Special Section: Transplantation Ethics: Old Questions, New Answers?

Autonomy's Limits: Living Donation and Health-Related Harm

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In late December 1998, Renada Daniel-Patterson's father offered to donate a kidney to his daughter and ignited a controversy in the bioethics community. Renada had been born with only one kidney, which began to fail early in her childhood. At age 6, Renada had to receive dialysis three times a week. She was unable to attend school or venture very far from home. This pattern continued until Renada was 13, when Mr. Patterson called from prison to offer her his kidney. Renada was surprised to hear from her father, who was serving 12 years at California State Prison for burglary and drug convictions. Mr. Patterson was determined to be a compatible donor, and the family proceeded with the transplant operation. As a result of this surgery, Renada was able to live the life of a healthy girl for 2 years. Because the medication to prevent rejection of the transplanted organ made her feel ill and bloated and caused her to develop a hump on her back, Renada gradually began to skip doses. As a result, her donated kidney began to fail. It was under these circumstances that David Patterson offered to donate his second kidney to his daughter in 1998.

This situation presents several complicated ethical issues that deserve more thorough consideration than this forum can afford. However, the central question raised by the possibility of a person donating both of his kidneys concerns the nature and possible limits of autonomous decisionmaking: how much can one person be permitted to sacrifice in order to assist another? After identifying and briefly discussing other significant issues raised by this case, we will focus on this primary question.

Personal values and beliefs, including beliefs about altruism and responsibility, are obviously involved in people's decisionmaking about donating an organ (and also in seeking or accepting a donated organ). As in all decisions that involve balancing risks and benefits, empirical information is also relevant. For decisions about organ donation and transplantation, this empirical information includes data about the health-related risks of donation; the prospective recipient's prognosis and quality of life with, and without, transplantation; the availability and relative burdens of alternatives to transplantation, including the likelihood that a cadaveric organ will become available in a timely manner; the immediacy of the prospective recipient's need; and the likelihood of transplantation's success, which may vary with the timing of the operation, the quality and source of the transplanted organ, and the recipient's overall health and adherence to posttransplantation medical care. Thus, data as seemingly purely scientific as the likelihood that the recipient has developed or will develop antibodies that increase the likelihood of organ rejection are pertinent to the decisionmaking of prospective living organ donors and organ recipients.

Cambridge Quarterly of Healthcare Ethics (2001), **10**, 399–407. Printed in the USA.

So too are data as obviously socially mediated as organ-donor rates among different racial groups. Prediction of both the likelihood and the importance of a recipient's adhering to posttransplantation medical regimes is notoriously difficult; moreover, social factors frequently play a role in recipients' adherence.[1]

According to the Health Care Financing Administration report, in 1998 more than 230,000 Americans were being treated for End Stage Renal Disease (ESRD)[2]; 1.8% of these dialysis patients were below 19 years of age, and 32.3% of the patients were Black.[3] This statistic demonstrates that African Americans, who compose only 12% of the American population, disproportionately suffer from ESRD.[4] This is due in part to greater incidence of hypertension and diabetes in the African-American population. Furthermore, because African-Americans (and members of other underserved populations) are more likely to experience a lack of access to healthcare, frequently cases of diabetes and hypertension are discovered later and treated less aggressively than in persons with better access to care. This fact certainly contributes to the greater proportion of Blacks suffering from ESRD.

The length of time that dialysis patients survive varies by age, sex, and race. The average for a White male between 40 and 44 years old is 6.9 years. The remaining years of life for a Black male of the same age is 10 years. A White female in the same age bracket will survive, on average, for 7.1 years; the average for a 40–44-year-old Black female is 9.8 years.[5] Aside from numbing of the skin and needle insertion, hemodialysis itself is not painful; however, dependence on hemodialysis affects patients' quality of life, as it generally requires frequent travel to a dialysis center and rather stringent dietary restrictions.

