Living Organ Donation: Always Ethically Complex

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Balancing Risks and Benefits

In a recent editorial, Reese et al. (1) discussed the “ethics of accepting complex living kidney donors” (i.e., donors at added risk). We take exception to three of their main points. (Note that our comments refer to all potential living donors, “complex” or not.)

Reese et al. (1) imply that when determining donor acceptability, the risk of donor harm should be balanced against anticipated recipient benefit. We disagree. Such a standard asks physicians to change the primary focus of their loyalty in a major and, we believe, unacceptable way. More than 20 yr ago, Levinsky (2) argued cogently that “in caring for an individual patient, the doctor must act solely as that patient’s advocate.” Physicians cannot accomplish this goal if, when trying to decide whether to recommend a procedure for one patient, they are asked to balance the risks for that person against the benefits for another. Such an approach would pose a clear conflict of interest, the recognition of which has led to the sensible recommendation that potential donors and recipients be evaluated by separate physicians (3), a position that Reese et al. support (1).

How then should physicians decide whether a volunteer is acceptable? We propose that, as is true of other medical situations, for a physician to support her patient as an organ donor, she must believe that there will be benefits for her patient (i.e., the potential donor) that are sufficient to offset the risks (4).

People can benefit greatly from organ donation by reaping large psychological rewards. An example is provided by the reflections of one set of parental donors (5): “There is no doubt in our minds that we, as kidney donors, have gained much more than we lost. Of inestimable value, of course, is the restoration of our daughter’s life and health.” How likely psychological benefits are to occur depends on individual values. Therefore, the evaluating team should give great weight to the potential donor’s own assessment regarding the probability and importance of any anticipated self-benefit.

Balancing donor acceptability to donor benefit respects individual values, avoids conflicts of interest, and directs physician loyalty to where it belongs: solely with his or her patient. In our opinion, the likelihood of recipient benefit is important information not because it balances donor risk but because it affects the probability that the volunteer will benefit (4).

Must Valid Consent Always be Fully Informed?

More than 35 yr ago, Fellner and Marshall (6) interviewed 20 kidney donors and found that most of them decided to donate immediately; furthermore, “Not one of the donors weighed alternatives and rationally decided.” These observations led the authors to conclude that for some donors informed consent is a myth (6). A recent study of 98 living kidney donors suggests that this has not changed: more than 75% of them decided almost immediately, and disclosure of relevant information made little difference to their decision (7).

Reese et al. (1) imply that such rapid decisions should be rejected because “donor autonomy can be respected only by strict adherence to informed consent.” We disagree. As noted by the Nuffield Council on Bioethics (8), “The ethically significant requirement is not that consent be complete, but that it be genuine.” But without “strict” informed consent, how can we know if a person’s decision to donate is truly his or her own?

We believe that the answer lies in understanding how people make choices in close personal relationships (which typify living related organ donation), a context for which informed consent is not designed (9,10). As Majeske et al. (10) pointed out, “informed consent is based on an impartialist understanding of the requirements of autonomy that deemphasizes personal relationships. ... [In personal relationships] our actions are not a result of fixed rules or some sort of decision-making calculus but of affection and regard for the related other.”

Parent to child organ donation exemplifies this point. For the many parents who would do anything to save their child’s life, a detailed understanding of the donation process and its attendant risks may be much less important to them than the welfare of their sick child (6,9). This is illustrated clearly by the recollections of two parents, each of whom had donated a kidney to their daughter (5): “with our daughter’s life at stake, possible future risks to the donor were not a consideration. There was no question as to ‘whether.’ Suzy needed, and that was all there was to it.” In such cases, there is little doubt that parents’ decisions to donate are really their own.

These observations suggest that it does not make sense to require the same stringent informed consent from devoted parents that we would demand from unrelated volunteers.
Clearly, we must try to educate fully all potential donors and insist that they listen to what we have to say. But we should recognize that despite our best efforts, donor understanding may remain incomplete. We believe that provided the volunteer has a basic understanding of the risks, benefits, and alternatives, rapid consent that emanates from deep affection and concern may reflect autonomy just as surely as consent that is fully informed (9). In agreement with this view, Sauder and Parker (11) concluded: "to fail to accept a prospective donor’s decision because it was made too immediately or on the basis of emotion, not rational and prudential consideration of foreseeable risks and benefits, would violate the spirit of informed consent in mistaken service of the doctrine’s requirements. To discount or declare invalid such a decision is to largely ignore the context in which the offer was made, the relevance of the relationships of the parties involved, and the importance of those relationships for the values of the decisionmaker."

The Fundamental Ethical Problem with Accepting Living Donors

Finally, according to Reese et al. (1), "The fundamental ethical problem with accepting complex living donors is limited medical information about the magnitude of potential risk." We disagree here too. Often people must make medical treatment decisions in the face of limited information, yet no one claims that all of these consents are invalid. As Price (12) pointed out, "Uncertainty is not a stumbling block to informed consent" as long as the uncertainty is communicated to the potential donor.

What then is the “fundamental ethical problem” for health professionals who evaluate potential living organ donors? Elliott (13) identified it in an insightful editorial. He argued that “The most worrying part of living organ donation is not freedom of choice. . . . The worrying part is the chance of harm to a healthy donor.” He then pointed to an important correlate of this conclusion (13): “If a patient undergoes a harmful procedure, the moral responsibility for that action does not belong to the patient alone; it is shared by the doctor who performs it. Thus a doctor is in the position of deciding not simply whether a subject’s choice is reasonable or morally justifiable, but whether he [the doctor] is morally justified in helping the subject accomplish it.” In our view, this is the major ethical problem presented by living organ donation.

Disclosures

None.

References