patient stops taking the anti-rejection medication, whatever the reason, the likelihood of fatality is high. So at a minimum, we must screen patients during the selection process for their ability to secure the needed immunosuppressants, through whatever means, to eliminate one very dire potential for complication.

A second medical concern is the fact that the procedure has not yet been refined to a point where all the nerves and blood vessels between the transplanted tissue and the recipient can be perfectly connected, and, as a result, it is likely that the patient would not have full facial expression and mobility. Some have even suggested that the transplant would be more like a mask than like a part of the patient's body and that life with this unanimated "mask" would be no more desirable or socially acceptable than life with the original, malformed face, especially when one considers the risks of rejection. First, I will say in response to this point that no one really knows how precise the surgery will be, and I would argue that most face transplant candidates would probably consider limited expression and movement an acceptable trade-off for a more normal appearance. Furthermore, if the candidate does not consider these risks

and potential consequences acceptable, he or she could simply opt not to have the surgery. It seems right, however, to give the patient that choice.

Major ethical and psychological dilemmas surround the idea of “wearing someone else’s face,” ie, a face removed from a cadaver. It is very likely that the patients who will undergo the face transplants will experience a good deal of intense psychological distress and anxiety while making the adjustment to wearing a new face. Some medical ethicists have argued that, since the patient is going to have to endure distress and anxiety as a result of adjusting to a new appearance, the additional dangers and unknown risks associated with an experimental surgery should be avoided; patients should devote their energies to adapting to life with a newly deformed face. This point has been raised many times during the ongoing debate over the ethics of face transplantation: the patient is going to have to go through massive re-adjustment, so why not adapt to the newly burned, diseased, or otherwise deformed face? My answer is that it’s all well and good to say that people should adjust to wearing their own deformed faces until you live a day in the life of someone with facial deformities so severe that children cry when they see you and adults simply look away. While the *lives* of face transplant candidates often are not threatened, their *quality of life* is. In fact, if you have to live your life depressed and afraid to leave your house for a very real of fear social rejection, some would argue that is not much of a life at all, and that wearing someone else’s face is an excellent alternative.

The question of what would look more normal or be more desirable—a transplanted face with limited movement or a severely malformed, scarred face—is at the root of the discussion on the values of face transplantation, if not cosmetic surgery overall. As cosmetic surgery becomes more common, and as our societal standards for appearances become less realistic, at what point do we start to question the values that underlie this movement towards an increasingly narrow range of social acceptability? I believe we need to re-assess the values that brought us to the point where someone who does not fall into our acceptable range of “normal” appearance cannot live an otherwise “normal” life. People, including friends, acquaintances, and passersby, must learn to be sympathetic and compassionate to people who have experienced disfiguring injuries to their faces and not look away or make them feel unaccepted.

My point is *not* to say that we shouldn’t pursue face transplants as an option for burn victims or other candidates. But, as many ethicists have argued and will surely continue to argue, this procedure should not be taken lightly. All angles—medical and ethical—need to be considered, and the candidates, if we do choose to undertake the surgery, will have to be chosen with extreme care.

I have several suggestions for the next steps in the process toward implementing this procedure. First, I recommend further animal testing, which, up until now, has been very limited. Second, I would suggest additional experimentation using alternative antirejection methods, such as the transplantation of donor bone marrow, which may encourage the body to be more accepting of such a large transplant in another region of the body. And third, we must continue to have conversations and debates about the many ethical questions associated with the procedure in an attempt to come up with the best possible answers. Keeping in mind that many of the greatest medical

breakthroughs and innovations were, in their beginnings (and some remain), vastly controversial, we owe it to ourselves and to prospective patients to make the most informed and deliberated decisions possible about the future of face transplantation.

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# Virtual Mentor

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## The Living Code

### The Power of the *Code*

by Andrew Nelson

The American Medical Association's *Code of Medical Ethics* has long been a guide to help physicians distinguish between right and wrong. But the *Code* does more than that; through its tone and language, the issues it chooses to address, and the timing of its opinions, it has the potential to affect social policy and societal norms.