Kidney transplantation—with an organ from either a cadaveric or a living donor—provides an alternative to dialysis. In 1998, 9,343 persons donated kidneys for transplant: 5,327 cadaveric donors and 4,016 living donors.[6] These kidneys were used in 11,990 transplant operations.[7] Living kidney donation is a relatively safe procedure with an estimated mortality rate of 0.03% and a low rate of complications.[8] There is a better chance of organs' being compatible when the donor and recipient are of the same race.[9] Because some research demonstrates that antigenic similarity between donor and recipient improves success rates in transplantation, antigen-matching is one criterion used to allocate organs.[10] The HLA antigens used to determine compatibility occur in different proportions among various ethnic groups.[11] Although a disproportionate number of those awaiting transplantation are African-American, in 1998 only about 10% of cadaveric donors and 9.5% of living donors were Black.[12] To the degree that organs are allocated based on antigen-matching, then, Blacks have a reduced possibility of obtaining good matches and may therefore wait longer for a kidney (or receive an organ that is less antigenically compatible).[13]

As of August 1999, there were nearly 43,000 patients waiting for kidney transplantation.[14] The longest living adult kidney recipient to date was 34 years and 11 months posttransplantation. Similarly, the longest living pediatric recipient was 34 years and 7 months.[15] The option of transplantation permits recipients to maintain a normal diet and schedule and eliminates the need for dialysis. Recipients must, however, maintain a strict regimen of medications to prevent their bodies from rejecting the transplanted organ(s).

These data, when applied to Renada's case in particular, raise some difficult ethical issues. Her history of noncompliance in taking posttransplantation medications might suggest to some that Renada does not deserve to be the recipient of a second kidney—a second chance—especially because so many others are awaiting a "first chance," and because the option of dialysis means that refusal to provide her with a second transplanted organ is not an immediate "death sentence." In the absence of more specific details regarding the reasons behind and circumstances surrounding her noncompliance, however, this would be at best a tenuous and premature argument. The argument is undermined further when one considers that Renada's receipt of a second donor kidney would not in any way diminish the pool of donor kidneys available to other ESRD patients because the donated kidney was offered by her father, who presumably would not make it available for use by any other patient. (Of course, Renada's father, who would need dialysis to continue living, might join the list of those in need of kidney transplantation.)

It is noteworthy that Renada's body had already begun to reject one of her father's kidneys. Further testing would be required to determine whether her father is an eligible donor or whether she is likely to have developed antibodies to his tissues. Given the increased risks and obvious burden that would be placed on her father with the loss of his second kidney, it might be reasonable at least to demand that there be a greater-than-minimal chance of a successful operation and well-functioning kidney for Renada.

Some additional ethical concerns stem from Mr. Patterson's being a prisoner. If there were any evidence that he was being pressured to donate by those who have power over him in his institutional setting or who may influence the conditions for his release, there would be strong reason to question the voluntariness of his decision. However, most concern about his status as a prisoner has focused not on his vulnerability to pressure, but on society's vulnerability to increased costs because of his decision to donate.[16] Because the government generally pays for prisoners' healthcare, it has been argued that it is unfair for Mr. Patterson to elect to place an increased financial burden on taxpayers. Dialysis treatments are quite expensive (up to $50,000 per patient per year),[17] particularly if patients require off-site transportation to obtain the treatments. In fact, the majority of dialysis patients, not merely those who reside in state institutions, receive some governmental reimbursement for dialysis in accordance with the ESRD benefit of the Medicare program, and many receive further aid from state medical assistance programs. However, in this case, either Renada or her father will be on dialysis, so there would not necessarily be a net increase in expenditures (from some source) on dialysis. Concern about a prisoner further burdening taxpayers suggests an attitude toward those convicted of crimes that part of their punishment should include not being allowed to impose social costs to the same degree as nonprisoners. Only explicit articulation of this position, social debate and resulting social consensus about it, and its subsequent consistent implementation could justify basing public policy on this (now merely implicit) belief.

Some might argue that Mr. Patterson should not be permitted to donate his kidney and begin dialysis treatments because he might then receive special privileges in prison because of his health status. A frequent procedure viewed as onerous by most patients could be perceived as a reprieve of sorts for a person accustomed to monotonous incarceration. Such a claim, however, gives little credence to Mr. Patterson's ability to make an informed decision. Because his release date is in 2003, it would be remarkably myopic for him to choose to exchange a healthy kidney and relatively unimpeded lifestyle for a shortened lifetime on dialysis merely to acquire more frequent diversions in his current life situation. To regard Mr. Patterson's offer as self-centered is to presume a remarkable lack of foresight. Of greater concern might be the possibility that Mr. Patterson would hold unrealistic expectations that his donation might result in additional benefits for him; for example, a favorable parole board review or reconciliation with his estranged family. Such, often unrealistic, expectations are of concern with all living organ donation;[18] however, it is difficult to determine whether a prospective donor actually harbors such hopes, whether they are realistic or not, and whether they impede, or are actually factors in, autonomous decisionmaking.

