Perspectives

Providing a Medical Excuse to Organ Donor Candidates Who Feel Trapped: Concerns and Replies

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Many transplant programs are willing to provide a contrived medical excuse for potential organ donors who wish to say no but feel unable to do so publicly.[1] The availability of these excuses is thought to facilitate freedom of choice—a necessary component of informed consent—by allowing donor candidates to bow out gracefully.[2] In a recent editorial, Simmerling et al. discuss possible harms raised by this practice and note that there is no empirical evidence to support it.[3] Given the importance of this issue for transplant centers that accept living donors, a review of the authors' concerns is in order. After careful consideration, I conclude that although some of their points are valid, much of their analysis is flawed.

Before detailing my criticisms, I wish to call attention to two types of contrived medical excuses: (1) those that are provided at the behest of the candidate and (2) those constructed without the candidate's knowledge. According to Simmerling et al., some transplant centers employ the latter (although no reference for this statement is provided).[4] I find this surprising and unacceptable. Excuses should only be provided at the request of the donor candidate.[5] Physicians have a general obligation of veracity,[6] and therefore they should be completely honest with all their patients, including donor candidates. The ensuing discussion assumes that this is the case.

Simmerling et al. argue that "The use of the medical excuse in transplantation shares many features with the use of deception in medical practice generally."[7] More specifically, these authors assert that, "Using the medical excuse in the evaluation of living organ donor candidates shares features with the practice of concealing a fatal diagnosis from patients. . . . This is true [even] for those cases in which the excuse is used with the knowledge and permission of the donor candidate."[8] I disagree. I believe that there is a clear difference between withholding information from a patient about herself and honoring a request by an informed person to help her terminate the donor process via a contrived excuse. It is one thing to argue that the latter is wrong, but quite another to say that these practices are conceptually the same. How can, as the authors imply, provision of a medical excuse "engender false hope" the way that concealing a poor prognosis can do? What does the fact that patients "wanted to know the truth of their diagnosis and prognosis" have to do with providing a medical excuse for a fully informed donor candidate?

Simmerling et al. also assert that, "If physicians' use of deception becomes widely known, this would probably

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damage trust in the medical profession as a whole."[9] Although this may well be true for medical deception in general, there is no evidence that this admonition applies to a medical excuse here. A physician's primary fiduciary responsibility is to her patient,[10] not to her patient's family and friends. I believe that it is at least as likely that the public would accept (rather than reject) the idea of offering medical excuses to donor candidates if it understood the purpose of the excuse, the fact that the candidate must request it, and the way it is communicated to potential recipients. Regarding the latter, it is important to understand that, although the donor team is a party to contrived excuses, it rarely if ever transmits them to potential recipients.[11] This is left for the donor candidate to do. Thus, although the donor team may help the candidate to deceive, it need not and should not lie. Furthermore, it should be clear to all interested parties at the outset that the donor candidate's evaluation is confidential[12]; the recipient team should not review the donor candidate's record without her permission. Under these circumstances, like the donor team, the recipient team should not be in a position of having to lie. According to Beauchamp and Childress, "deception that does not involve lying is generally less difficult to justify than lying, in part because it does not threaten as deeply the relationship of trust between deceiver and deceived."[13]

In my view, the plight of a pregnant teenager scared to tell her parents[14] is another inappropriate analogy. The former involves a minor, not a competent adult. More importantly, although the pregnant teenager may feel she has let her parents down, this is not the same kind of letdown as that experienced when a family member fails to come through for a relative in need. The suggestion that clinicians can facilitate communication of a family member's unwillingness to donate in a way that will not damage relationships sounds good but is another speculation that in many cases may not be true.

Simmerling et al. also suggest that the availability of medical excuses "may serve to reinforce the idea that the only legitimate reason to not donate is a medical contraindication."[15] Even if this is true, it does not provide sufficient justification for eliminating medical excuses. I suspect that for most donor candidates who feel trapped, their major concern is not what is considered a legitimate reason for not donating, but rather avoidance of shame, guilt, and/or alienation. Furthermore, there is no reason to believe that candidates who fear that "moral ignominy ... would ... fall to them if their unwillingness were revealed"[16] would be less concerned about this were medical excuses unavailable.

The potential negative impact of contrived medical excuses on future employability and insurability may be minimized or eliminated by limiting excuses to those that imply little if any long-term risk, such as anomalous renal vascular anatomy, and by not falsifying the medical record, something that should never be done.[17] Furthermore, it should be up to the donor candidate, not the transplant center, to decide whether or not the risk of such nonmedical harm is worth the benefit of being able to bow out gracefully.

