



Surfing for Organs

THE CASE

Editor's Note—In this issue we look at the subject of organ transplants. The efficacy and ethics of transplantation are largely accepted; recently, however, controversy has arisen over patients and their families who wish to take the matter of organ procurement into their own hands. In a November 22, 2005 essay in the New York Times, "An Internet Lifeline, in Search of a Kidney," Sally Satel MD eloquently describes how she listed her name with the United Network for Organ Sharing (UNOS), the traditional path to becoming a recipient of a cadaver donor, while simultaneously trying to find a live donor through the Internet before dialysis became necessary.

Satel noted that more than 88,000 Americans are on the UNOS list, most waiting for kidneys. The average wait is four to five years, and about eighteen people on the list will die each day. Satel has no siblings, and the friends who initially came forward to donate were found to be unsuitable or their spouses objected or they themselves were frightened. So Satel turned to an internet site: matchingdonors.com.

If you are seeking an organ, the site charges you several hundred dollars to list your name. If you have yourself pledged to be a donor, there is no charge to list your name. If there is financial hardship, the site says it will waive the fee.



Recipients can post photos, write lengthy biographies, or be succinct as Satel was, giving a few sentences and including her demographics. She reports that "within a week I found someone, and barring complications—he has so far passed most of the medical hurdles to qualify—the surgery will take place this winter."

Satel is aware that this website troubles some physicians and ethicists in the field of transplantation. She quotes Dr. Douglas Hanto, head of the ethics committee at the American Society of Transplant Surgeons, who said such "brokered transplants undermine trust in the whole system." His group asked its members to boycott any transplants which have been privately arranged. She counters that the website is dealing with live donors and thus has no effect on the UNOS donor pool.

View From a Patient

SB received a liver transplant at Strong Memorial Hospital in Rochester, New York in July 2005. SB is 62 years old and previously worked as an assembly man in a window factory where he framed windows. I met with him in December 2005 in his home.

JP. What was the problem that led to your liver transplant?

SB. It's still not clear to me. I had a problem with recurring ulcers in my legs for years, and in 2002, I was taken out of work to help heal my legs. When the legs healed, the wound care doctor discharged me, and I went to my primary care doctor to get cleared for work. She told me I couldn't go back to work because of my liver. But no one has been able to say exactly what the liver problem was, or at least they didn't tell me. I've had 2 liver biopsies, and when they gave me the new liver, they sent my liver to be studied. I've asked if they have a diagnosis several times, but they said the report is not back yet.

JP. Tell me about your illness.

SB. In 2003, I noticed I got tired pretty easily. For example, I play old-timers lacrosse, and after a game I'd be tired, but then I rested up and felt better. I like to bowl, and over time the bowling ball became heavier and heavier and I almost couldn't lift it, so I

Bioethics *in brief*

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Perspectives on Tx

During the past decade, the efforts of UNOS (United Network for Organ Sharing) have increased public awareness that "Organ donations save lives." Public service announcements have informed and educated the public about the importance of organ donation and transplantation, and the opportunity to become an organ donor via our driver's licenses has heightened the positive image of organ donation. Despite this increased attention, the supply of available organs has not kept up with the demand, and greater numbers of patients are placed on waiting lists each year.

50% OF DONORS ARE LIVE

Although approximately half of organ donations are made by live donors motivated to save the life of another person, usually a family member, the other half come from cadavers. Most of these donations after death are the result of a traumatic event or sudden illness. More often than not the potential organ donor is brought into an acute care situation on an emergency basis, accompanied by family members

who are grief stricken at the possibility of the death of their loved one. If all possible interventions to provide treatment that will save the life of the person fail, and death is inevitable, it is at this time, probably the worst moment in the life of that family, that a request for donation of organs must be made (usually by an organ procurement specialist). Permission for any organ donation must be requested.

