

Too poor for transplant: finance and insurance issues in transplant ethics

Context—Donor organs are a scarce gift. Additionally, transplantation is very expensive and the United States lacks universal health insurance for all citizens. These facts combine to make personal finance and insurance some of the criteria for wait listing at US transplant centers. Previous research has shown that the poor and the uninsured (as well as women and nonwhites) are less likely to receive a transplant. Living donor candidates are also limited by the US insurance system.

Objective—To determine the effect of finance and insurance variables on access to transplant and living donation.

Design—A qualitative descriptive study of ethics consultation data contained in a research registry approved by the institutional review board at California Pacific Medical Center.

Setting and Participants—This study analyzes research registry data from a large community hospital in Northern California that serves patients from California, Oregon, and Nevada. The registry data are derived from transplant ethics consultations occurring between January 1, 2007, and June 30, 2009.

Main Outcome Measure—This study explores the restriction of access to transplantation and of participation in living donation.

Results—More than a quarter of all transplant ethics consultation reports described the restriction of transplant-related treatment for reasons rooted in finance or insurance. Individuals on the recipient side and on the donor side were hindered with regard to access. Insurance status and personal ability to pay significantly affect access to transplantation in the United States, and this theme is a frequent feature of ethics consultations at California Pacific Medical Center. (*Progress in Transplantation*. 2010;20:178-185)

**Kyle Alexander Laurentine,
Katrina A. Bramstedt, PhD**
California Pacific Medical Center, San
Francisco, California

Corresponding author: Kyle Alexander
Laurentine, Transplant Ethics Intern,
Program in Medicine & Human Values,
Department of Transplantation, Cali-
fornia Pacific Medical Center,
2395 Sacramento Street, 3rd floor,
San Francisco, CA 94115 (e-mail:
kylelaurentine@gmail.com)

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Organ transplantation is a well-established and highly effective treatment for end-stage renal disease (ESRD) and end-stage liver disease, generally offering patients a dramatic improvement in quality of life. The cost of this treatment, however, is astonishingly high. According to Transplant Living,¹ a Web site operated by the United Network for Organ Sharing, the average first-year billed charges in 2008 were US\$259 000 for a kidney transplant and US\$523 400 for a liver transplant. These estimates do not include the costs of lifelong immunosuppressive medication, which is also enormously expensive, often costing several thousand dollars per month. As these costs are so high, most organ recipients must rely on health insurance to pay for their transplant expenses. In cases where patients receive organs from live donors, the recipient's insurance usually pays for the donor's evaluation, surgery, and postoperative complications (for a limited period).

Unlike many other developed nations (such as France, the United Kingdom, Canada, and Australia), the United States currently lacks a universal health care system to fund medical care for all its citizens. Public insurance in the form of Medicare (a federally managed health insurance program) or Medicaid (a state-managed health insurance program) is limited to certain populations, including the elderly, the disabled, and certain extremely poor people. Many Americans turn to private insurance to pay for their health care. Nevertheless, 45.7 million persons (15.3%) were completely uninsured in 2007, gravely limiting their access to health care services.² What happens if one of these uninsured persons requires an organ transplant?

Organs are extremely scarce resources, and transplant teams avoid putting anyone who is incapable of being a good steward of the graft on the waiting list. The uninsured generally cannot afford immunosuppressant medication and thus would face graft rejection

after surgery if they lacked a sufficient supply of medication. Uninsured persons are therefore more likely than insured persons to be declined for placement on transplant waiting lists when presenting with similar clinical histories, out of fear that their financial circumstances will cause the organ to fail. Many transplant teams now include a financial coordinator to evaluate the financial suitability of potential recipients; that is, their ability to pay for evaluation, surgery, postoperative care, and lifelong immunosuppression. In short, because of the high cost of transplantation and the extreme scarcity of organs, finance and insurance are listing criteria at transplant centers in the United States.

Issues of finance and insurance also affect the practice of living organ donation. Although donor medical costs for pretransplant evaluation, organ removal, and short-term postoperative care are typically covered by the insurance of the recipient, living donors may still incur considerable expenses as a result of their participation in the transplant process. These expenses may include travel to the transplant center, lodging, incidental medical expenses not covered by insurance, dependent care, lost wages, and lost productivity at work or at home.

