

David Steinberg, "How Much Risk Can Medicine Allow a Willing Altruist?" *The Journal of Clinical Ethics* 18, no. 1 (Spring 2007): 12-16.

# How Much Risk Can Medicine Allow a Willing Altruist?

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## INTRODUCTION

With the advent of live organ donation, the traditionally low risk permitted altruists in medicine escalated to include death. In 2005 there were 6,020 live kidney donors, 302 live liver donors, and nine live pancreas, intestine, and lung donors combined.<sup>1</sup> Although data is limited, a live kidney donor assumes a mortality risk of about 0.04 percent<sup>2</sup> and the donor of a lobe of liver a mortality risk of 0.2 percent or higher.<sup>3</sup> The probability of death would increase if organs were retrieved from donors with medical risk factors or if surgery was performed in low volume or at lesser skilled transplant centers. Although the available information may be imperfect, recent data confirms that live organ donation is associated with donor risk.<sup>4</sup> That low risk could translate to painful reality was illustrated in the well-publicized deaths of liver donors Danny Boone and Mike Hurwitz.<sup>5</sup> In addition to deaths, there may be serious complications. Serious donor complications in transplantation of the right lobe of the liver include bile leak or stricture in 6 percent, the need for blood transfusion in 4.9 percent, re-operation in 4.5 percent, major postoperative infection in 1.1 percent, and rehospitalization in 8.5 percent.<sup>6</sup> The death or injury of a healthy altruist is disturbing, and a reason to confront this difficult question: How should the amount of risk that medicine can impose on a willing altruist be determined?

## RISK AND RELATIONSHIP

In many transplant centers, live kidney donation by altruistic strangers has become accepted practice.<sup>7</sup> Donation by altruistic strangers may be approximated by the number of living unrelated anonymous donors reported by the United Network for Organ Sharing (UNOS) and the Organ Procurement and Transplantation Network (OPTN), which, for 2005, consisted of 68 kidney donors and five liver donors; in 2000 there were 20 kidney donors and one liver donor.<sup>8</sup>

Donation by altruistic strangers has led to debate over whether the permissible amount of risk imposed on an altruist should be determined by the relationship between donor and recipient. It has been claimed that familial and other intimate relationships entail inherent obligations so that "what is supererogatory between strangers may be expected between family members" and other intimates.<sup>9</sup> Lainie Friedman Ross claims intimates have a *prima facie* obligation to donate organs and, for that reason, advocates that intimates should be permitted to accept greater risk than strangers.<sup>10</sup> Although it is descriptively correct that many people feel an obligation to donate an organ to an intimate, the translation of those emotions into a moral obligation inappropriately conflates what is with what ought to be. Although intimates may have mutual obligations, it has not convincingly been demonstrated that organ donation is one of those obligations. We strongly respect

personal autonomy in matters of bodily integrity and should be reluctant to impose an obligation on intimates to donate an organ or perform some other dangerous altruistic act. Although sound ethics does not necessarily make for appropriate legislation, the absence of momentum for laws that obligate organ donation between intimates suggests a lack of widespread support for this position.

The American Society of Transplant Surgeons, which accepts the retrieval of kidneys from altruistic strangers, does not approve the more dangerous retrieval of a lobe of a liver unless the donor is "emotionally related to the recipient."<sup>11</sup> I suspect that this position is based on the higher risk of liver donation and concern that inappropriately motivated altruistic strangers will escape detection. Although a competent and stringent evaluation should be mandatory for all altruists who are willing to assume substantial risk, there is no theoretical reason to exclude altruistic strangers. Although they are nominally strangers, people may feel a sense of kinship with their intended beneficiaries and "in a cosmic sense consider all human beings to be an extended family."<sup>12</sup> Many religions emphasize the interconnectedness of all persons under a supreme being.<sup>13</sup> Buddhist belief considers the separation between ourselves and others to be illusory.<sup>14</sup> Thomas Nagel notes that logic dictates "we must recognize other persons as persons in fully the same sense in which one is a person oneself."<sup>15</sup> Some altruists, such as rescuers of Jews during the Holocaust, were found to have provided assistance at considerable personal risk because of a belief in "the common humanity of all people."<sup>16</sup> In contrast, related individuals such as spouses and siblings may have troubled relationships. The importance of relationship is expressed in the higher percentage of people who are willing to donate to an intimate or relative compared with those willing to donate to a stranger;<sup>17</sup> however, the nominal nature of a relationship, in itself, does not provide a reliable basis for determining permissible altruistic risk.