The best argument against offering excuses is the "difficulty in maintaining a lie."[18] Another concern is that, in the future, the donor candidate may wish to donate to someone closer to her than the original potential recipient. But even Simmerling et al. do not see these problems as absolute barriers; they conclude that in the interest of protecting candidates from harm,

"In some cases, however, an excuse may prove justifiable and appropriate."[19] Furthermore, it is paternalistic for centers to decide for candidates which harm is greater—that resulting from admission of unwillingness or that which comes from the lifelong need to maintain a deception.

Simmerling et al. state that, "transplant teams have not one but two patients and those patients stand in an inverse health relationship to one another. The requirements of beneficence may on occasion come into conflict."[20] This should not happen. Appropriate concerns about conflicts of interest have led to the recommendation that potential donors and recipients be evaluated by separate health teams.[21] When this important guideline is followed, each team has one patient, not two. Under these circumstance, duties of veracity and beneficence should not collide (as the authors' title suggests) because the donor team can (and should) always be both truthful with and protective of the donor candidate.

Simmerling et al. propose a mechanism that saves face for the donor candidate without lying: "transplant teams may say up front to all parties that the program has the right to refuse a living donation without detailed explanation."[22] This is a puzzling proposal from a group that is concerned about deception. If, as I believe, the donor team has an obligation to inform fully, then rejected candidates are entitled to an honest and complete explanation for refusal. This is part of showing respect for persons.[23] And note that not sharing information can itself cause harm, for example, by inducing unnecessary anxiety.

In conclusion, I agree with Simmerling et al. that there are downsides of providing contrived medical excuses for organ donor candidates, and therefore they should be used only as a last resort when there are no better options. But I believe that it is a mistake to suggest that deceiving patients about their own diagnosis and prognosis is similar to creating a deception aimed at someone else at the request of a fully informed donor candidate. In my view these situations are very different, and therefore the lessons learned in other areas of medical deception cannot simply be extrapolated to offering medical excuses to people who wish to be excused from organ donation. Unfortunately there are no systematic data to guide us here and, as Simmerling et al. suggest, formal studies of this issue are needed. In the meantime, what are we to do? The authors' suggested criterion for acceptable deception, that is, it must be defensible to the public,[24] makes a lot of sense. I suspect that providing a medical excuse for fully informed donor candidates, who, after careful consideration see no other way out of a very difficult situation, would have little trouble passing this test.[25]

Notes

1. Simmerling M, Frader J, Franklin J, Angelos P. When duties collide: Beneficence and veracity in the evaluation of living organ donors. *Current Opinions in Organ Transplantation* 2007;12:188–92; Price D. *Legal and Ethical Aspects of Organ Transplantation*. Cambridge: Cambridge University Press; 2000:303–4.
2. Abecassis M, Adams M, Adams P, Arnold RM, Atkins CR, Barr ML, et al. Live Organ Donor Consensus Group: Consensus statement on the live organ donor. *JAMA* 2000; 284:2919–26.
3. See note 1, Simmerling et al. 2000.
4. See note 1, Simmerling et al. 2000.
5. See note 2, Abecassis et al. 2000.
6. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*, 5th ed. Oxford: Oxford University Press; 2001:284.
7. See note 1, Simmerling et al. 2000:189.

8. See note 1, Simmerling et al. 2000:189.
9. See note 1, Simmerling et al. 2000:189.
10. Levinsky NG. The doctor's master. *New England Journal of Medicine* 1984;311:1573–5.
11. Sterner K, Zelikovsky N, Green C, Kaplan BS. Psychosocial evaluation of candidates for living related kidney donation. *Pediatric Nephrology* 2006;21:1357–63.
12. See note 11, Sterner et al. 2006; Wright L, Faith K, Richardson R, Grant D. Ethical guidelines for the evaluation of living organ donors. *Canadian Journal of Surgery* 2004;47: 408–13.
13. See note 6, Beauchamp, Childress 2001:284.
14. See note 1, Simmerling et al. 2000.
15. See note 1, Simmerling et al. 2000:190.
16. See note 1, Simmerling et al. 2000:190.
17. See note 2, Abecassis et al. 2000.
18. See note 1, Simmerling et al. 2000:190.
19. See note 1, Simmerling et al. 2000:190.
20. See note 1, Simmerling et al. 2000:190.
21. See note 2, Abecassis et al. 2000; see note 11, Sterner et al. 2006; Spital A. Donor benefit is the key to justified living organ donation. *Cambridge Quarterly of Healthcare Ethics* 2004;13:105–9; The Ethics Committee of the Transplantation Society. The Consensus Statement of the Amsterdam Forum on the Care of the Live Kidney Donor. *Transplantation* 2004;78:491–2.
22. See note 1, Simmerling et al. 2000:191.
23. See note 6, Beauchamp, Childress 2001.
24. See note 1, Simmerling et al. 2000.
25. See note 1, Price 2000; see note 11, Sterner et al. 2006.