Although payment for organs is widely outlawed in developed nations, a movement toward reimbursing donors for the expenses they incur as part of their generous participation in the transplant process is growing. In France, transplant centers must reimburse donors for travel and lodging costs; in the United Kingdom, reimbursement by the National Health Service is permitted but not required.³ The governments of the Canadian provinces of Ontario and Manitoba have joined the government of British Columbia in deciding to reimburse living donors and their families for out-of-pocket expenses and lost wages.⁴

Postoperative insurability is another issue facing living organ donors. Although none of the insurance companies surveyed in a 2002 study claimed that they would deny living kidney donors life insurance and only 3% claimed that they would raise premiums,⁵ other evidence suggests that such may not entirely be the case. A 2007 systematic review of 23 studies dealing with living donor insurability found that 3% to 11% of kidney donors had difficulties obtaining health and/or life insurance after donation and that 11% to 13% of potential donors felt stress about their future insurability.⁶

How can transplant-related care be dispensed equitably when income and insurance status restrict the participation of certain recipients, and when unreimbursed costs and the potential for increased health and life insurance premiums may act as disincentives to poorer living donors? Is it fair for US transplant teams to turn down uninsured but medically suitable potential recipients when this would most likely not be an

issue in other developed nations with universal health insurance? This study seeks to confront these questions by examining the finance and insurance issues occurring in transplant ethics consultations performed by the bioethics staff at San Francisco's California Pacific Medical Center (CPMC). At CPMC, ethics consultations are free and can be requested by anyone. Once a consultation is requested, a bioethicist will examine the case at hand, meet with case participants, and explore relevant medical and ethical literature in order to form a recommendation or opinion. As such, transplant ethics consultations provide a lens through which to examine finance and insurance issues at the level of individual cases.

Methods

We analyzed ethics consultation reports contained in the research registry database of the Program in Medicine and Human Values, which is approved by the institutional review board at CPMC. Specifically, registry documents were examined for consultations that occurred between January 1, 2007, and June 30, 2009. Specific details about the ethics consultation reporting system are described elsewhere.⁷

These consultation reports were electronically sorted by the key word "transplant" in the medical subspecialty category (service line) to isolate only those consultations issuing from the Department of Transplantation (ie, transplant ethics consultations). The resulting registry records were then read and manually sorted by one of the authors (K.A.L., transplant ethics intern) for consultations that had an economic, financial, or insurance variable. Notably, a distinction was made between consultation files that only mentioned finance/insurance issues (a broader category) and files in which finance/insurance issues played a role in restricting medical treatment (a narrower subset of the preceding category). The narrower category of consultations where "finance/insurance restricts treatment" includes, for instance, cases in which patients lack insurance coverage for transplant or in which living donor candidates express anxiety over the cost of travel to the transplant center for their screening evaluations.

Both categories of finance-related consultations were then sorted into 3 subcategories: recipient-focused, donor-focused, or policy consultations (ie, consultations not related to patients but pertaining to general hospital policy or organizational ethics).

A faculty ethicist (K.A.B.) reviewed the sorting of all cases. If there was a discrepancy between the 2 authors, they worked together to finalize the category choice by reading and discussing the case together.

Results

Between January 1, 2007, and June 30, 2009, 218 ethics consultations were performed by ethicists

Table 1 Ethics consultations, January 1, 2007, to June 30, 2009

Type of consultation	No. of consultations	% of 218 ethics consultations	% of 58 transplant ethics consultations
Total ethics consultations performed	218	100	N/A
Total transplant ethics consultations	58	26.6	N/A
Policy-related transplant ethics consultations (ie, consultations not related to patients)	8	NA	13.8
Transplant ethics consultations mentioning finance/insurance	23	NA	39.7
Transplant ethics consultations where finance/insurance restricts treatment	16	NA	27.6

Abbreviation: NA, not applicable.

at CPMC. Of these, 58 (27%) were transplant ethics consultations (Table 1). Of these 58 transplant ethics consultations, only 8 were classified as policy consultations and the remainder pertained either to identified patients or to donors/donor candidates. Economic, financial, or insurance-related variables were present in 23 (40%) of the transplant ethics consultation files. Within these 23 records, 16 described the restriction or limitation of medical treatment for reasons rooted in finance or insurance. These files represent 28% of all transplant ethics cases at CPMC during the given period.