The most obvious example of this power is probably the *Code's* opinion on abortion. Already in 1972, the *Code* stated that “the Principles of Medical Ethics of the AMA do not prohibit a physician from performing an abortion that is performed in accordance with good medical practice and under circumstances that do not violate the laws of the community in which he practices”—this at a time when abortion was illegal in most states [1]. The opinion was cited in the 1973 Supreme Court decision *Roe v Wade*, which invalidated many of those laws.

The *Code's* abortion opinion is brief and reserved in tone, reflecting the continuing social unrest and political debate that surround the issue. Not so for the *Code's* opinions on organ donation and transplantation. Since the Judicial Council (now the Council on Ethical and Judicial Affairs) first issued guidelines on the subject in 1969, the overall disposition of the *Code* toward organ donation has shifted from caution to encouragement. Some of these opinions correlated with changes in public attitudes and the law. Others, in the spirit of the AMA's Principles of Medical Ethics, have actively sought increases in scientific knowledge and reconsideration of public policy.

### A New Procedure

The first successful kidney transplant was performed in 1954 by Dr Joseph Murray in Boston. In the following decades, physicians would learn how to transplant the lungs, the liver, the heart, and other organs. Improvements in the understanding of organ rejection and human body chemistry would later enable the recipients of donated organs to survive for years longer than expected. Now, thousands of transplants are performed each year in hospitals all around the country. Transplantation has gone from an experimental procedure to a standard form of therapy.

In 1969, the first year the *Code* included an opinion on organ donation, transplantation was still relatively novel [2]. The first heart transplant had been performed just 2 years before in South Africa. Immunosuppressant drugs like cyclosporine had yet to be discovered, so organ recipients were not surviving nearly as long as they do today. In light of these facts, some worried that media attention was encouraging futile transplantations.

The 1969 opinion on organ donation addresses this fear through guidelines on how physicians should communicate with the media. “Medicine recognizes,” the opinion says, “that organ transplants are newsworthy and that the public is entitled to be correctly informed about them” [2]. The opinion instructs physicians to protect their patients’ privacy and to make a full, objective scientific report available to their peers as soon as possible. The opinion also attempts to prevent futile transplants by warning physicians that they and their patients should carefully consider all alternative therapies before attempting transplantation.

These parts of the opinion may now seem antiquated, but the bulk of the 1969 guidelines on organ donation have remained unchanged in the *Code*. The opinion reminds physicians that their primary duty is to their patients and that no one’s level of care should be diminished because of a choice to be an organ donor. It seeks to eliminate conflict of interest with the rule that a potential donor’s death should be certified by at least 1 doctor who is not caring for the potential recipient. It stresses that fully informed consent must be received from the donor or the donor’s responsible relatives. Finally, the opinion instructs that physicians should only attempt the surgery if they have the facilities and skills to do so. These basic ethical guidelines for organ donation have not changed in the past 35 years.

### **The Shortage**

What has changed over the years is the medical profession’s perception of the potential of organ donation to save lives. In its early years, transplantation was viewed as a medical miracle. Now, a generation of physicians has been trained to perform transplants, and hospitals around the country are equipped to support the procedure. The only limiting factor is the supply of organs. According to the Organ Procurement and Transplantation Network, more than 88 000 people were on a waiting list for organs in July 2005, but only about 27 000 transplants were performed in all of 2004. In 2003, more than 7000 people died while waiting for organ transplants. The number of donated organs is growing each year, but the waiting list is growing faster [3].

This shortage was first acknowledged in the *Code* in the 1981 opinion regarding the allocation of scarce medical resources, among which were listed donated organs and tissues. While the opinion stated that physicians should do everything they could for their individual patients, it also stressed that doctors should not be forced to make political decisions about resource allocation. This opinion also rejected distributing health resources on the basis of criteria unrelated to medical need and making judgments about who should be a donor or recipient based on social worth [4].