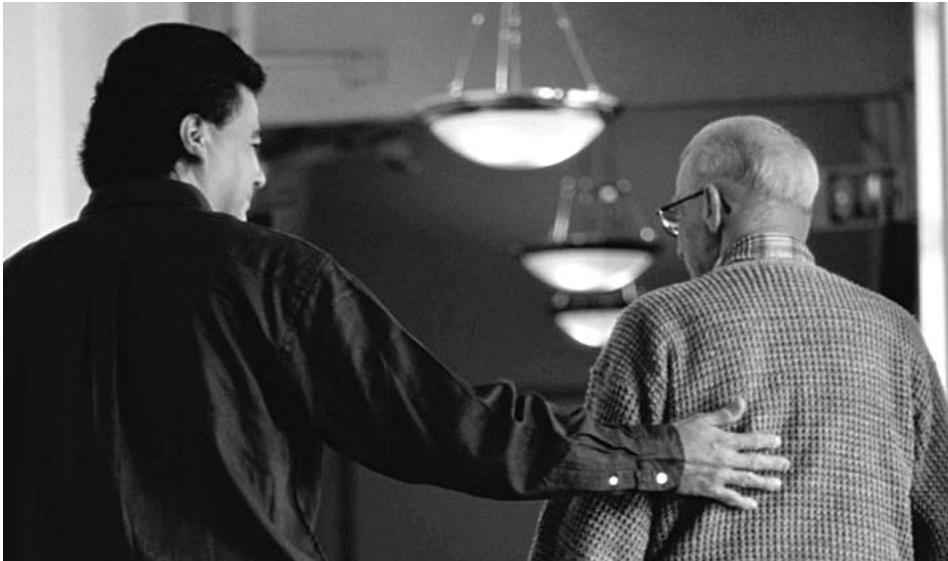
Sometimes the person nearing death has made his or her wishes about donation known to others by signing a donor pledge on their driver's license, or on an organ donor card, or on an advance directive form. More often, however, there is no available indication of what the person would want done. In the United States, there is not currently a policy of presumed consent for donation of organs such as is found in some other countries. Presumed consent would mean that organs could be retrieved unless there was written evidence that the deceased did not want to donate.

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Other Questions to Consider

Currently, staff people hired by the organ procurement agency ask the families of dying patients to donate organs. Given that the primary job of organ procurement specialists is to obtain organs, ought they be the ones family rely on for information about the pros and cons of organ donation, or does this present an unacceptable conflict of interest?

Financial incentives for donation are strictly prohibited in the United States. A number of states are considering offering medical leave, life insurance, and/or highest priority status for transplantation for donors if they themselves should require a transplant. One or two states already provide burial expenses for cadaveric donors. Are there ethically important differences among these incentives for donation?



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Perspectives on Tx

THE PROCUREMENT SPECIALIST

In this area of upstate New York, the request for donation of any organs comes from an organ procurement specialist who has expertise in stepping in at these worst of times, not only asking for the donation, but also providing support and comfort to the family. In a recent interview, I asked one of these specialists to describe her own feelings and reactions when she approaches the bereaved families. She talked about the need to provide both time and information to help the family decide. She sees her role as being there for the family, listening to them and understanding their needs, a process she described as “getting outside herself.” In this way, she can work through a variety of issues that might be troubling to the family. Respect for their decision is paramount; in addition, she will support them in whatever decision they make.

DONATION GIVES MEANING

At the same interview, I also conversed with a mother who had agreed to donate the organs of her teen-aged son after his tragic death. Although she described the time of

his death as devastating, heart breaking, the worst time in her life, she found that the decision to donate organs provided some comfort. She reasoned that if he couldn’t live, at least someone else who might have otherwise died could be saved. This fact gave some meaning to her son’s death. She also emphasized that families want honesty in communication at this time. They do not need “sugar coating” of news or status reports. Although health care professionals want to protect families from painful experiences, unfortunately they can’t protect against the emotional pain that the death of a loved one inflicts. She said unrealistic hope can be harmful. The family needs accurate information given in a comprehensible way. The words used can make a huge difference in how the idea of organ donation is accepted by the family members.

We can expect the demand for organ transplantation to continue to grow; therefore, we must work on strategies to increase the supply. Part of the solution will be increasing the success rate of consent to donation from families.