Of the 23 transplant ethics consultation files merely mentioning a finance/insurance variable, 11 were recipient-focused, 10 were donor-focused, and 2 were policy consultations (Table 2). Of the 16 transplant ethics consultation files describing restriction or limitation of treatment because of finance/insurance issues, 8 were recipient-focused and 8 were donor-focused (Table 3). No policy consultations were in the “restriction of treatment” category because policy consultations do not directly involve patients.

The 16 cases in the narrow “restriction of treatment” category are presented in Table 4, grouped by case type as described in the legend. Most of the cases involving potential organ recipients (numbers 1-6) described financial barriers that limited the patients’ access to transplantation. One of the potential-recipient cases, however, related to organ commerce (number 5). Not surprisingly, both cases involving people who had already received an organ focused on access to immunosuppressive medication (numbers 7 and 8). Most of the donor candidate cases (numbers 9-15) involved psychosocial issues that called into question the donor candidate’s suitability for donation. However, 1 donor candidate (number 13) was psychosocially suitable for donation but expressed concern about the potential for increasing insurance premiums after the surgery. Only one case involved a person

who had already donated an organ (number 16) and it involved unusual elements: a donor with a major psychiatric history and the accidental death of the transplant recipient.

A quarter of the cases in the “restriction of treatment” category involved illegal aliens (numbers 1, 7, 9, and 15).

Discussion

More than a quarter of all transplant ethics consultations performed at CPMC between January 2007 and June 2009 involved the restriction of transplant-related interventions for reasons rooted in insurance or finance. We argue that the influence of these variables is most likely unique to the United States (among developed nations). As the United States lacks universal health insurance and cannot guarantee health care to all its citizens, individuals seeking an organ must rely on personal insurance policies, cash, or equity to proceed through the transplant process, and this inevitably favors the wealthy over the poor for getting on the waiting list. Because transplantation and immunosuppressive therapy are so costly, persons who are underinsured or completely uninsured are hindered in their access to this lifesaving technology. Patients who receive transplants and subsequently lose insurance are at risk for graft rejection (eg, cases 7 and 8 in Table 4) due to inability to access immunosuppressant medication. Such cases illuminate why transplant centers are reluctant to list poor and uninsured patients for transplantation when they initially present for evaluation.

From the 1990s onwards, several studies have identified certain population groups as more likely to receive transplants than others. One group of researchers⁸ retrospectively analyzed rates of heart and liver transplantation from the late 1980s and found that persons with the highest ability to pay were

Table 2 Transplant ethics consultations mentioning finance/insurance, January 1, 2007, to June 30, 2009

Type of consultation	No. of consultations	% of 23 transplant ethics consultations that mentioned finance/insurance
Recipient-focused	11	47.8
Donor-focused	10	43.5
Policy (not patient-related)	2	8.7

much more likely to receive transplants. The same researchers also found that racial minorities were one-fourth as likely as whites to receive a heart transplant and about half as likely to receive a liver. In another study from 1993, researchers found that female dialysis patients with ESRD had a 28% lower kidney transplant rate than men, and that black patients had a 61% lower rate than whites.⁹ Also, for each US\$10 000 increase in patient income, the transplant rate rose by 16%. Notably, this study determined that these sociodemographic disparities in access to transplantation were not statistically accounted for by comorbidity factors that might also affect access.

Results of later studies indicated that sociodemographic barriers are active at multiple stages of the kidney transplant process (from expressing interest to receiving a graft)¹⁰; that race, insurance type, and educational attainment all affect the odds of preemptive listing¹¹; and that California patients with ESRD on Medicare insurance are more likely to be listed than those on Medicaid (who are disproportionately female, black, diabetic, and impoverished).¹² A 2008 study also established that US organ recipients are approximately 4 times as likely as other inpatients to be insured.¹³ Possible causes of these health care disparities among transplant recipients include biological variables (eg, poor antigen matches); fear of the financial burden of transplantation; geographic isolation; cultural, linguistic, and educational barriers; and subjective biases against certain populations on the part of providers.