The relevance of medico-scientific and social factors that constitute the context of the donation-transplantation decision cannot be disputed. Questions of costs to society arising from individual decisions have some relevance to ethical analysis of the permissibility of a person donating both of his kidneys and becoming dialysis-dependent. It would be unfair, however, to place disproportionate weight on these costs because they are so temporally proximate and certain in a case like this, when others' personal decisions place perhaps more distant burdens on society but are not subjected to similar scrutiny. Society, for example, condones (and frequently encourages) persons to pursue high-stress professional occupations or risky pastimes, despite knowledge of the emotional and financial burdens that such stressful employment or risky pursuits place on others (e.g., family members or members of an insurance pool). Similarly, although the health risks and financial costs associated with smoking are well documented, and smoking is currently subject to some social censure, the sale and use of tobacco products are not prohibited.

The central question presented by this case is one that would arise if prospective donor and recipient were both vastly wealthy and if there were no more than the usual level of medical uncertainty regarding the likelihood of the transplantation's being successful and benefiting the recipient. That question remains: how much can one person be permitted to sacrifice to benefit another? Three main issues are useful in addressing this question: the concept and requirements of autonomous choice, the relationship between self-endangerment and autonomy, and the interplay between a patient's sacrificial decision and the medical tenet "do no harm."

First, how can we understand the concept of autonomous choice? Traditionally, bioethics has conceived of autonomy as an individual's capacity for and right to self-governance in decisionmaking regarding her person and her actions. In other words, an individual should be able to decide and act in a manner that resonates with her values and belief system. Respect for autonomy has become a cornerstone value of contemporary bioethics that, along with recognition that individuals are often best situated to protect their own welfare interests, grounds the doctrine of informed consent.

Obtaining informed consent to medical interventions has typically required five components: (1) the decisionmaker's competence; (2) disclosure to the decisionmaker of any information particularly relevant to the decision, especially risks and benefits of the intervention; (3) the decisionmaker's understanding of the risks and benefits that are disclosed; (4) the voluntariness of the decision; and (5) communication of the final decision. Evidence of meeting these five requirements is generally deemed necessary to ensure autonomous choice in contexts requiring informed consent. In some contexts, however, although decisionmakers assert that their decisions are autonomous and accurately reflect deeply held values and preferences, their decisions appear not to meet standard informed-consent requirements.

Living organ donation, especially by those emotionally related to the recipient, is one such occasion. Frequently, a prospective donor, particularly a parent or sibling of the prospective recipient, will experience the decision to donate as automatic.[19] They frequently report feeling that they had no choice but to donate, and proceed to offer their organs willingly and without hesitation, sometimes even before hearing of the risks involved in such a donation.[20] Disclosure of risks frequently has no effect on the decision to donate.[21] These decisions hardly seem to meet the traditional requirements of informed consent. Failing to take risks of an intervention into account when deciding whether to consent to it, and feeling compelled to consent, are typically hallmarks of a failure of the informed-consent process. Yet we are reluctant to suggest that these prospective donors are not making autonomous decisions to donate and, consequently, that their decisions (and organs) should not be accepted.[22]

According to the traditional doctrine of informed consent outlined above, the decision to offer oneself as a living donor prior to full disclosure and consideration of risks is a red flag of invalid informed consent. Certainly, disclosure should be made and the potential donor should be prompted to consider carefully the risks. But 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 supposed letter 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. After all, informed consent seeks to ensure that patients make decisions that reflect their values. A parent, for example, may offer to donate a kidney to their child without hesitation or forethought. Although such a decision does not reflect the informed consent process traditionally considered necessary for autonomous decisionmaking in medical contexts, it may resonate with a clear history of self-sacrifice that marks many parent-child relationships. Additionally, by contributing to the well-being of their children, parents may be acting to fulfill their own chosen life plans. Although such a decision to donate does not meet each checklist requirement of informed consent, it does not appear irresponsible or uninformed when viewed in light of the value system previously adopted by the decisionmaker, a value system that informs the relationship between prospective donor and recipient. Indeed, such a decision may most truly fulfill the autonomy-oriented goal of informed consent for healthcare decisionmaking: to allow persons to act in medical contexts in ways that respect their autonomy by reflecting their deeply held values.