—Barb Ferro

**IS IT ACCEPTABLE
TO LET PEOPLE DIE WAITING
FOR AN ORGAN TRANSPLANT
WHILE THERE ARE PEOPLE
WILLING TO DONATE?**

**BY THE SAME TOKEN,
IS IT ACCEPTABLE TO LET PEOPLE DIE
WAITING FOR AN ORGAN WHILE
OTHERS CAN JUMP AHEAD IN LINE
AND BUY THEIR HEALTH BACK?**

At University Hospital

The Kidney Transplant Donor program at University Hospital does not have a formal policy related to internet-based organ procurement or other forms of aggressive solicitation. “But as a team,” says Ann Roman, transplant coordinator, “we agree that this is not the best avenue to take. Not only does this activity usurp the efforts of UNOS (United Network for Organ Sharing) in procuring and appropriately distributing human organs,” she continues, “there could also be something other than altruism involved.” There is a significant disadvantage, she says, for those who are unable to pay the monthly fee to remain active on such web sites (one of the most popular being matching-donors.com). “Organ availability should be equal among all economic backgrounds,” she says. “There should not be an advantage for those who can pay.” Roman feels that this could also lead down the “slippery slope of organ trafficking for money.”

**IF OUR BODIES ARE PRIVATE
PROPERTY, CAN'T THEY BE USED
AS WE CHOOSE?
ISN'T IT MY RIGHT TO DONATE—
OR NOT — AS I SEE FIT?**



Culture and Transplantation

Members of minority populations donate their organs at the same rate as others, but because they suffer a higher rate of certain diseases—such as diabetes and hypertension that results in kidney disease—they might need transplants more often. Further, finding a close match between donor and recipient is more difficult for minorities than for European Americans.

Patients from some cultures may be reluctant to receive an organ transplant. It is important for clinicians to know their patients' cultural backgrounds and how those might influence their decisions about transplantation. Here are some snapshot instances where culture may affect someone's decision to be either an organ donor or an organ recipient.

Older members of the **Hmong** community may resist the idea of transplantation or even surgery,

blood transfusions and immunization because of a strong belief in reincarnation. It is important to them that their bodies are whole and essentially unaltered at the time of death. However, younger Hmong are increasingly accepting of western medical procedures and may even help older family members feel more receptive to them.

For some **Muslims**, cadaver transplantation is problematic, unless the donor made his or her wish to donate very clear prior to death. For these Muslims it is imperative that physicians and relatives respect the rights of the deceased.

Many **African Americans** have a general distrust of the health care system due to a long history of disparities and the experience of racism in general. They have questions about the fairness of the allocation system and fears that organ procurement might also mean the

hastening of a loved one's death by an over-eager system.

In **Japan**, the understanding of "brain death" has not been as readily accepted as in western countries; therefore, organ transplantation is much more rare than it is in the United States. The **Shinto** religion stresses the purity and wholeness of the body, even after death, which has resulted in a resistance to organ donation. **Japanese Americans** may share these beliefs.

Obviously, physicians and nurses need to know their patients' beliefs and understandings of organ transplants by discussing these issues with them. Knowing in advance their culture's general position regarding organ donation is a good first step but much more essential is learning whether and how they have incorporated those beliefs into their own lives.

—Rebecca Garden

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Surfing for Organs

Her article illustrates the complexities of organ transplantation. As demand for organs increases, people's ingenuity and pursuit of donors will likewise rise. The debate about what is fair, ethical, and permissible will continue. We asked John Leggat, MD assistant professor in the Department of Medicine, whose specialty is nephrology, to comment upon this new trend of advertising for organs. His comments follow.

—Deirdre Neilen

Imagine driving Rt. 690 and seeing a billboard with the picture of a young man and the caption: "I Need A Liver. Please Help Save My Life." The billboard also gives a website and an 800 number to contact this man.

As of December 11, 2005, there were 90,542 patients waiting for an organ transplant. In 2004, only about 27,000 transplants were done. Over 7,000 patients died in 2004 waiting for a transplant. There is an obvious disparity between the number of patients waiting for a transplant and the number of donors. UNOS, recognizing the perennial disparity, has set up distribution rules to try to fairly allocate the limited numbers of deceased donor organs.

DIRECTED DONATIONS

Patients have also recognized this disparity and are doing what they can to circumvent the rules. The major "loophole" is the directed deceased donor. Because we in the transplant community recognize that donor families are in a fragile state at the time of donation, we have allowed them to direct an organ to someone they know who needs it. In the past, this was a rare event, since it required knowing someone in need of an organ at the time of the family member's death. Directed donation was limited to family members and close friends. Now, however, with the Internet and more aggressive appeals such as the billboard noted above, donor families are more likely to be aware of a particular recipient in need of an organ.

