Lecture 9: Transplantation

I. History of transplantation

The history of transplantation – the bioethical history of transplantation -- is to some extent the confluence of two streams in the second half of the last century: two streams of technological development.

A: Dialysis

Let’s start with the invention in the ‘60s of dialysis for kidney failure. The kidneys are basically the garbage disposal of the body. They extract undesired elements from the blood and dump them into the urine. If the kidneys fail, the poisons accumulate in the blood, and people die.

During WWII the idea was suggested of extracting the blood from the body and cleansing it external to the body of the toxins that the kidneys were no longer able to remove. It was able to be used only as a one-off until in 1960, when a couple of people in Seattle came up with a shunt that could be semi-permanently implanted in the body so that this procedure could be repeated. Kidney failure began to be seen as an incredible inconvenience, a chronic disease, instead of a sentence to a quick death.

They opened the first dialysis center. For a cost of $10-20,000 a year per patient, the life of critically ill people with kidney failure could be extended; and it was estimated that there were somewhere between 5 and 20 people per million who could profit from this procedure. So dialysis became a paradigmatic scarce resource—a scarce and an expensive one. So the Seattle hospital had to figure out who could be saved when not all could be saved—a severe problem of resource allocation.

They established two committees: a committee of physicians who evaluated possible candidates for the medical feasibility of successful treatments; and a second one to choose among medically acceptable candidates who had been passed by the first committee. The second committee was basically a citizen’s committee: the membership changed, but it had at one point a minister, a lawyer, a housewife, a labor leader, a businessman, and two doctors from unrelated areas.

In 1962 a journalist (Shana Alexander) learned about this second committee, officially termed the Allocation and Policy Committee, and wrote an article about it for the *Saturday Evening Post* in which she dubbed it “the God committee”—for, as she noted, this committee ‘decided who would live and who would die.’ The criteria by which they decided included such things as marital status, income, occupation, educational background, past performance and future potential—social worth criteria, basically. The ideal candidate was a Boy Scout leader with 6 kids; and there was a scandal at some point about the denial of candidacy of an Indian man with a history of drinking. *(If this is a rare and expensive procedure, should we not restrict it to people who “deserve” it? Who will take proper care of it, from the perspective of the organ? The paper option about whether alcoholics should receive liver transplants is an occasion to explore this ethical issue at greater length.)*
The article opened a national dialogue about the conflict of social worth and social justice. 10 years later the End Stage Renal Disease Amendment provided federal funding for people with end-stage kidney failure; probably the first precursor of Medicare. It was an attempt to bypass forever the question about how much social worth should count in access to scarce resources. (Of course the same questions resurface in connection with every scarce resource—and all health resources are scarce.)

B: The second parallel development: organ transplantation.

The possibility of transplantation of solid organs was driven by the technology associated with and developing around kidney transplantation—the first successful kind of transplantation, and still today the most frequently requested (and most frequently performed) organ transplant.

The nice thing about the kidney is that it has this great back-up system: most people have two; and many people can function quite nicely with only one. So the possibility of transplant was first approached with the transplantation of a kidney from a living donor. The first one lived 18 days. The next lived 594 days (in the hospital, of course). In 1954 the most successful transplant was performed in Boston, from one 24 year old monozygotic (=identical) twin to his brother. (That recipient lived for 8 years.) In the 10 years between 1954 and 1964 there were 600 attempted transplantations. By 1969 there had been 160 procedures of kidney tx, and 10 survivors. The 2 year survival rate was 50%. In the process, much was learned about the necessary technology and conditions; compatibility between donor and recipient, for instance. In 1978 Cyclosporin, the first anti-rejection drug, was invented, and things got a little less risky.

The ethical issue raised by successful transplantation was the question of whether a person could voluntarily mutilate himself for the sake of another. There was a lot of discussion about that, including a lot of theological discussion. Opinions varied; some early Jewish law, for instance, forbade self mutilation, but some theologians suggested that if it was really voluntary and informed, it could be allowed (but not, of course, required). In 1968 one of those model laws of the sort we’ve encountered before (PSDA, UDDA) was passed about transplantation: the Uniform Anatomical Gift Act (UAGA). By 1970 it had been adopted by all 50 states.

By that law, competent adults could indicate their willingness to donate their organs after death by signing a legally valid document. In its absence, specified family members could authorize donation, unless the person had specifically denied his intent to donate. And—the language is very important: donation. The ‘gift of life’ can be freely offered by one person to another. It’s a gift, a supererogatory act—not a duty.

The first heart transplant was performed in 1967, in South Africa. Liver transplantation was developed in Pittsburgh over several decades.

Kidney transplantation took people off dialysis. It restored them to virtually normal function. You can see how the convergence of the two parallel developments was interesting. Remember, we were talking about the development of dialysis; which after...
1972 was deemed appropriate for federal support, via the End-Stage-Renal-Disease-Amendment, which added dialysis to social security support. Should the transplantation of the kidney be subject to the same kind of support?