Intuitively, these decisions make sense, but this altered concept of acceptable contextual consent warrants further exploration. One specific concern is whether this understanding of autonomy and this apparent modification of informed consent to emphasize its spirit by reinterpreting the letter of its requirements would allow individuals to be too self-sacrificing. For the sake of a conception of autonomy that is more closely tied to individuals' deeply held values than to norms of rational deliberation, would this interpretation of the requirements of informed consent allow individuals to sacrifice too radically their own welfare? Or, does allowing individuals to eschew norms of prudence and rational deliberation, in their pursuit or preservation of deeply held values and interests, actually serve a deeper sense of autonomy and a higher sense of well-being?

If bioethics' commitment to promoting autonomous decisionmaking is not undertaken merely to ensure that decisions accord with values about which there is broadly held social consensus, if it instead seeks to ensure that individuals' decisions reflect their own values, then bioethics' doctrine of informed consent must be able to accommodate decisions that are altruistic and even self-sacrificing beyond the point that most people find acceptable. When the decisionmaker makes a convincing appeal to a deeply held, though perhaps idiosyncratic, value system, the decision should receive the prima facie respect of the bioethical and medical communities. Nevertheless, there are limits to autonomy, and there may be limits to what society or bioethical, legal, and medical communities may allow a person to consent to, even in pursuit of the most deeply held values.

Traditionally, the scope of a person's autonomy is limited by the rights or socially protected interests of others. In the case of Mr. Patterson's decision to donate his second kidney, however, the question is whether his own health-related interests should be protected from his autonomous decision to sacrifice them for the sake of both his values and his daughter's potential benefit. If we can assume that Mr. Patterson understands the burdens and risks that his donation would entail, should he be permitted to accept them? In answering this question, we must strive to avoid a medico-centric perspective that gives primary weight to health-related risks and benefits. We must give appropriate weight to the psychological and social benefits that Mr. Patterson may reasonably anticipate from donation of his second kidney. If his hopes were utterly unrealistic—if, for example, he mistakenly believed that his prison sentence would be commuted or that full reconciliation with his family would result from his donation—then we would have reason to question Mr. Patterson further and to question his understanding, appreciation, and weighing of the risks and benefits that he himself considers material to his decision.

Moreover, because his donation would place some potentially severe restrictions on his current and future lifestyle (e.g., dialysis, the possibility of a shortened life span), it would be important for Mr. Patterson to understand these realities, including the particular health-related risks that prison life, including suboptimal healthcare, may pose. He must also understand that other options are available for Renada (including continued dialysis and the possibility of a cadaveric kidney donation) and the chances that transplantation with his donated kidney will improve her quality of life. He should also be prompted to consider that his donation may impose some psychological and social burdens on Renada; for example, a sense of obligation or guilt, or a social bond to her father that she might not desire. He might not want to place her in the position of accepting a "gift of life" that so severely compromises his health. If, however, Mr. Patterson considered all of these factors and still wished to donate his second kidney, is there any reason not to permit him to do so?

If there were superior or comparable options available to Renada, as with dialysis there indeed seemed to be, then there is reason not to ask or to allow Mr. Patterson to sacrifice his health-related interests. If, however, there were no option, or no option that afforded Renada a similar quality of life in the reasonably foreseeable future, then the primary ethical barrier to permitting Mr. Patterson's donation might be concern about the medical profession's complicity in a procedure that so severely compromised one person's health-related interests for the benefit of another's.

Medicine is supposed to be governed by the norm: "first, do no harm." Of course, medical procedures often involve doing some harm for the greater benefit of the patient. Incisions are made to remove the tumor; side effects of chemotherapy are imposed and endured with the hope of cure or prevention of recurrence. These harms are imposed, however, for the direct health-related benefit of the person harmed. And, quite importantly, only the minimum harm that can reasonably achieve the desired benefit is imposed. The question Mr. Patterson's decision raises is whether medical practitioners can ethically be complicit in imposing harms on one person for the health-related benefit of another person (e.g., Renada) when the person harmed (e.g., Mr. Patterson) seeks and may reasonably receive social and psychological benefits and accepts the health-related harm. Our answer is a tentative "yes."