Another ethical question associated with the nation’s organ shortage was addressed in 1986 when the council rejected financial incentives for donors. The opinion noted that voluntary organ donation “is to be encouraged”—the first time the *Code* had explicitly said so. But it did not address specific methods to increase donation or provide guidance as to the best way to talk with patients or their families about giving their organs [5].

The *Code's* overall attitude toward organ donation, then, was one of caution. But speculation about how to increase transplants led to new opinions that would substantially reshape the *Code's* position.

### **New Approaches**

Physicians' primary duties are always toward their patients. But that is not the only duty acknowledged by the AMA's Principles of Medical Ethics. Doctors are encouraged to advance scientific knowledge, to improve their communities, to seek changes in the law that would benefit their patients, and to support access to care for all people. These social duties can be seen as mandating that physicians encourage organ donation by the population at large.

Indeed, these principles were cited to justify a series of new opinions on organ donation issued by the council in the early 1990s. The new opinions were also based on a 1993 resolution from the Medical Schools Section urging the AMA to study methods for increasing the organ supply [6]. One of the proposed methods was financial incentives, which the council had previously rejected. The other 2 were mandated-choice—under which nearly all people would be forced to make binding decisions about whether into donating their organs—and presumed-consent—a system in which all people are assumed to be willing donors unless there is evidence to the contrary. Around the same time, the council also presented reports that addressed minors as organ and tissue donors, donation by condemned prisoners, the commercial use of human organs, and organ and tissue allocation in general.

These reports reveal how drastic the national organ shortage was perceived to be. CEJA found that “the shortage of organs for transplantation results in a tragic number of potentially preventable deaths” [7]. (The idea that a lack of donated organs causes deaths continues to be part of the rhetoric of AMA reports; in 2002, patients were described as dying “from lack of an organ transplant” rather than from a particular disease [8].) The report on mandated-choice and presumed-consent weighed the risks to autonomy and informed consent against the greater social good of increased donation—the sort of utilitarian exercise the AMA was usually loathe to consider [7]. Doctors were, as they are now, frustrated by a large number of deaths which, under different circumstances, could have been prevented.

The result of these reports was that between 1992 and 1994, 3 opinions on organ donation were added to the *Code* and 4 were updated [9]. The opinions made clear that the AMA and the medical profession as a whole were searching for ways to increase donation but were also concerned about their duties toward their patients and society. The only method for procuring organs that the *Code* condemned outright was financial incentives to living donors [10]. The council did not find anything inherently unethical about future contracts for cadaveric donors, mandated-choice, or presumed-consent (though they urged caution in pursuing each) [11]. Though federal government and the states had yet to attempt such programs, the *Code* provided guidelines for future trials. The main opinion on transplantation was also modified to remind physicians that donated organs should be considered a “national, rather than a local or geographic resource” [12].

### **Protecting the Vulnerable**

At the same time that it expanded possibilities for organ donation, the council was modifying the *Code* to protect classes of people who might be more vulnerable in an environment of increased demand. The first group considered was minors who were most likely to be relatives of a person in need of a donation. When someone needs an organ, family members who might be living donors naturally feel pressure to give, not only because of their attachment to the individual, but because their organs are less likely to be rejected, and the recipient can bypass the national waiting list. But physicians and the public were concerned that children might be pressured into donating organs. The council relied on developmental psychology in crafting guidelines to ensure that children and minors could donate in appropriate and limited circumstances that did not unduly endanger their well-being and with judicial intercession, if necessary [13].

In the 1994 *Code*, the AMA also adopted a strict standard on the use of the organs of condemned prisoners. The *Code* stipulates that physicians can only recover organs from executed prisoners when the prisoners had made a clear decision to donate before their conviction [14]. While no explanation is offered in the opinion or supporting reports, the *Code's* prohibition of physician participation in capital punishment may be behind this opinion.