### **RISK AND DONOR BENEFIT**

Aaron Spital believes that the justification for live organ donation must be "benefits for the potential donor that are sufficient to offset the risks for the donor."<sup>18</sup> He notes that intimates obtain "the inestimable benefit of seeing a loved one restored to health and then having that person available for sharing the joys of life."<sup>19</sup> Spital claims that relatives and intimates should be allowed to accept greater risk because they are likely to derive more benefit from helping each other.<sup>20</sup>

It has not been proven that donor benefit, in general, is higher for related and emotionally bonded individuals than it is for altruistic strangers.<sup>21</sup> Spital correctly notes that the nature of donor benefit is "psychological and emotional" and "cannot be quantified precisely."<sup>22</sup> Difficulty in the quantification of donor benefit is a serious problem for a justification that defines a continuum of acceptable donor risk that increases with donor benefit; also, it is not obvious how to weigh psychosocial benefits against the qualitatively different parameter of medical risk. Were the potential psychosocial benefits worth the risk that Mike Hurwitz took when he donated a lobe of his liver to his brother in an operation that cost his life? We don't know how to perform these calculations. Also, as illustrated in the Hurwitz and Boone cases, donor benefit is more realistically considered a potential benefit; donors who die reap no benefit, and some donors regret their donation.<sup>23</sup> Because the rewards of altruism in medicine are psychosocial, uncertain, and at best vaguely quantified — and significant material benefits are inconsistent with altruism — donor benefit should not be the barometer used to set the permissible level of altruistic risk.

### **CUMULATIVE RISK AND BENEFIT**

The calculus of medical decision making entails the weighing of risk and benefit and the selection of options likely to provide benefits that outweigh the attendant risks. Individual risk-benefit calculations are flawed in altruism because the person who accepts the medical risk is not the person who reaps the medical benefit.<sup>24</sup> These calculations can, however, be performed on a wider scale that measures cumulative medical benefit and cumulative medical risk on the affected population. Live organ donation is publicly accepted and currently best justified because its cumulative medical benefit far outweighs its cumulative medical risk.

Compared to deceased donor organ transplantation, live organ donor transplantation is associated with an outcome that is generally better, reduced patient waiting time and recipients who are generally healthier at the time of transplantation. Although one healthy person in about 400 may die after donating a lobe of a liver, many more lives are salvaged.

There is a direct relationship between risk and benefit in liver and kidney transplantation. The higher risk of liver retrieval is taken to save a life because there is no procedure comparable to dialysis to keep patients with advanced liver disease alive; whereas the lesser risk of kidney retrieval spares dialysis but typically is not immediately lifesaving. The permissible risk to an altruist may be less apparent when the beneficiary's prognosis is uncertain, such as when a previously resected malignancy has, with only some degree of probability, been cured. To be consistent with the goals of medicine, an altruistic intervention must provide benefit to its population of beneficiaries that overwhelmingly outweighs the risks to its population of altruists.