Even those who wish to participate as living organ donors may face limitations (up to and including the inability to donate) as a result of their lack of financial resources. Willing and suitable donors may decline to participate when faced with the threat of rising insurance premiums (eg, case 13). The unreimbursed, non-medical expenses that occur as part of the donation process¹⁴ may also dissuade donor candidates from following through with donation (eg, case 10). It is reasonable to assume that the potential costs of living donation present a greater relative burden to the poor, making it easier for wealthier donors to proceed through the donation process.

Table 3 Transplant ethics consultations where finance/insurance restricts treatment, January 1, 2007, to June 30, 2009

Type of consultation	No. of consultations	% of 16 transplant ethics consultations where finance/insurance restricts treatment
Recipient-focused	8	50
Donor-focused	8	50
Policy (not patient-related)	0	0

In 2006, Clarke et al¹⁵ did a systematic review, analyzing 35 studies from around the world to examine the costs incurred by living kidney donors. In a retrospective study¹⁶ of kidney donors included in the review, 11% of respondents found donation to be a burden; average costs were US\$579. In the same study, the researchers also found that loss of income during recovery from surgery was stressful for 14% of donors. Income loss was also reported in a more recent study.¹⁷ Results of another study¹⁸ from the review indicated that 99% of US donors faced transportation costs and 88% faced lodging costs. In a 1997 study¹⁹ on the psychosocial impact of kidney donation, 23% of respondents reported experiencing negative financial consequences from donation. In the United States, transplant centers and national donor assistance funds may pay donors for their expenses, but are not required to do so.²⁰ Recently, Sickand et al¹⁴ reported that Kuwait does not allow reimbursement of non-medical expenses, and some countries will not reimburse if the donor is a nonresident. If they remain unreimbursed, these expenses may serve as disincentives to living donation, penalizing an altruistic and lifesaving act.

Furthermore, certain transplant centers may take insurance status into account when evaluating donor candidates, particularly when other psychosocial issues increase the risk of postoperative complications (eg, cases 9 and 11). According to a NATCO survey cited in a 2006 NATCO position statement,²¹ only 4% of responding transplant centers require living donor candidates to have personal health insurance in order to donate. It is possible, however, that many more centers weigh insurance status as a factor in their psychosocial evaluations of donor candidates, even if they do not explicitly forbid uninsured donors.

Awareness of the financial burdens faced by living donors has recently increased. Reimbursement programs are expanding in Canada⁴; in the United States, the National Living Donor Assistance Center allows donors to apply for up to US\$6000 of reimbursement for travel, lodging, and incidental expenses incurred

Table 4 Ethical issues in cases where finance/insurance restricts treatment, January 1, 2007, to June 30, 2009

Case ^a	Clinical issues
1 Potential kidney recipient	Focal glomerulosclerosis; on dialysis; seeking transplant from live related donor
2 Potential liver recipient	Fulminant liver failure due to intentional acetaminophen overdose; seeking to be listed for transplant
3 Potential liver recipient	End-stage liver disease associated with hepatitis C; seeking to be listed for transplant
4 Potential liver recipient	Hepatocellular carcinoma and hepatitis B; seeking to be listed for transplant
5 Potential kidney recipient	End-stage kidney disease; on dialysis; seeking transplant from live unrelated donor
6 Potential liver recipient	Fulminant liver failure due to inadvertent acetaminophen overdose; physicians seeking to list patient for transplant
7 Liver recipient	After liver transplant; episodes of rejection due to inconsistent immunosuppressant regimen
8 Liver recipient	After liver transplant; episodes of rejection due to inconsistent immunosuppressant regimen; history of substance abuse; bipolar disorder
9 Kidney donor candidate	Healthy adult; seeking to donate to brother
10 Kidney donor candidate	Healthy adult; seeking to donate to a stranger via a chain donation
11 Kidney donor candidate	Healthy adult; seeking to donate to grandmother; daily marijuana use; underage alcohol use
12 Kidney donor candidate	Healthy adult; seeking to donate to a stranger found on the Internet
13 Kidney donor candidate	Healthy adult; seeking to donate to a stranger
14 Kidney donor candidate	Healthy adult; seeking to donate to brother
15 Kidney donor candidate	Healthy adult; seeking to donate to coworker's relative
16 Kidney donor	After kidney donation; panic disorder and depression

