

PRIMUM NON NOCERE: BENEFICENT DECEPTION

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INTRODUCTION

In an attempt to address donor coercion, organ transplant teams have long allowed potential donors to opt out of donation by providing blameless medical excuses, which are intended to shield donors from external pressures, real or perceived, to donate.¹ The *Consensus Statement on the Live Organ Donor* suggests that this practice allows potential donors to “decline gracefully” and “helps facilitate a fundamental component of informed consent, freedom of choice to be a donor or not.”² Although these stated intentions form the basis for the wide use of this practice, there may be unintended consequences from the routine use of blameless medical excuses.³

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1. Carl H. Fellner & John R. Marshall, *Kidney Donors—The Myth of Informed Consent*, 126 AM. J. PSYCHIATRY 1245, 1245–46 (1970); Jean Hamburger & Jean Crosnier, *Moral and Ethical Problems in Transplantation*, in HUMAN TRANSPLANTATION 37, 40 (Felix T. Rapaport & Jean Dausset eds., 1968); Roberta G. Simmons & Richard L. Simmons, *Organ-Transplantation: A Societal Problem*, 19 SOC. PROBLEMS 36, 53 (1971); Thomas Tomlinson, *The Physician's Influence on Patients' Choices*, 7 THEORETICAL MED. 105, 119 (1986).

2. Authors for the Live Organ Donor Consensus Group, *Consensus Statement on the Live Organ Donor*, 284 JAMA 2919, 2921 (2000) [hereinafter *Consensus Statement*].

3. Scott J. Cotler et al., *Adult Living Donor Liver Transplantation: Perspectives from 100 Liver Transplant Surgeons*, 9 LIVER TRANSPLANTATION 637, 640, 643 (2003); Fellner & Marshall, *supra* note 1, at 1245–46; Sander Florman & Charles M. Miller, *Live Donor Liver Transplantation*, 12 LIVER TRANSPLANTATION 499, 502 (2006); Anthony K. House et al., *Adult-to-Adult Living Donor Liver Transplantation for Fulminant Hepatic Failure*, 175 MED. J. AUSTRAL. 202, 204

For instance, a blameless medical excuse may reinforce the idea that, while donation is not a duty, there are certain circumstances under which potential donors should be willing to accept its risks and hardships, such as where the donor and recipient are related. Consequently, offering potential living, related organ donors a blameless medical excuse may reinforce that the only legitimate reason not to proceed with donation is a medical contraindication and that donation is something they *should* do in the absence of one. That is, the practice may reinforce the idea that unwillingness to donate is so shameful that it cannot be openly disclosed. Another problem related to the routine use of the blameless excuse is that it may damage doctor-patient relationships by undermining individual and public trust in what physicians say. Nevertheless, some argue that *not* providing potential donors with a blameless way not to donate unfairly puts them at risk for negative psychological and social repercussions.⁴ Some proponents of this view also believe that providing a medical excuse to reluctant, healthy donor candidates protects their privacy.⁵

Providing a medical excuse as a blameless way out of organ donation is certainly not new to transplantation. Originally intended to reduce the pressures on potential living, related organ donors, this practice has become a routine part of the donor evaluation and informed consent process of many transplant programs in the United States and elsewhere. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) recently suggested that transplant programs must provide a “blameless explanation” for potential donors who do not want to donate.⁶ The blameless medical excuse implicates either an anatomical or physiological anomaly that prohibits donation, thereby providing a medically “legitimate” reason for not pursuing donation. In reality, the donor may be unwilling or unable to express her reluctance to pursue donation. Under certain circum-

(2001); Chung-Mao Lo & Sheung-Tat Fan, *Living Donor Liver Transplantation: Donor Selection, Evaluation, and Surgical Complications*, 6 CURRENT OPINION IN ORGAN TRANSPLANTATION 120, 121 (2001); Chung-Mao Lo et al., *Applicability of Living Donor Liver Transplantation to High-Urgency Patients*, 67 TRANSPLANTATION 73, 74, 76 (1999); Amadeo Marcos, *Right Lobe Living Donor Liver Transplantation: A Review*, 6 LIVER TRANSPLANTATION 3, 7 (2000); Leslie R. Schover et al., *The Psychosocial Impact of Donating a Kidney: Long-Term Followup from a Urology Based Center*, 157 J. UROLOGY 1596, 1597, 1599 (1997); Javaad Zargooshi, *Iranian Kidney Donors: Motivations and Relations with Recipients*, 165 J. UROLOGY 386, 388 (2001).