Finally, in the early 1990s the AMA was involved in a controversy over when and how physicians could participate in the donation of organs from neonates with anencephaly, the congenital absence of the brain, skull, and scalp. For a few years, the *Code* stated that physicians could consider such neonates organ donors before they died, since they lacked a past consciousness and had no potential for a future one. However, the council eventually reversed itself on the issue. (For more on this decision, see [August 2004's issue of \*Virtual Mentor\*](#)).

The guidelines developed for organ donation from minors, anencephalic newborns, and prisoners can be seen as part of a long medical tradition of protecting the vulnerable. But by making it clear that donation by 2 of these groups was acceptable—at least under some conditions—the *Code* was also encouraging an increase in the organ supply for all patients.

### **Experiments in Ethics?**

The latest trend in the *Code's* opinions on organ donation has been a move toward pilot studies to determine the advantages and disadvantages of different systems for organ procurement. While the AMA does not actually conduct such studies, Opinion 2.151, “Cadaveric Organ Donation: Encouraging the Study of Motivation,” issued in December 2002, says that physicians should support innovative approaches to encourage organ donation, including ethically sound research studies of financial incentives. On the whole, this opinion asks physicians to be proactive in encouraging organ donation and to participate in research studies on the subject. The AMA House of Delegates has also passed policies supporting studies of mandated choice and presumed consent [15].

At first glance, it might seem odd that pilot testing these plans for their effectiveness in increasing organ donation would be thought to provide information about whether they are right or wrong; it's certainly not how people answer ethical questions most of the time. The pilot studies proposed by the *Code* do not seek to answer the basic ethical questions, rather, they are designed to determine potential harms of methods that the AMA has already determined to be morally acceptable in themselves with appropriate safeguards. An analogy might be made to tax policy. Most people agree that the government ought to levy taxes for the public good. But the effects of taxes on society are not easily predicted, so the tax code changes even when the moral basis of taxation does not.

Similarly, many of the objections to mandated choice, presumed consent, and financial incentives do not arise from the nature of the concepts, but from possible outcomes (like accidental procurement of organs, exploitation of the poor, or increased distrust of doctors). There is no way to tell whether these harms will occur at all until the concepts are tested. If harms do occur, they need to be compared to a potential increase in organ donation—the magnitude of which is also unknown.

One model to follow might be the trial programs that led to the *Code's* current opinion on organ donation after cardiac death [16]. Protocols to allow for donation under these circumstances have increased the nation's organ supply. On the other hand, experiments in mandated choice have not turned out so well—in Texas, a mandated-choice law actually resulted in a decrease in the organ supply before it was repealed [15]. And 2 of the techniques with perhaps the greatest potential to increase the number of available organs—financial incentives and presumed consent—have never been tried within the United States (though some countries in Europe rely on a presumed-consent model). Twelve years after the AMA first encouraged the American public to study some of these methods, the data has yet to come in.

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# Virtual Mentor

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## Op-Ed

### Should Alcoholics Be Deprioritized for Liver Transplantation?

by Fritz Allhoff

#### Introduction

Alcoholic cirrhosis of the liver, which is characterized by severe scarring due to the heavy use of alcohol, is the major cause of end-stage liver disease [1]. For those afflicted with cirrhosis, a liver transplant often offers the only possibility for survival. Unfortunately, the demand for liver transplants for both alcoholic cirrhosis and other conditions exceeds the supply. Thus we arrive at an important question, which has both medical and moral dimensions: should those whose end-stage liver disease was caused by alcohol abuse be deprioritized for liver transplantation [2]?

#### Medical Considerations

It is largely uncontroversial that limited resources should be allocated where they will do the most good. In triage situations, for example, we try to save those who stand the greatest chance, rather than invest our limited resources in those who are likely to die regardless of the medical care they receive [3]. If we are going to try to invest our resources in ways that generate the greatest return, we could ask what medical considerations would be relevant to this assessment. Two jump out as obvious: likelihood of success and life expectancy [4]. Starting with likelihood of success, we might reasonably postulate that, all else equal, we should invest our finite resources in cases where the investment is likely to be most effective. For example, imagine that 2 people are in need of a transfusion. Imagine that their blood types are A and B respectively, and that our blood supply consists only of type A blood. In this case, we should obviously transfuse the A patient since the other transfusion would face rejection. Similarly with life expectancy, it should be uncontroversial to postulate that, all else equal, we should invest in those with the longest life expectancy. For example, if we had 1 organ that could be transplanted into a patient with 6 months of life expectancy or into an adolescent patient with 50 years of life expectancy, many would argue that we should transplant to the adolescent.