### **THE ARBITERS OF PERMISSIBLE RISK**

Potential organ donors (and altruists in other arenas of medicine) and the professional transplant community (or other purveyors of medical altruism) are the current arbiters of acceptable altruistic risk. Although they check and balance each other, both are imperfectly positioned to establish appropriate standards. Potential altruists can set the upper limit of risk because, if they deem the risk to be too high, they can refuse to participate; however, their role in setting the standards of altruistic risk is problematic, because altruists may be subject to the internal coercion of conscience, family pressures, and rational deliberation — for better or for worse — and can be overwhelmed by emotion.<sup>25</sup> Zell Kravinsky, a man who had already donated one of his kidneys, set the barometer of risk too high when he volunteered to donate his remaining kidney. Transplant centers appropriately refused his request.<sup>26</sup>

Conflicts of interest may exist for medical providers. For example, the professional transplant community employs altruism as a means to save or improve lives. The protection of donors is a vital concern, but it may risk subordination to the goal of obtaining more organs when that goal subtly conflicts with moderating altruistic risk. The reverse is also possible; inordinate fear of donors' deaths or injuries might cause the inappropriate rejection of an altruistic intervention. An important reason that the determination of acceptable altruistic risk should not wholly reside in the medical community is that these decisions entail value judgments for which medicine has no special expertise.

### **ABSOLUTE LIMITS**

The requirement that the cumulative medical benefit of an altruistic act far exceed its cumulative medical risk is a necessary but insufficient limitation. The retrieval of all organs and tissues from a healthy live donor could save more people than the one doomed altruist; yet few of us would endorse participation in such blatant human sacrifice. But where should we set the limit? Is a 1 percent risk of death excessive? Or should we accept a 2 or perhaps a 3 percent risk?

In general, people have the right to determine what is done to their own body. If a person chooses to accept a high risk of death and swim against a forceful current to save a drowning child, that decision will likely be considered morally laudable, if not heroic. It does not, however, follow that a similar degree of risk can be imposed on medical altruists, because altruism in medicine requires the participation of morally accountable healthcare professionals. Retrieval of the heart from a parent who is willing to die to save a child entails certain death and would blatantly challenge the time-honored medical dictum "Do no harm." Lower levels of altruistic risk are also problematic. A 2 percent risk of death in an altruistic intervention that will ultimately be performed on hundreds or thousands of people will, with near statistical inevitability, result in deaths. Similar considerations apply to the imposition of serious harm.

I propose as the guideline for determining altruistic risk that the cumulative medical benefit of an altruistic intervention overwhelmingly outweigh its cumulative medical harm, and that some absolute level of

permissible risk is not exceeded. The claim that an altruist's personal autonomy should take precedence over a healthcare professional's duty to avoid inflicting harm must take account of both the harm of any specific action and the broader consequences of weakening the principles that constrain healthcare professionals from hurting people. If significant numbers of people die or are harmed in altruistic medical interventions, physicians will appropriately be seen as violating the Kantian dictum to avoid using a person as means to an end, and trust in the protective role of medicine will erode. A license to inflict excess harm in the sphere of altruism might facilitate cavalier risk taking in other areas of medical practice. For these reasons, there should be limits on the amount of risk that may be imposed on medical altruists.

### **A PROPOSED PROCESS**

A process is required to translate this proposed general guideline for determining permissible altruistic risk for practical application. How do we determine whether the cumulative medical benefit of an altruistic intervention overwhelmingly outweighs its cumulative medical risk? How do we quantify the appropriate limit for altruistic risk? Ethical theory has limitations and cannot provide a quantitative answer. The risk to an altruistic donor is medical; the benefits to the donor are psychosocial. These, like "apples and oranges," are incommensurable parameters and cannot quantitatively be weighed one against the other.<sup>27</sup> The quantification of acceptable risk is beyond the capability of ethics and must be decided by another mechanism. A process is necessary. Because medical altruism in its various forms affects many people and has societal implications, its conundrums should be resolved, at least in part, as matters of public policy.

The public or its representatives, in some appropriate forum, would be informed by the medical community of the anticipated risk and benefit of specific transplant or other interventions based on altruism. In transplantation, a registry will need to be established to track donors' morbidity and mortality. Decisions would be made behind a "veil of ignorance" that could be similar to that described by John Rawls.<sup>28</sup> Ideally, involved citizens would be blind to whether they or their intimates were destined to be asked to perform the relevant altruistic act or would be its beneficiary, and thus would be motivated to justly represent the interests of both altruists and beneficiaries.