BUILT-IN CONFLICT

The conflict for the physician is apparent. There is an obvious duty to the patient at the bedside. For many patients, no transplant means death. Working to obtain an organ becomes paramount, and aggressive approaches are both allowed and understandable. However, a conflict arises from the societal duty, as

defined by UNOS, for equitable distribution of a limited resource. Directed donation arguably violates principles of fair distribution of this limited resource.

Live donation raises a set of completely different issues. As far as I can determine, the Internet so far has been most successfully used to solicit live renal transplant donors. Families who have just lost a loved one are not going to the Internet to decide who should get the organs. Renal failure patients have the "luxury" of dialysis and the time to search for a donor.

WHEN IT'S A BENEFIT...

Nephrologists have always told patients to identify potential live donors and have them contact a transplant center to be tested. The Internet solicitation is an unanticipated development, but certainly an understandable one. Donors solicited on the Internet are in fact a benefit to all on the kidney waiting list, since they typically have not otherwise identified themselves as live donors. By removing a recipient from the kidney list, the list is shortened to the benefit of the other listees without use of donor kidneys known to the UNOS system.

... AND WHEN IT'S NOT.

The downside is that the Internet in general is clearly an open marketplace; just go to eBay for a brief encounter (although the site has pulled these ads once they are aware of them). There is a serious and real concern that organ donation could easily fall into the same commerce mentality. Sale of organs is illegal in the US, but a resourceful recipient and donor pair might fool a transplant center into believing the donation is altruistic. Outside the US, there is a brisk gray and black market in live kidney donation. Do you need a kidney? Just sign up for our Transplant Cruise and by the time you return, you too can have a new kidney. Countries from the former Soviet block, Middle East, South America, and Pacific Islands are popular destinations for these "vacations." Sale of organs should clearly be banned at all levels, but what do we do about recipients who cast a wide net and catch an altruistic donor? Dr. Hanto, as quoted above, has suggested we ban all such transplants. For a real success of such a transplant, I would refer you to syracuse.com/news/angel/ about a local transplant identified through newspaper and internet solicitations.

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View From A Patient

had to stop bowling. Once at the state fair, I went for a walk, and got confused and when I got back to my family, it was 6-8 hours later; I guess I just wandered around. I was shaky, dizzy and unstable on my feet. The paramedics took me to the ER. My blood ammonia levels were high and this affected my mind and my body. I ended up in the VA



hospital, and near the end I was in the hospital for my ammonia level about every two weeks. No one really told me what was wrong with my liver.

JP. When did you learn about liver transplants? How did you get on the transplant list?

SB. I was sent to Rochester for a workup. In September 2004, the doctors at Strong Memorial told me I would need a liver transplant at some point. At first that news made me feel terrible, but then I thought, well, the doctors know best. I never really got depressed or thought about dying. I didn't know when I would need a transplant; nobody was specific about that. In January 2005 I went back to Strong for a workup. While I was there they checked my heart, and told me I needed a bypass operation, so they did that. They sent me home in three days. In June 2005 I went back for another checkup: blood tests, X-Rays, MRI, EKG, and an evaluation by a

psychiatrist. On July 20th Rochester called and told me I was put on the transplant list. Two days later they called me and said a liver was available and to come to Rochester right away. Four hours later I was in Strong, and they took blood to do a match for the liver. They said it was not really a good match but they would go ahead anyway. I didn't

realize I was that sick. I still didn't have any deep thoughts and wasn't afraid. I trusted the doctors.

JP. How was the operation and recovery?

SB. The operation took around 10 hours. I was in pain for about two weeks: I had staples, three drain tubes. I started eating in five-six days. They got me out of bed right away. They treated my pain and encouraged me to be active. Everybody was really nice: the nurses, the technicians, the doctors—they were all courteous. The nurse said, 'This is my only job—to help people who have transplants.' For a while I had to go

back to the hospital every week for a checkup. Twice they kept me overnight. Now I drive myself, but I always bring someone with me. Now I don't have to go back for another two months. They told me the first year is the toughest. It wasn't until I came home after the transplant that I realized how sick I must have been.