If nothing else, it raised a question that health economists could address with some chance of getting a clear answer. Two procedures, one expensive and life long, the other more expensive initially, but removing the need for life-long dialysis (and as a bonus, a bit better quality of life for those who survive it). The federal decision to fund dialysis was extended to renal transplantation fairly uncontroversially, by an economically justifiable calculation on length of life and the expense of the % of that time that would be spent under costly medical care.

There is NO federal support for transplantation of other organs, though.

II: Transplantation today:

OK: enough about history. That’s how we got here. Now let’s talk a little bit about where we are today.

Some statistics:

Since 1988 more than 360,000 organs have been transplanted, 80% of them from deceased donors. (ST) (There are some donations of kidneys from living donors, and some from people dead by cardiac criteria.)

In 2007 there were 28K transplants performed in the US. (GLI) The number of organs available for transplantation remains pretty constant: between 20-30K a year. But: The number of donors increases by about 1K each year. The number of people listed increases by about 5K each year. (The growing gap leads to the language of ‘organ shortage.’).

As of yesterday: there are 104K people on waiting lists: 82K of them waiting for kidneys (UNOS). About 10% of people listed die before they receive an organ.

What about that gap between donors and recipients?
Some of the answer is certainly in the legal provisions of that uniform anatomical gift act: I can volunteer to give (to you, or in general) an organ, the absence of which will not cause my death. (That seems to mean, at our current stage of medical science, one kidney, or a liver lobe. No hearts.) And: I can decide, while living, upon the disposition of my organs when dead. But: there’s not a lot of choice involved in whether I get a disease that leads to end stage liver disease—but there has to be choice involved in whether organs are donated or not. And not a lot of people donate. So our options are to reduce kidney disease, or increase organ donation.

Now in the US today, so far as we can tell, there may be something like 12-15K ideal candidates for organ donation a year: people who are by the strictest UDDA criteria, brain-dead, folks for whom their heart or lung will be of no further use to them. Fewer than half of those people are actually donors. Why?
Well, as a first approximation I can refer you back to our discussion of the Advance Directive: most people don’t have one. I can, while living, decide upon the disposition of my organs after death in that California form; but less than 30% of adults do so.

Certainly some people object to the idea of donating organs; but public opinion polls suggest that many—indeed, most—people don’t fall into that class. The problem is not resistance to donation—but of those who express willingness to donate after death, few have taken steps to assure that it will happen.

Our surrogates can donate on our behalf; and apparently some percentage of surrogates do so (although apparently less than half). Again, some of this can be explained as choices for reasons: individual, or cultural: aesthetic, sentimental, religious. But it’s hard to know how much. The main problem, again, is that our surrogates don’t donate on our behalf as often as their expressed intentions indicate.

I ran into an interesting book recently by Richard Thaler and Cass Sunstein called “Nudge.” He talks about what he calls “choice architecture” and has a very nice little chapter on organ donation. I recommend it. His analysis is that the “organ shortage” is a product of how we have set up the donation process in this country, the interplay between our options, and our natural tendencies—to procrastinate, to avoid dwelling on our death, or the death of our loved ones…

What are the options for obtaining organs?

Some of the readings for today talk about options for increasing donation of organs from the living: the ethical issues associated with the propriety of selling organs when the donor (or as one of our authors has it, vendor) is alive—organs the living can (or think they can) spare.

[And there are some nicely cynical remarks in some of them, too. “The rich and healthy are against anything that is to the advantage of the destitute and dying.” Or: “Why should the person who gives the organ be the only person in the entire transaction that cannot profit from it?”] Some of the same issues can have application to organs from the dead or dying as well.

What are our options in this country?

We could assume that upon death, a person’s organs become public property, a social asset: to be distributed as that society decides.

That wouldn’t go over very well in this society. Wouldn’t fit with all the other structures that we’ve set up around the illusion/fantasy/ideal of “autonomy.”

For historical and cultural reasons, we have grown up with an “opt in” choice architecture for explicit consent. The organ is—well, not my property, exactly, because I can’t sell it—but we the living have the right to say what happens to our bodies, and this continues after our death—either transferred to our surrogates, or if not, presumed not to exist.
There are mechanisms in practically every state for indicating on our drivers’ licenses whether we are in principle for donation; but in practice, even with a pink dot on the license, institutions defer to surrogate preference.

One suggestion for change is mandatory choice: In Illinois, for a 18 month pilot program, the DMV would refuse to give you your license unless you had indicated either that you were interested or that you were not. *The Institute of Medicine report does not recommend this, saying that it requires ‘an informed citizenry that trusts the system,’ and worried that that condition does not hold in this country at this point.*

Another suggestion for change is presumed consent: instead of asking people whether they want to “opt in,” ask them if they want to “opt out.” Since most people prefer to do nothing or not think about it, this would increase the pool of theoretical donors. If there were no surrogate to consult, the potential donor would be presumed to have agreed to donate.

