Incentive Models to Increase Living Kidney Donation: Encouraging Without Coercing

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Kidney transplantation is a superior treatment strategy than chronic dialysis for end-stage renal disease patients. However, there is a severe shortage of cadaveric kidneys that are available for transplantation. Therefore many patients are turning to living donors. We describe four models of incentives to improve rates of living kidney donation: the market compensation model, the fixed compensation model, no-compensation model and the expense reimbursement model. We discuss the advantages and disadvantages of each of these models. Any incentive to improve rates of living kidney donation must be accompanied by safeguards. These safeguards will prevent living donors from being viewed primarily as a resource for transplants. These safeguards will also prevent vulnerable individuals from being coerced into donation and will monitor long-term outcomes of donors using a donor registry. We recommend the use of the expense reimbursement model along with these safeguards, in order to increase rates of living kidney donation.

Key words: Incentive models, safeguards for donation, living kidney donation

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Recent evidence indicates that even if all potential cadaveric organ donors actually donated their organs, the supply of kidneys would be insufficient to meet the growing demand (1). Despite the enormous demand for cadaveric kidneys, the number of renal transplants from cadaveric donors performed in the United States has remained relatively unchanged at approximately 9000 per year for the last 7 years (2). A significant increase in this number of donors over the next few years is not expected.

Because transplantation is both more effective and less costly than long-term hemodialysis, the shortage of cadaveric organs results in both increased mortality among end-stage renal disease (ESRD) patients and increased Medicare expenses (3, 4). The prevalence of ESRD in 1998 was 397,971 persons with associated treatment costs that exceeded $16 billion cumulatively. These totals will exceed 650,000 persons, and $28 billion by the year 2010 (5).

Current proposals to alleviate the shortage of cadaveric kidneys are unlikely to resolve the problem of the shortage of kidneys in the next few years (6, 7). One such proposal is a Georgia state program that discounts renewal fees for drivers’ licenses for organ donors (8). Another proposal is a Pennsylvania state program that gives $300 in vouchers to cadaveric donor families (9) or living donors (10). Though xenotransplantation, the use of stem cells to grow cells and tissues, and artificial organs all hold promise, there is presently no evidence that these methods might soon resolve the shortage of kidneys.

Living organ donation not only promises to increase the pool of donor organs, but may improve the overall efficacy of transplantation because organs harvested from living donors typically produce better outcomes for recipients. The half-life of renal allografts from living donors is 21.6 years, compared with 13.8 years among allografts from cadaveric donors (11). These advantages are even more pronounced among patients receiving transplants prior to initiating dialysis (12–15).

One key obstacle to expanding the use of living donors is the risk of developing a market for human organs. There is a grave concern that a blackmarket already exists among those seeking to provide and receive organs in the United States and in other nations, and that this market will expand if there is a greater reliance on living sources of organs. In light of this concern, it is important to explore what options are available for developing incentives for living donation without compromising donor safety and autonomy.

Commodification of Kidneys

Affluent patients seeking kidney donations can now circumvent the long waiting list by buying their kidneys from brokers who locate overseas ’vendors’ willing to sell their kidneys (16–18). Finding brokers using American Web sites is becoming increasingly easy, and some brokers are now offering kidney transplants at major U.S. hospitals (18, 19).
Because kidneys are being sold for between $18,000 and $145,000 (18,19), some now view them analogously to other commodities that are available only to the rich. Such sales of kidneys through these brokers are illegal under the U.S. National Organ Transplant Act (NOTA) (20).

Besides relying on waiting lists or brokers, patients are turning to spouses, friends and strangers as possible donors. In many U.S. transplantation centers, the number of kidneys transplanted from living donors has surpassed the number obtained from cadavers (21). Some experts suggest that ‘under the table’ financial exchanges are an increasing presence in donations from friends and family (22). Advances in immunosuppressive therapy have made unrelated living donation possible, and transplant centers and organ procurement organizations are now using unique schemes to match willing donors with immunologically compatible recipients so as to maximize the procedure’s utility (23). As a result, it is now critical to evaluate different incentive programs for promoting living kidney donation without furthering the commodification of these organs.