So, in confronting the issue of whether we should deprioritize alcoholics for liver transplantation, we must ask whether such transplants would be successful and whether alcoholics have a shorter life expectancy than nonalcoholics, all else being equal. If alcoholics score poorly on either of these medical criteria, then we could presumably justify their deprioritization. Regarding likelihood of success, I do not think there are compelling reasons to believe that alcoholics who have been abstinent for at least 6 months would be any riskier as transplant candidates than any other population of patients who need livers. It could be the case that their immune system has been weakened by alcohol consumption, or that they suffer other health-related problems because of their alcohol consumption. However, these cases would have to

be investigated individually, and it is clearly inappropriate to assume that alcoholics, as a group, necessarily carry a lower likelihood of success. And if they have health issues that would lower that likelihood, it is not their *alcoholism* that is (proximately) relevant, but rather the manifestation of other health risks. For this reason, we cannot categorically discriminate against them for their alcoholism, though we could discriminate against them on the grounds of other health problems which they might be more likely to manifest.

Let us now consider life expectancy: do alcoholics who receive transplants have a lower life expectancy than nonalcoholics? Again, there is no necessary reason to think so. Alcoholics might, on average, have shorter life expectancy than nonalcoholics, but this would not provide any reason to discriminate against a particular alcoholic for a transplant. In some cases, the alcoholic can have a longer life expectancy than the nonalcoholic; imagine that the latter has cardiac disease and the former does not. We certainly can discriminate against an individual alcoholic because he or she might have a lower life expectancy, but this is no reason to deprioritize alcoholics as a population. And again, it would not be the alcoholism that was deprioritizing them, but rather their shortened life expectancy. While the latter might have resulted from the former, the alcoholism is still (proximately) irrelevant for the assessment.

While I have thus far maintained that, by medical criteria alone, alcoholics should not be deprioritized, there is at least 1 more feature that we should consider. If the alcoholic is nonreformed (ie, destroyed his liver through alcohol consumption and *continues* to drink), this is certainly going to be a relevant medical consideration. I do not think that we can deprioritize a reformed alcoholic on medical criteria, though a case might be made against him on moral ones. However, the nonreformed alcoholic is arguably a different case. Remember that our guiding principle thus far has been to invest our limited resources in such a way as to maximize their efficacy. A nonreformed alcoholic might, in theory, destroy a *second* liver through alcohol consumption and, thus, would suffer a lower life expectancy. In these cases, we would have a medical reason for the deprioritization. However, we should be careful about too hastily invoking this argument against alcoholics. In many cases, an alcoholic has ruined his liver through decades of serious drinking, and it is quite possible that he or she will be unable to redevelop cirrhosis in a second liver before dying of other causes.

### **Moral Considerations**

Thus far, I have tried to argue that a compelling case cannot be made for deprioritization of alcoholics for liver transplantation on medical criteria alone. But certainly there are considerations other than medical ones, namely, moral ones. The central question here is whether alcoholics should be deprioritized on the grounds that their own actions caused their illness, while nonalcoholics might have been afflicted for reasons beyond their control. A related issue is whether failure to deprioritize alcoholics condones their alcohol abuse. First, let's try to make the case for deprioritization on moral grounds. Imagine that there are 2 homeowners, and that each has his or her home destroyed. In 1 case, the homeowner sets his own house on fire and watches it burn down. In the other, the homeowner watches her house be destroyed by a tornado. If we only had enough relief to provide for 1 of the

homeowners, whom should we choose? Intuitively, we would fund the second homeowner since her house was destroyed through no fault of her own. This intuition might drive some more general moral principle which says that we must hold individuals accountable for what they do and prioritize those who are blameless over those who are blameworthy. If we accept this principle—and I expect most all of us would—then we might have a reason to deprioritize alcoholics on the grounds that they are to blame for their condition.