4. Interview with Patrice Al-Saden, RN, CCRC, Senior Clinical Research Associate, Division of Organ Transplantation Surgery, Feinberg Sch. of Med., Northwestern Univ., in Chicago, Ill. (2004).

5. *See id.*

6. JCAHO, *Preparing to be a Living Organ Donor*, http://www.nicelungs.com/donor_brochure.pdf (last visited Nov. 16, 2007).

stances, and to satisfy the transplant center's own biases in a particular case, the center might provide a medical excuse to a living donor where the donor is unaware that the excuse is unsubstantiated.

Although the *Consensus Statement on the Live Organ Donor* condones the use of an appropriate medical disclaimer, it specifically states that transplant teams should not fabricate medical conditions when creating excuses.⁷ It is unclear where the boundary between the two lies. Even if that boundary could be defined, it is important to remember that the fundamental intention of the medical excuse is to deceive through stretching or fabricating medical facts. It is also important to note that the deception will continue as long as there is a familial or other relationship between the now "ineligible" donor and the recipient, as well as a relationship between the recipient and the transplant team. The "excused" donor may need to perpetuate the fabrication in future family or social interactions, which may force her to mythologize or embellish the deception. As Sissela Bok has argued, difficulty in maintaining a lie provides a strong prima facie reason to avoid lying in the first place.⁸

II. EXAMPLE CASES

The transplant community has not fully considered the wider social implications and potential harms to individuals that may be associated with the regular use of blameless medical excuses. Routine and comfortable use of the medical excuse as a way to support and enhance donor autonomy deserves further scrutiny. In order to illustrate this conclusion and better understand some of the pressures that may affect a person considering live organ donation, we present and discuss several cases below involving medical excuses that have arisen during recent years.⁹

A. Case 1—Potential Donor Refusing Medical Excuse

Not all potential living donors want to use a blameless excuse, even when the transplant team advises them to do so. Consider the following case, in which the transplant team offered the potential donor a medical excuse, but the potential donor opted not to use it. A sixty-seven-year-old man with liver cancer needed a transplant. Both of his

7. *Consensus Statement*, *supra* note 2, at 2921.

8. See SISSELA BOK, *LYING: MORAL CHOICE IN PUBLIC AND PRIVATE LIFE* (Vintage Books 1999) (1978).

9. Although these examples are based on real cases that occurred at a transplant center in the United States, personally identifying details have been altered to protect privacy and confidentiality. The name of the center is not disclosed here to further ensure this protection.

children agreed to be evaluated for possible donation. The daughter indicated that she took oral contraceptive pills, which would ordinarily require a one-month “wash-out” period before she could undergo the donation procedure. The son’s evaluation showed that he was a good candidate medically. However, the son informed the transplant team that he and his lover needed more time to consider the donation, indicating that his father had never accepted his homosexuality and had always treated his partner with disrespect. The transplant team offered to provide the son with a medical excuse that he could give to his family. The son refused, indicating that he wanted to tell the truth—that he was a good candidate medically, but was choosing not to donate. The transplant team arranged for the son to discuss this decision with a psychiatrist to ensure that he had considered the implications of his decision. The son felt strongly that he wanted to be forthright with his father about why he did not want to donate. Although the daughter agreed to stop taking her birth control medication in order to proceed with a donation, a one-month reevaluation of the intended recipient revealed the disease’s progression, rendering the patient unsuitable for transplantation, and he subsequently died.

This case raises a number of important issues. First, it suggests that there are acceptable, nonmedical reasons not to donate. Specifically, given his relationship with his father, the son did not believe that he had a duty to donate. It was not that he was shirking his responsibility, but rather that he believed no such responsibility existed. The transplant clinicians worried that the son’s truthful disclosure of his decision not to donate could add to family conflict at an already difficult time, and so they suggested that the son use a blameless medical excuse rather than take responsibility for the decision not to proceed. However, the son wanted to be truthful and tell his father that it was *his* decision—rather than the medical team’s—not to proceed. Thus, he declined a blameless excuse. Rather than supporting the son’s decision not to lie to his family about why he was not donating, the transplant team urged him to use an excuse and referred him for psychiatric evaluation when he refused to do so. Thus, this case exemplifies how the use of the medical excuse may limit, rather than support, donor autonomy. The practice of foisting unwanted lies on potential organ donors who do not want to proceed with donation as a means of respecting their autonomy also distorts the very principles upon which respect for autonomy is based.