JP. Do you wonder about who the donor was?

SB. The transplant doctor told me the liver was from a 78 year old who was deceased. I asked if I could speak to a family member of the donor, but the doctor said he didn't think that was a good idea for the family.

JP. Did you ever worry about dying?

SB. Not really. In June 2005 when I was in the VA Hospital, they wanted to discharge me to a nursing home. I asked them what a nursing home could do for me that I couldn't get done at home. I asked them what the nursing home would do if my ammonia got high. They said the nursing home would send me to the emergency room: it could be a matter of life or death. But I knew that we would do the same thing at home—go to the



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View From A Patient

ER. If it's a matter of life or death, and I'm dying, I would prefer to die at home. Rochester gave me the phone number of an organization dealing with transplants I could call, but I didn't feel the need to. I thought: it's nothing I can't control. I'm not going to let it get me down. The doctor said, 'You are pretty different from other people needing liver transplants; you don't seem to get in a down position.'

JP. How did your family deal with all this?

SB. They are not over-protective. They went along with what I wanted. We didn't tell many other people. I was surprised how many people knew I had a transplant when I came home.

JP. How are you doing now?

SB. My body feels a lot different. It's adjusting. I get more energy every day. I'm looking forward to being more active. I'd like to play old-timer's lacrosse next season. I mentioned it to the doctor, and he said not yet, but he didn't rule it out. I'm looking forward to traveling. I couldn't travel before because of my ammonia problem and I might get sick.

JP. What do you think of organ transplants now?

SB. I never really thought about organ transplants, until the day they called me and said I was on the list. I'd encourage anyone needing a transplant to get one. I never thought of being a donor before, but if possible, I would like to give my organs when I die. I'd recommend that everyone sign organ donor cards. It's something you can do to help other people.

JP. Thanks for talking with me.

Note: SB is a patient of mine and a Native American. I also spoke with an Elder of the Onondaga Nation about the role of the community when a member of the Nation faces a difficult decision such as an organ transplant. The person may wish to (but does not have to) consult a Clan Mother or a Chief. The role of the Clan Mother or Chief would be to help the person clarify his or her own wishes regarding the transplant. If the person wants to have the transplant, then the goal would be to keep up the person's spirits and belief in one's self so that the individual is the least apprehensive and has the greatest peace of mind entering into the transplant.

(Note: Patients waiting for liver transplants are prioritized based on a statistical score called MELD, which predicts who is most likely to die from liver disease in the next 3 months. Scores range from 6 (less ill) to 40 (gravely ill). The patient with the highest score will get the next available liver regardless how long he or she has been waiting.)

—Joel Potash

Transplant Man

The new man sings the body
eclectic: his thigh's from

New Delhi, one kidney's from
Sydney. That glass eye

you adore's from Kuala Lumpur
and they found one to match

in upper Saskatch. His shoulder
you lean on's a beauty from

Boulder and his knee from Poree
cancans with *esprit*.

Take his heart for your own
flown in fresh from Pike's Peak.

His spare part's from Jakarta
ice-packed for next week.

—BA St. Andrews

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Surfing for Organs

RECOMMENDATIONS

If a recipient solicits a deceased donor, I see two responses, although neither will prevent deaths on the waiting list. **First**, unless there is an established relationship between donor and recipient, **directed donation should not be permitted**. Society, through UNOS, has determined how organs are to be distributed. We should not allow patients to co-opt the process that was set up to benefit the most number of patients.

Second, we should work to **identify and elicit more donations from dying patients**. A large number of patients who die could have been donors but either were not referred or the families refused. The increase in organ donation from these patients will not remove the need for an allocation system, but it will reduce the disparity between the waiting list and the organ supply.

Regarding live donation, I have reservations about internet solicitations, but do not see the utility of

an outright ban. I don't believe these solicitations play a significant role in deceased organ donation. They can and do play a role in live organ donation. If done properly, they can benefit the transplant

community as a whole. However, it is up to the transplant center to assure that these "non-traditional" donors are truly donating out of altruism and not for some financial or other secondary gain.

—John Leggat

Websites of Interest

<http://www.unos.org>



<http://www.matchingdonors.com>



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