But *are* alcoholics to blame for their condition? Is their case really analogous to the thought experiment proposed above? Arguably not. In the thought experiment, we imagined that 1 homeowner willfully destroyed his own house, and this was supposed to be a thinly veiled allusion to the alcoholic willfully destroying his own liver. But maybe this is not a good analogy; it depends on how we conceive of alcoholism. To put the question simply: does the alcoholic choose to drink? If the answer is yes, then perhaps we can blame him for his cirrhosis. But, if the answer is no, then maybe we cannot. I cannot solve this issue here, but let me gesture toward some avenues of inquiry.

Consider the hypothesis that the alcoholic does *not* choose to drink; let us call this the “disease concept” of alcoholism [5]. This approach could work in either of 2 ways, which I shall label the weak and strong approaches. On the weak approach, the alcoholic chooses to start drinking, but then cannot stop because he is then addicted and lacks volitional control over his actions. This is not to say that he does not know that he is drinking, nor that he fails to engage the means-end reasoning necessary to drink (eg, going to the store to buy alcohol). Rather, the thesis is that he is “unable to do otherwise” because he is in the grasp of an addiction [6]. We might compare this weak disease concept of alcoholism with a strong disease concept wherein the alcoholic does not even choose to take the first drink but rather is compelled to start. The compelling could come from genetic predispositions or be due to environmental influences. Or, lest we be accused of genetic or environmental determinism, the compelling might derive from some interaction between genes and environment.

I think that lots of us are likely to find the disease concept of alcoholism (whether weak or strong) unconvincing because of an intuition that, at some level, alcoholics still *choose* to drink. And, because they choose to drink, they are therefore blameworthy for their cirrhosis. Maybe this is true, and maybe alcoholics do choose to drink. But certainly we cannot reach this conclusion from where we sit without access to the alcoholic’s phenomenology. Those who do not suffer from addictions can have great difficulty imagining how crippling an addiction can be, and it might be easy to hasten to the conclusion that cravings, no matter how strong, could nevertheless be resisted. However, this is almost assuredly false. Whether alcoholism is resistible or not is an empirical question, and not one which I claim to be capable of answering. But, insofar as our moral condemnation of alcoholics (and their potential deprioritization for liver transplantation) hinges upon their blameworthiness, it is a question we must engage.

## **Conclusion**

In this short essay, I have tried to highlight some of the medical and moral issues at

play in deciding whether alcoholics should be deprioritized for liver transplantations. I argued that medical considerations are not likely to be substantial on a population level insofar as alcoholics are not likely to be riskier transplant cases nor to have lower life expectancies than nonalcoholics. In certain cases, some alcoholics will do poorly in regards to these criteria, though this does not justify deprioritizing them *in virtue of* their alcoholism since they will already be deprioritized on straightforward medical criteria alone. The moral dimensions are harder to evaluate, though the critical question is whether alcoholics are blameworthy for their cirrhosis. If we endorse a disease concept of alcoholism, then they arguably are not blameworthy and should not be subjugated to a deprioritization. However, if we reject the disease concept, then we might legitimately deprioritize them on moral grounds.

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# Virtual Mentor

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## Op-Ed

### **Xenotransplantation and the Problem of Boundaries**

by Michael Reiss, PhD

It is widely known that an increasing number of countries have severe shortages of organs for transplantation. Tens of thousands of people worldwide die each year waiting for organs. Perhaps, ironically, the shortages have been exacerbated in some countries by reductions in the number of people killed in car and motorcycle accidents and by improvements in transplant surgery.