Participation by the medical community would be critical but not exclusive. The mechanism for involving the public would present pragmatic challenges, but some form of participation, perhaps similar to the employment of community members on institutional review boards (IRBs) or ethics committees, should be feasible. The public would judge protocols and not make case-by-case decisions. They would set the upper limit of acceptable morbidity and mortality for a liver transplant or a lung transplant or some other altruistic act. Whether the public would accept more or less risk than the medical community would be a matter for empirical inquiry. Although it might limit its decision-making powers, involvement of the citizenry would be helpful in transplants and in other areas of medicine that involve altruism. If there were a mishap, such as the unavoidable death of a healthy organ donor, the burden on the medical community would be eased. The emotional impact on the transplant team might not be altered, but external criticism would be muted because the transplant would have been endorsed by a public cognizant of the risks.

### **ACKNOWLEDGMENT**

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### **NOTES**

1. <http://www.optn.org/latestData/rptData.asp>, accessed 17 January 2006.
2. In a three-year period from 1999 to 2001, of 15,782 kidney retrievals from live donors, seven deaths were reported for a rate of one death for every 2,255 donors (0.04 percent). This is data as of 19 April 2002, reported to the Organ Procurement and Transplantation Network and provided by the United Network for Organ Sharing.

3. R.S. Brown et al., "A Survey of Liver Transplantation from Living Adult Donors in the United States," *New England Journal of Medicine* 348 (2003): 818-25; O.S. Surman, "The Ethics of Partial-Liver Donation," *New England Journal of Medicine* 346 (2002): 1038; J.F. Trotter et al., "Adult to Adult Transplantation of the Right Hepatic Lobe from a Living Donor," *New England Journal of Medicine* 346 (2002): 1074-82.

4. Based on OPTN data as of 19 August 2005, supplied by the United Network for Organ Sharing, for the period 25 October 1999 to 31 May 2005, of 34,433 living kidney donors, there were 23 deaths (eight within the first week of donation); of 2,115 liver donors, there was one death; of 181 lung donors, there were no deaths; when live pancreas, intestine, and kidney-pancreas donors are added to live kidney and liver donors for a total of 36,762 live organ donors, 24 deaths were reported. Based on OPTN data as of 23 June 2006, in 2005, of 308 reported living liver donors, 15 required rehospitalization in the first six weeks postdonation; and of 307 reported living liver donors, five required re-operation during the first six weeks postdonation. In 2005, of 6,325 reported live kidney donors, 90 required rehospitalization in the first six weeks postdonation; and of 6,333 reported cases of live kidney donation, 26 required re-operation in the first six weeks postdonation.

5. C. Miller et al., "Fulminant and Fatal Gas Gangrene of the Stomach in a Healthy Live Liver Donor," *Liver Transplantation* 10, no. 10 (2004): 1315-9; "New Protection Eyed for Living Organ Donors," *Boston Globe*, 31 March 2005; <http://www.lodepp.org/default.html>, accessed 13 July 2005; "New Yorker Dies After Surgery To Give Liver Part to Brother," *New York Times*, 15 January 2002; "A Healthy Patient Dies In A Hospital," *New York Times*, 15 March 2002.

6. Brown, see note 3 above.

7. C.L. Jacobs et al., "Twenty-Two Nondirected Kidney Donors: An Update on a Single Center's Experience," *American Journal of Transplantation* 4 (2004): 1110-16.