B. Case 2—Potential Donor Requesting Medical Excuse

Sometimes a medical excuse may not involve a purported physical condition. Consider the following case: a forty-eight-year-old woman with long-standing end-stage renal disease had been on the kidney transplant list for some time. She had encouraged her adult sons and daughters to consider being evaluated for donation. The oldest son, married with young children, was eventually evaluated and showed no medical contraindications to donation. He sought consultation with the transplant-liaison psychiatrist, because he felt tremendous countervailing pressures from his mother, who wanted him to donate, and his wife, who did not. In the end, the potential donor decided that he did not want to donate, but requested that the transplant team tell his mother that they were not allowing him to proceed with the donation, because he was the sole wage-earner of a young family.

Here, the blameless excuse moves the locus of responsibility for the decision not to donate away from the potential donor and onto the transplant team. While this approach may help avoid some uncomfortable interactions among family members, it risks impeding future interactions between transplant team members and recipients. Other potential donors may not come forward for evaluation if recipients and families wrongly believe that the transplant center has a policy that precludes all donors who have young children. Conversely, if the mother encounters a patient who received a kidney from an adult child in similar circumstances, her trust in the transplant team might be seriously impaired. Perhaps most importantly, by lending its authority to the son's reasons for not wanting to proceed with donation, the transplant team reinforced the idea that the only legitimate reasons not to pursue donation come from medical professionals.

C. Case 3—Potential Donor's Family Member Requesting Excuse

Consider another case that raises different issues with respect to the medical excuse. The son of a woman in need of a liver transplant came forward to be evaluated for donation. The potential donor's wife did not accompany him to any of the medical evaluation visits. The donor told the transplant team that he had the full support of his family with regard to his decision to proceed with donation. Less than a week before the scheduled transplant, the donor's wife called the transplant surgeon to say that she had recently learned about her husband's plans to donate from their young child. The wife was extremely upset that she had not been informed of the planned surgery. She said that she was vehemently opposed to the donation and that, if

anything happened to her husband, she would sue the surgeons and the hospital. She stated that her husband had a history of poor judgment and had lost several good work opportunities in the last year, hurting their family's financial security. The wife said that they had only recently restored their lives to normal and that she feared that the donation could seriously jeopardize their progress. Despite these objections, she refused to openly oppose the donation in front of her husband, because he had once made it clear that he would leave her and take their child with him if she did not support his wish to become a donor. Thus, she asked the transplant team not to disclose her knowledge of, or opposition to, her husband's decision to proceed with donation.

The team members decided not to compromise the wife's request for secrecy and did not reveal her opposition to the donation. They concluded that it would be best to invent a medical excuse for the transplant candidate's son. In response to the difficulties presented in this case, the institution adopted a policy requiring the spouse of a potential married donor to participate in the donor evaluation and informed consent process. The transplant team's actions in this case extend the complexity and deception involved with medical excuses: the potential donor himself was not made aware of the excuse, and he may have come to see himself as "damaged goods," both physically and morally. Such an approach would seem acceptable only if one believes that the transplant team knows better than the potential donor what will be in her best interests or that pragmatic interests in avoiding potential litigation should take precedence over honoring a potential donor's decision to proceed with donation. The first reason involves a blatantly paternalistic claim and ignores the patient's own assessment of her personal best interests. The second reason may threaten the health or life of a patient in need and poses a serious ethical question about the goals and priorities of transplant programs.

III. DISCUSSION

As noted above, "gracefully" opting out of donation by using a blameless medical excuse has a long tradition in living, related kidney transplantation.¹⁰ Informal discussions with clinicians at numerous transplant centers suggest roughly wholesale adoption of the practice so that potential donors can save face and avoid pressure or disdain from the potential organ recipient or other family members.¹¹ How-

10. See *supra* note 1 and accompanying text.

11. Cotler et al., *supra* note 3, at 643.

ever, the transplant community does not appear to have fully considered the wider social implications and potential harms to individuals that may be associated with the regular use of blameless medical excuses. This practice deserves further scrutiny.