Many European countries have adopted this system, including Spain, that has some of the highest donation rates in the world. *Thaler/Sunstein compare donation rates in two adjoining European countries, one with an explicit consent standard, one with a presumed consent standard. In Germany, 12% of the population agree to donate; in Austria, 2% opt out of donating.*

Also considered are various incentives for donating—which in this country often take the form of financial incentives. And that is the subject of several of our readings this week. Our present situation not only precludes financial incentives—there are also various financial disincentives. For instance, one family was willing to offer the organs of their terminally ill daughter for donation. If the organs had been accepted, the expenses of the transfer to another institution would have been paid for. But if the organs had not been accepted, they would have been responsible for those costs. Because the family did not have the resources to pay for the transfer and evaluation, they could not take the risk; so the organs were not offered.

The readings for last Tuesday relate to one of those questions—organs from the dead, organ retrieval from non-living donors. Is there an ethical question around cadaveric organs? I suppose so. One question is: how dead is the donor? How is that determined? There have been perpetual stories related to the international traffic in organs: (1) purported ‘theft’ of organs: people waking up in hotels with scars on their back; (2) international tourism, where people go to India or China and receive kidneys that were (or were not) voluntarily “donated” (and if they were not Chinese prisoners from whom they were taken, they may be impoverished people in Indian slums who were paid nominal sums for one of their kidneys).

*We remain committed in the US to the vocabulary of “gift” and very leery of anything that may undermine that rhetoric; for that reason the IOM report does*
not recommend any kind of ‘incentives’ to donation. But the growing gap between the number of people hoping for organs and the stable number of people donating them means that discussion of ‘incentives’ continues to resurface.

And here the questions center around a fairly important issue: who is dead? Who is dead enough? Specifically, in this context: who is ‘dead’ enough that his or her body can be sustained for purposes of life-saving transplantation—considering that the person must be able to be declared, legally, dead—but the organ itself must be ‘alive’ enough to be able to resume its function in another person’s body?

As we said several weeks ago, 50 states and c. 80 foreign countries have adopted the provisions of the Uniform Definition of Death, legally allowing for diagnosis of death on neurological criteria (=brain death). For the last few decades, and increasingly discussed recently, declaration of death on cardio-pulmonary criteria (=cardiac death) has also been invoked for people who are imminently dying but are not brain dead. Recently hospitals have been required to have policies in place that discuss DCD. On the east coast, something like 20% of organ retrievals have been by such criteria; on this coast, it’s still down around 5%.

The readings on DCD—donation after cardiac death—are particularly interesting in light of this question (and in terms of the phrasing of the UDD). Some critics suggest that the only thing ‘irreversible’ in the procedures being adopted under that heading is that the stakeholders decide that they won’t attempt resuscitation, so the ‘permanence’ of death is—permanence by their decision, rather than by the physiology of the circumstances. (This abuts on some of the philosophical / legal issues we raised about the difference between letting people die and actively killing them.)

It is the fit between the technological possibilities and the social attitudes that generates the desire to fiddle with the legal definition (and social understanding) of death that we read about last week.

What kind of treatment IS appropriate for our human dead? Are they respected in their own right, or viewed only as means to the end of another? As the Childress article and some of the history I have recounted make clear, the increasingly precise and qualified definitions of death, and various procedures around organ retrieval, are a consequence of the development of parallel technologies that make possible treatment of the dead that are not and could not be taken into consideration by the several million years of development of our attitudes toward our dead.

Is it respectful of the dead or dying to view them as the temporary possessors of things of value that can be ‘recovered’, surgically removed—for the advantage of the living? The property of my heirs? If there are none, is it the property of my society, to be used for its own purposes? Is my body and its possibly sustainable organs a social resource? Is it property at all? Mine, or not? Mine, or—ME?
If it is (increasingly) medically feasible to obtain organs—from dead or from living donors, what are the social conditions surrounding it? Under what conditions are the organs obtained? Can you buy them? Can you (for the living, at least) sell them?

Transplantation of not only the corneas, the kidneys—but the liver, the heart, and fairly recently, lungs and part of the bowel—has become accepted medical practice. But it has never been free of ethical controversy, and probably never will be.

I suspect that one of the reasons people at the moment are so obsessed with stem cell research is a science-fiction hope—that some day from information now being learned it will become possible to grow from my cells a replacement for my heart, without having to take my continued life at the cost of anyone else’s.

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My sources:

Some excellent reading: Renee Fox and Judith Swayze: *The Courage to Fail* (1978); *Spare Parts* (1992); and an article in the Hastings Center Report in 2005 called “Leaving the Field.”

Organ Donation: Opportunities for Action: Childress et al. A report by the Institute of Medicine on various social options for increasing donations, and their recommendations.

Thaler and Sunstein, *Nudge: Improving Decisions about health, wealth and happiness* has a chapter on structuring donation options.

If you go to Google and type in CHW’s position on donation after cardiac death, the result is a powerpoint by our local Carol Bayley on why Catholic Healthcare West will not be encouraging their hospitals to introduce the DCD protocol. (Bayley is ‘vice president for ethics and justice education.’ How’s that for a job title?)