8. United Network for Organ Sharing Data, <http://www.unos.org>, accessed 19 February 2006.

9. W. Glannon and L.F. Ross, "Do Genetic Relationships Create Moral Obligations in Organ Transplantation?" *Cambridge Quarterly of Healthcare Ethics* 11 (2002): 153-9; R.A. Crouch and C. Elliott, "Moral Agency and the Family: The Case of Living Related Organ Transplantation," *Cambridge Quarterly of Healthcare Ethics* 8 (1999): 275-87; V.A. Sharpe, "To What Extent Should We Think of Our Intimates As 'Persons'? Commentary on Conceiving A Child," *The Journal of Clinical Ethics* 1 (1990): 103-7; J. Dwyer and E. Vig, "Rethinking Transplantation Between Siblings," *Hastings Center Report* 25 (1995): 7-12; E.G. Howe, "Allowing Patients to Find Meaning Where They Can," *The Journal of Clinical Ethics* 13 (2003): 179-87.

10. L.F. Ross, "Solid Organ Donation Between Strangers," *Journal of Law, Medicine and Ethics* 30 (2002): 440-5; L.F. Ross et al., "Should All Living Donors Be Treated Equally?" *Transplantation* 74, no. 3 (2002): 418-26.

11. <http://www.ast.org/livingliverdonor/updated.cfm>, accessed 12 July 2005.

12. A.S. Daar, "Strangers, Intimates, and Altruism in Organ Donation," *Transplantation* 74, no. 3 (2002): 424-6.

13. S.G. Post, "The Tradition of Agape," in *Altruism and Altruistic Love* (Oxford University Press, 2002), 51-64.

14. L.F. Habito Ruben, "Compassion out of Wisdom: Buddhist Perspectives from the Past toward the Human Future," in *Altruism and Altruistic Love* (Oxford University Press, 2002), 362-78.

15. T. Nagel, *The Possibility of Altruism* (Princeton, N.J.: Princeton University Press, 1970).

16. S.P. Oliner and P.M. Oliner, *The Altruistic Personality* (Free Press, 1988); P. Hallie, *Lest Innocent Blood Be Shed* (New York: Harper Perennial, 1994), 131.

17. In several informal surveys, I found a much greater proportion of people willing to donate to a relative or an intimate than to a stranger; 97 percent of Australian nephrologists would donate a kidney to a family member, but only 4 percent would donate a kidney to a stranger: J. Cunningham et al., "Australian Nephrologists' Attitudes Towards Living Kidney Donation," *Nephrology Dialysis Transplantation* 21, no. 5 (2006): 1178-83.

18. A. Spital, "Donor Benefit Is the Key to Justified Living Organ Donation," *Cambridge Quarterly of Healthcare Ethics* 13 (2004): 105-9.

19. A. Spital, "Justification Of Living Organ Donation Requires Benefit For The Donor That Balances The Risk: Commentary On Ross Et Al.," *Transplantation* 74 (2002): 423-4.

20. Ibid.

21. J. Kahn and A.J. Matas, "What's Special About The Ethics Of Living Donors? Reply To Ross Et Al.," *Transplantation* 74, no. 3 (2002): 421-2; J. Kahn, "Commentary: Making the Most of Stranger's Altruism," *Journal of Law, Medicine and Ethics* 30 (2002): 446-7.

22. See note 18 above.

23. E.M. Johnson et al., "Long-Term Follow-up of Living Kidney Donors: Quality of Life After Donation," *Transplantation* 67 (1999): 717-21; N. Weizer et al., "Suicide by Related Kidney Donors Following The Recipient's Death," *Psychotherapy and Psychosomatics* 51 (1989): 216.

24. Donors' risk may also be psychological or financial.

25. C.H. Fellner and J.R. Marshall, "Kidney Donors — The Myth of Informed Consent," *American Journal of Psychiatry* 126 (1970): 1245-51; H.M.E. Karrfelt et al., "To Be or Not To Be a Living Donor," *Transplantation* 65 (1998): 915-8.

26. "An Organ Donor's Generosity Raises The Question of How Much Is Too Much," *New York Times*, 17 August 2003.

27. M. Powers, "Bioethics As Politics: The Limits of Moral Expertise," *Kennedy Institute of Ethics Journal* 15, no. 3 (2005): 305-22.

28. J. Rawls, *A Theory of Justice* (Boston: Harvard University Press, 1971).