Frequent use of the medical excuse in the context of living donor transplantation (LDT) shares features with the then-prevalent practice of concealing a fatal diagnosis from patients in the early- to mid-twentieth century in the United States. Physicians desired to shield patients from the truth of a poor prognosis, believing that they were protecting the patient's hope.¹² With various cultural and social changes, as well as psychosocial research on the thoughts and feelings of actual patients, it became clear by the 1960s that most Westerners preferred to know the truth about their diagnoses.¹³ Many patients resented the medical profession's paternalistic judgments about what was best for them, and others simply wanted to know in order to better plan their time remaining before death.¹⁴ On both empirical and ethical grounds, the deceptive practices proved unacceptable.

IV. ANALYSIS

While recognizing that there may be cases in which the use of a blameless medical excuse might be necessary and appropriate—cases in which potential donors are in fact being coerced to donate—the transplant community should consider abandoning routine use of the medical excuse in the context of LDT. Decisions about whether to offer or use a medical excuse should occasion reflection on the reasons that might justify lying in a given situation. Rather than seeing the medical excuse as an essential part of the informed consent process, the transplant community should view it as an exception to be used only in certain circumstances. Bok suggested a process for singling out those lies that are justifiable from those that may only appear so.¹⁵ Justifiable lies must be “publicly defensible” to “reasonable persons.”¹⁶ Application of this principle is useful in countering the self-deception and bias inherent in the liar's perspective and in chal-

12. Harold A. Wilkinson, *Hope, False Hope, and Self-Fulfilling Prophecy*, 63 *SURGICAL NEUROLOGY* 84 (2005).

13. Donald Oken, *What to Tell Cancer Patients: A Study of Medical Attitudes*, 175 *JAMA* 1120, 1120–21 (1961); Fred Rosner, *Emotional Care of the Cancer Patient: To Tell or Not to Tell*, 74 *N.Y. J. STATE MED.* 1467, 1468 (1974); Fred Rosner, *Informing the Patient About a Fatal Disease: From Paternalism to Autonomy—The Jewish View*, 22 *CANCER INVESTIGATION* 949, 949–51 (2004).

14. See Oken, *supra* note 13; Rosner, *supra* note 13.

15. Bok, *supra* note 8, at 90–106.

16. *Id.* at 90–93.

lenging privately held assumptions and hasty calculations, because it will require clear and understandable formulation of the arguments used to defend the lie.

If this condition were applied to decisions regarding the use of a blameless medical excuse in the LDT setting, the transplant team might be able to identify those cases in which offering a blameless excuse is justifiable. Although such a process would not resolve what should be done in those cases that do not meet the condition, it might help to identify those cases in which using a blameless medical excuse might not be morally permissible. The authors are unaware of any empirical evidence that currently supports the view that routine use of medical excuses fosters the short- or long-term benefits commonly attributed to the practice. Although a blameless medical excuse may appear to expediently eliminate a potential donor from consideration, the practice may have ramifications that are not yet well understood and may lead to long-term psychological discomfort and disharmonious relationships for "excused" donors. Carefully facilitated early discussions with potential donors aimed at minimizing the pressures they may face might help avoid the ethical and practical problems outlined in this Article by avoiding altogether the need to invoke a medical excuse in order to gracefully decline donation.

V. CONCLUSION

Although intended to protect reluctant donors from countervailing pressures to proceed with donation, routine use of the blameless medical excuse may also bring with it unintended consequences. Transplant professionals who offer a medical excuse to these reluctant donors may be inadvertently reinforcing the idea that there are certain circumstances in which potential donors should be willing to accept the risks and hardships of donation, such as where the donor and recipient are related. Moreover, it may reinforce the ideas that the only justifiable reason not to donate must be medical in nature and that unwillingness to donate is too shameful to be honestly disclosed. The medical excuse may also damage both familial and doctor-patient relationships by undermining the trust that is so important to both. Still, there may be occasions when its use might be justified and necessary to protect potential donors who are at real risk of being coerced or exploited and turn to the transplant community for protection. While the transplant community deserves praise for its attempts to provide this protection, use of the medical excuse may not be the best, or the only, way to mitigate these harms.