^a Potential kidney/liver recipient, someone who is under evaluation for kidney or liver transplant candidacy; kidney/liver recipient, someone who has received a kidney or liver transplant; kidney donor candidate, someone who has expressed interest in donating a kidney; kidney donor, someone who has donated a kidney.

through the donation process.²² This program is funded by the US government through the Health Resources Services Administration. The American Foundation for Donation and Transplantation is also expanding the donor insurance program offered by its Living Organ Donor Network (LODN).²³ Trans-

plant centers may purchase the LODN insurance (which consists of life, disability, and catastrophic health care policies) for their donors and their families with a 1-time payment of US\$550 per donor. The insurance is also available for donors to purchase directly from LODN. As of November 2008, only 4

Ethical issues	Outcome
Patient was an illegal alien who borrowed a friend's identity and insurance documents in order to remain in the United States and receive medical care.	Patient was not reported to immigration authorities. Hospital lost contact with patient.
Patient's wife was not acting as an appropriate surrogate. Patient had no insurance and spouse had delayed completion of insurance application that was necessary for patient to be listed for transplant.	Bioethics intervention led to the appointment of a new surrogate. By that time, patient was too ill for surgery and died.
Patient's nurse considered it unreasonable for transplant team to require State public health-insured patients to have \$5000 on hand to cover post-transplant expenses such as lodging and food, because such patients are very poor at baseline.	Patient did not follow through with evaluation process. Declined for listing for medical, psychosocial, and financial factors.
Patient displayed indifference to medical situation and was noncompliant with medication. Patient had unsupportive family and no insurance.	Declined for listing due to psychosocial and financial factors. Hospital lost contact with patient.
Patient intended to buy kidney from foreigner with whom he lacked any relationship. Donor candidate might not have insurance in native country.	Removed from living-donor transplant program. Remains in deceased-donor program.
Patient's insurance provider refused to cover transplantation because patient reportedly had abused alcohol recently.	Patient remained critically ill for several weeks and died in the intensive care unit.
Patient was an illegal alien. Despite desire to be compliant with immunosuppression, patient had run out of medication due to poverty and lack of insurance.	Social worker helped patient get insurance. Patient is compliant with immunosuppression and receives follow-up care.
Patient was released from prison with only a 30-day supply of medication and no insurance. Patient was poor but ineligible for State public health insurance.	Patient eventually acquired insurance and resumed immunosuppression. Hospital lost contact with patient.
Candidate was an illegal alien. Candidate had no insurance and limited finances.	Candidate put on hold for financial reasons.
Candidate lived out of state and could not afford travel. Candidate's nephrologist wondered if recipient could ethically pay travel expenses, or if hospital fund should pay.	Candidate did not pursue workup at California Pacific Medical Center, although a hospital donor assistance fund does exist.
Candidate lacked insurance and exhibited low maturity level and limited understanding of financial burdens of donation.	Deferred as candidate for 1 year.
Candidate concealed criminal history from transplant center, misused funds from the National Living Donor Assistance Center, and asked potential recipient for money. Also lacked insurance.	Declined as candidate.
Candidate concerned about higher insurance premiums after donation.	Candidate did not pursue donation due to threat of rising insurance premiums.
Candidate offered conflicting facts regarding probation history, insurance coverage, and financial situation.	Candidate put on hold.
Patient was an illegal alien. Was possibly receiving compensation or coercion to donate. Lacked insurance.	Declined as candidate.
Donor's recipient died accidentally soon after transplant. Concerns in light of donor's psychiatric history. Transplant staff wondered if recipient's insurance could still cover donor's treatment costs, should donor require future care.	Social worker followed up with donor who reported no mental health consequences after recipient's death. Team to bill recipient's insurance for any future costs.

hospitals had taken part in the program, insuring 517 donors. But demand for donor insurance appears high. The NATCO survey²¹ states that 82% of responding transplant centers believe that the government should provide catastrophic health care coverage for living donors.