One additional constraint must be observed: the harm imposed must be the minimum harm that can be imposed to achieve the desired benefit. In other words, if Renada could be expected to receive a kidney from a cadaveric donor and in the meantime remain on dialysis, without considerable disruption of the quality of her life or risk to her eventual prognosis, then it might be appropriate to refuse to impose the health-related harm on Mr. Patterson that he is nevertheless willing to accept. To proceed to impose that health-related harm on Mr. Patterson when the benefit to Renada may be achieved by other means would be unjustified, even if Mr. Patterson were to insist that he wanted to achieve the psychological benefit of being such an heroic donor or of compensating for past wrongs. The situation would be somewhat analogous to a case in which a surgical patient asked for a more invasive procedure than was necessary to remove his tumor because he wanted not only to achieve health-related benefit but additional psychological benefit that might accrue to him during a prolonged recovery period. Our analysis of Mr. Patterson's offer to donate his second kidney takes seriously potential psychological and social benefits and weighs them along with health-related risks and potential benefits but does not consider them to themselves justify a medical practitioner's imposing health-related harm. This analysis of the prescription to "do no harm" departs from the traditional analysis by weighing risks and benefits across two people, but only in cases where the person to be harmed for the sake of another considers incurring that harm for the sake of the other to be in accordance with his values and where the harm imposed is the minimum commensurate with achieving the benefit to the other.

Someone might argue that with the acceptance of Mr. Patterson's second kidney for Renada, an additional patient awaiting kidney transplantation might benefit from the cadaveric kidney that Renada would not use. It would seem that so long as Mr. Patterson's incurring the health-related harm of being without kidneys is acceptable to him, there would always be some additional health-related benefit (albeit to some third person) of Renada's receiving his kidney that would justify his donation, even if Renada could pursue an alternative that did not impose such harms on Mr. Patterson. However, this is not the case. So far as we can tell, Mr. Patterson wants to donate his second kidney for the health-related benefit of Renada and for the social and psychological benefits he anticipates in virtue of potentially benefiting her. His is not a desire to donate (to someone) out of general altruism and for the social and psychological benefits that it might bring. In the determination of the acceptability of imposing the health-related harms that he accepts, it is the potential benefits that Mr. Patterson actually anticipates (for himself and Renada) that may justify imposing harm on him, if he chooses to accept that harm under conditions of informed consent.

The considerations that may justify allowing Mr. Patterson to donate his second kidney and that may justify the complicity of society, medicine, and particular medical practitioners in his thereby being harmed do not justify accepting his donation for the benefit of those outside the scope of his concern (e.g., third parties on the waiting list) or taking that potential benefit into account in balancing harms and benefits. They also would not justify imposing an obligation to be self-sacrificing for the benefit of others in general or of particular emotionally related others. If, however, such sacrifice reflects a person's deeply held values and is consented to under conditions of informed consent, the decision to make such sacrifice should be respected and provides grounds for medical practitioners to violate the apparent prescription to do no harm.

Conclusion

If there had been no comparable or superior treatment alternative available to Renada, it might have been permissible to permit her father to incur the serious health-related harm and future risks to his health that he expressed willingness to accept. For his decision to donate his second kidney to be accepted, his decision would have to fulfill the demands of informed consent. As with many living donation decisions, that informed consent may be best evaluated in light of the donor's relationship with the recipient and the value system that informs the donor's decision, as well as traditional requirements designed to ensure understanding of the risks and benefits—health-related, psychological, and social—involved. Also, to act on a donation decision that imposes such severe health-related harms and future risks, it must be the case that doing so nevertheless imposes the most minimal harm commensurate with achieving the health-related benefit for the recipient, and this health-related benefit that may reasonably be anticipated must be a benefit that the prospective donor actually seeks to achieve by his donation.

The permissibility of a prospective donor's acting in such an apparently self-sacrificing manner lies in (1) the coincidence of his interests with the benefit to accrue to the recipient, (2) his belief in this coincidence based on his own values, (3) his informed consent to the myriad risks that he would incur by donating, and (4) his donation imposing the minimum health-related harm—when summed across donor and recipient—that may still achieve the health-related benefit to the recipient that he desires. In the case of Renada and her father, the fourth condition did not obtain; the availability of dialysis and the prospect of receiving a cadaveric organ meant that the option of receiving Mr. Patterson's second kidney was not the option that imposed the minimum health-related harm (even assuming that he was an eligible donor and that the chances of success were equivalent to those with a cadaveric organ). In this case, the reason for refusing Mr. Patterson's offer to donate would not reside with concerns about the autonomy of his decision nor with a blanket refusal to accept such self-sacrifice. Again, such self-sacrifice may be permitted if it is autonomously chosen and consented to with adequate understanding and if it imposes the minimum possible harm commensurate with the desired possible benefit.

Notes

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