It is unsurprising, therefore, that medical ethicists and others have explored the potential both for new technologies (including xenotransplantation and stem cell therapy) and for changes to existing ethical guidelines (eg, exploring whether there should be a presumption that the organs from someone who has died can be used for transplants unless the deceased explicitly opted out of donating) as ways of increasing the number of transplantable organs. In this short piece I wish to explore the issue of whether more consideration should be given to how people might feel about being beneficiaries of new technologies intended to tackle this problem. I shall specifically concentrate on xenotransplantation.

### **Moving Genes between Species**

It is becoming increasingly apparent that many of the ethical analyses of genetic engineering and other novel biotechnologies (including therapeutic and reproductive cloning), are missing some ethical concerns that large numbers of people say are of importance to them. This happens because such analyses focus, sometimes exclusively, on the likely consequences of the technologies, ie, the benefits (typically measured in lives saved or years of good quality life gained) and harms or potential harms (eg, safety risks). One obvious problem with this consequentialist approach to the ethical analysis of new technology is that accurate predictions of outcomes are virtually impossible, and as a result advocacy of the precautionary principle has become widespread in recent years. According to this principle it is not necessary to have proof that a particular agent or action causes harm in order to take precaution; evidence that the activity threatens or creates risk of harm is sufficient provocation to regulate the activity. Moreover while consequences are important, they may not sufficiently address ethical concerns about the practice. For some people, at least, the nature or essence of things is of greater importance than its consequences [\[1\]](#).

Much genetic engineering to date—including that done in xenotransplantation research—entails moving genes between species. The safety aspects of such a procedure continue to be exhaustively studied. But are there other considerations that should be explored? Should we be concerned, for example, that pigs are being engineered with human genes, however safely, in the hope that their internal organs

may be used for human transplants? One important psychological point is that, as we grow up, the boundaries between species help us to organise our understanding of the natural world and ourselves. Children learn as infants about living things in their immediate environment. In particular, they learn about animals—how to recognise different types, and what their familiar names are. It has been argued that the concepts “animal” and “plant” are fundamental ontological categories; that is, categories children use to organise their perceptions of the world in which they live [2]. How will our world be re-ordered when the line between animal and human becomes significantly blurred?

As an evolutionary biologist by background I presume that identifying boundaries (eg, between kin and non-kin; potential sources of food and sources of danger; male and female; neighbour and foreigner) has been adaptive. As we grow older, such boundaries are likely to persist unless they are successfully challenged. Many people, especially, but not exclusively, men, still feel that certain tasks are more appropriate for men to perform, and others, more appropriate for women.

In an age when academics, clinicians, and ethicists write regularly about the advent of cyborgs, it may seem a little old-fashioned to worry about boundaries for other than consequentialist reasons. However, the human-animal boundary is widely seen as an especially strong one, even if 150 years of Darwinism have caused many to feel that the distance between ourselves and other animals is not as absolute as had been previously supposed. What I would urge, though, is that if xenotransplantation does become a clinical reality, high-quality studies of its psychological consequences must be conducted. Nowadays we are used to considering the ethical, legal, and social consequences of new medical technologies. However, psychological consequences should not be set aside. Indeed, I would expect that psychological factors may prove more important than many would suppose (as recently demonstrated by the rejection in Europe of genetically modified foods).

My prediction is that, by and large, humans are sufficiently adaptable to accept the loosening of human-animal boundaries when the alternative to this established boundary is death. The limited amount of data that have been acquired from hand transplant recipients caution us from supposing that psychological considerations can always be trumped—and this may be even more the case with face transplants. It is known that in at least 1 case, the recipient of a hand transplant chose to stop taking the drugs that were helping his body accept his newly transplanted hand. It may be that xenotransplantation for internal organs proves less problematic, but we would be wise to investigate this at the earliest opportunity.

Finally, it is always worth emphasising that ethical knowledge changes over time. This, of course, is not a feature distinctive to ethics; all forms of knowledge change over time. Malcolm Muggeridge once referred to heart transplants as “the final degradation of our Christian way of life” [3]. Few would maintain that position today even if some societies (eg, in Japan) are still reluctant to accept transplantation. It will be important to see whether xenotransplants ever become feasible, and then if they become widely accepted.

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