Informed Consent in Living Organ Donors

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Author: Samuel D. Hensley
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Informed Consent has become one of the cornerstones of medical practice. A recent series of articles in the St. Louis Post-Dispatch raises questions concerning what constitutes adequate informed consent for well patients who offer to undergo surgery to provide organs for transplantation. While I do serve on the Advisory Committee on Organ Transplantation at the Department of Health and Human Services, this article expresses my personal thoughts and is not meant to represent the opinions of that committee.

In ethics, informed consent is important because of the belief that individuals should be able to make choices about their life, free from interference, unless other individuals are harmed. Accordingly, we owe it to patients to assure that their decision is freely made and informed.

Informed Consent generally is considered to have four components. In the case of living transplant donation, the donor should have the necessary decision making capacity to reflect on the benefits and burdens that reasonably can be expected from the procedure and to make this decision in the context of his or her own value system. The decision should be voluntary, that is, free from pressure or coercion. Especially when a relative’s life is at stake, family members or involved physicians may exert tremendous pressure or take advantage of the pressure the donor is already experiencing to get quick consent without adequate discussion of whether the patient is choosing freely to take these risks. It must be recognized that, in the emotion of the moment, a living donor may fail to consider how other family members would be affected by their own death or chronic medical complications.

No component of informed consent is more important than having adequate information on which to base a decision. In organ donation, it is critical that a donor understand the risks associated with the surgical procedure, possible long-term problems that may result based on careful follow-up studies of previous donors and how volunteering for organ donation may affect future medical insurability. Lastly, physicians have a clear responsibility to insure that the donor understands the
information that has been given. Understanding is the fourth prerequisite for truly informed consent. Without understanding and reflection, the other components are moot.

In advising living organ donors, two areas are of immediate concern. The first involves providing adequate information about long-term outcomes. This information simply does not exist. It is not an exaggeration to suggest that no one knows the number of complications resulting from living donor transplants because there has been no systematic follow-up of living donors. This lack of information renders the required information component of informed consent impossible. The federal government does not regulate living organ donation and does not require systematic follow-up studies. In addition, information regarding how living organ donation may affect future medical insurability in case of job changes is lacking. No regulations are currently in place to assure protection and future care for donors.

A second area of concern regards the scarcity of organs for transplant and the desperate medical needs of potential organ recipients. It is often literally a matter of life or death. These circumstances place the transplant surgeon in an extremely difficult situation with conflicting goals. He or she desires greatly to perform life saving surgery but must guard against coercing a donor or taking advantage of an emotionally volatile family dynamic. The critical need of the intended organ recipient cannot be allowed to deflect the surgeon's concern and responsibility from the living donor.

Standards vary widely from one transplant center to another often possibly to the determent of living donors. The United Network for Organ Sharing (UNOS) has recommendations on the proper procedures for working with living organ donors but compliance is voluntary. Many organizations are working to correct aspects of this problem but it is clear that much more still needs to be done. Based on required reporting of deaths and complications in living donors, stricter regulations of transplant centers can be accomplished without stifling innovation and research in organ transplantation.

Along these lines, new rules have been proposed by the Centers for Medicare and Medicaid Services (CMS) that are currently in the phase where public comments are solicited and reviewed.

The proposed standard requires centers to provide information to prospective living donors regarding all aspects of and potential outcomes from living donation, such as the evaluation process, surgical procedure, alternative treatments for the transplant patient, potential medical and psychosocial risks to the donor, specific transplant outcomes for both donors and recipients, and potential future health and life insurance coverage problems related to living donation.2

We should never lose sight of the fact that living organ donors are acting from a deep concern for others and a desire to give of themselves to help others who may be near death. For Christians, this serves as a reminder of Christ's sacrifice for us. We still are required, however, to make sure that such decisions are made freely and are well informed based on careful clinical follow-up studies and with adequate medical safeguards.
The St. Louis Post-Dispatch has a special section devoted to the series of reports at http://www.stltoday.com/organs.


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