In addition to the poor and the uninsured, researchers in this study identified 2 other vulnerable populations: illegal aliens and ex-convicts. Our ethics consultations were notable for illegal aliens seeking both to receive and to donate organs (cases 1, 7, 9, and 15). These cases are ethically problematic because

these individuals are present in the United States illegally and thus face the constant risk of deportation—potentially to a home country where they cannot obtain adequate postoperative health care for financial or logistical reasons. These individuals also tended to be poor and to work in manual labor jobs that are unlikely to provide disability pay or medical leave. Linguistic, cultural, and educational barriers also potentially limit the ability of health care providers to achieve informed consent for complex medical procedures on illegal aliens.

Also ethically troubling was our case involving the former prisoner (case 8) with limited access to immunosuppressant medication. Once the patient was released, the prison system took little if any responsibility for organ stewardship or referral to proper post-transplant care. Specifically, it provided a very limited supply of medication and sought no assurances that the patient would gain access to health insurance or continued immunosuppressive medication. There seems to be a lack of continuity of care between the US prison health care system and mainstream health care programs (whether government-sponsored or private). This placed the patient in case 8, who was dealing with other psychosocial issues and a strained financial situation, at increased risk for graft rejection.

Limitations

This was a single-center study. Other centers may have different policies regarding the role of finance and insurance issues in selecting donors and recipients for transplantation and may encounter different problems or concerns. No consistent policy has been established among US transplant centers.

Notably, the ethics consultation registry includes only those donor candidates and patients for whom a formal ethics consultation was requested. The ethicist attends weekly transplant committee meetings in which patients and donor candidates are discussed in a team setting with physicians, social workers, nurses, dietitians, and a financial coordinator. Finance and insurance variables often arise at these meetings; however, these discussions often do not proceed to formal ethics consultations and thus are not recorded in the consultation registry. Therefore, it is likely that the pool of patients and donor candidates who are affected by financial and insurance-related matters is much larger than the group included in this study.

Conclusions

The lack of universal health insurance in the United States is an impediment to the allocation of organs in a truly equitable manner. Clearly, the shortage of donor organs limits access to transplant; however, US transplant teams will continue to favor listing insured patients over uninsured ones, for the simple reason

that a transplanted graft cannot survive without expensive immunosuppression. Universal insurance coverage would help to level the playing field and allow the medical variables to play a more prominent role in the wait listing process. Additionally, as long as insurance premiums threaten to increase and incidental costs remain high, poor donor candidates will be disproportionately hindered from donating. Short of US health care reform, it seems impossible to eliminate all insurance- and income-based disparities in health care, despite the beneficence and commitment to justice of transplant teams and ethicists.

There are, however, steps that can be taken at both the legislative and the transplant center level to maximize equity and limit disparities. For living donors, certain solutions are obvious. First, in order to remove financial disincentives against donation, the United States should join France and parts of Canada in requiring that donors be reimbursed for all expenses incurred as part of the donation process. Second, the government should protect donors from postoperative insurance discrimination by forbidding insurance companies to charge higher premiums (unless they can empirically prove that these individuals are indeed higher risk patients with increased health care costs). Third, transplant centers and governments should seek to establish donor insurance programs along the line of the LODN insurance policy so that, in return for their beneficent act, donors are guaranteed to be protected against catastrophes and complications.

Solutions to the sociodemographic disparities on the recipient side are more difficult to articulate and legislate. Transplant teams can cultivate greater awareness of the barriers and biases that limit access for certain populations of patients. Greater efforts can be made to provide transplant-related education to patients in all racial and socioeconomic groups. But as long as the United States commodifies health care, and by extension transplantation, some patients will not be able to afford it.

Ultimately, transplantation of uninsured patients remains ethically problematic. When faced with case number 6—a parent in fulminant liver failure from an accidental acetaminophen overdose—physicians at our center vehemently pursued listing for transplant until the insurance company refused to provide coverage for transplantation, citing a vague prior history of alcohol abuse. The patient eventually died in the intensive care unit. Without insurance, her access to immunosuppression and follow-up care seemed impossible, putting a potential transplant (even one provided free of charge) at risk of total failure. It is not difficult to see the wrenching dilemma that cases such as these present for physicians and nurses. Despite having sworn to heal and protect their patients, clinicians must subordinate their immediate moral impulses to

the financial realities of the situation. One of the most difficult and essential roles of bioethicists is to balance the beneficent desire to help all patients with the economic pragmatism that allows ethical allocation of scarce and expensive technologies like transplantation.

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