**Four Different Models of Incentives for Living Donation**

There have been many proposals to create more generous incentives for organ donation (24–26). Most proposals can be placed into four different models, analogously to previously proposed models for the payment of research subjects (27). We first describe the four models and then consider the benefits and drawbacks of each of these models in an effort to identify the most ethical and efficient approach to removing barriers to donation.

**Market compensation model**

The market compensation model is based simply on the laws of supply and demand. As in other markets, the natural pressures of supply and demand would be allowed to determine whether and how much potential donors should be paid for donating a kidney. Some proponents of the market compensation model have proposed granting U.S. citizenship to any potential vendor from another country in exchange for a kidney or granting exemption from all future federal taxes to all U.S. donors (24). In poorer countries with many indigent donors, the payment for a kidney can be as low as $1000–$3000 (16). Given the enormous demand for kidney allografts, the market system would allow for large payments or other significant gains for donors. At the same time, the market system would offer little or no payment for altruistic donors. Therefore, it is possible that the market compensation model would deter altruistic donation.

**Fixed compensation model**

This model is based on a fixed payment for all donors. The payment is for the time, effort and the discomfort or potential side effects of donation. The fixed compensa-

**Expense reimbursement model**

The expense reimbursement model would allow payment to cover donors’ expenses only. These donor expenses could include lost wages and the costs of travel, meals, day care, parking and lodging that are related to the transplant process. The underlying principle of the expense reimbursement model is that the donor should not make a financial profit through donation, but also should not incur financial loss by virtue of their contribution. Therefore, the expense reimbursement model allows for compensation of lost wages and any expenses incurred due to the donation.

The expense reimbursement model differs from the other models in many ways. It allows for differing amounts of payments to donors based on the donor’s lost wages and expenses. At the same time, the expense reimbursement model prevents the donor from profiting financially from the process of donation. This model does not allow higher payments for any increased discomfort experienced by a particular donor or other ‘non-financial expenses’ incurred by the donor (27).

**No-compensation model**

The no-compensation model is utilized in the current legal system of kidney donation in the United States. This model originates from beliefs that donation should be based purely on altruism, and that the altruistic donor should be willing to incur any personal expenses associated with kidney donation. Because the model does not allow for any form of payment, it is possible that donors may become financially disadvantaged or risk losing their jobs if they choose to donate. This no-compensation model must be reformed because it fails to recognize the important contributions of donors to our health-care system and has not created an adequate supply of organs in the United States.

**Discussion of the four models**

**Market compensation model:** The market compensation model has potential advantages and disadvantages. Market forces will likely provide adequate number of donors in a short-time period. However, there is some concern that people may withdraw from altruistic donation if a market is created. There could also be opposition from religious and civic groups related to concerns about commodification. In the United States, there may be particularly
The market compensation model has many other disadvantages. Given the enormous demand for kidney allografts, market forces will drive up the payments to large amounts. Such large payments may drive donors to overlook the potential risks and discomforts of donation. Such a system being risks coercive would degrade the altruism upon which the current system of living and cadaveric organ donation is based. Under such a coercive system it is possible that the poor and vulnerable could be exploited. Also, this model of payment might also lead some candidate donors to withhold important health information in order to donate and thus, receive large payments. Experience with market compensation models currently utilized in many poor countries shows that they result in poor outcomes among donors (32–34) and recipients (35–38).

Another potential disadvantage of the market compensation model is highlighted by past experiences with monetary incentive systems for blood donation in wealthy Western countries. Paid donors of blood and blood components contributed significantly to the incidence of hepatitis because monetary rewards brought unsuitable donors forward (39–41). Similar concerns about safety have been raised for both sperm and eggs that have been purchased for use by infertile persons (42–44). Lastly, for a market compensation model to be legal it would require significant change in policy including repealing National Organ Transplant Act, the existing federal law (20).

No-compensation model: There are potential advantages and disadvantages of the no-compensation model. The no-compensation model is able to maintain a high level of moral and ethical framework. The disadvantage is that it is not fair to donors because it financially penalizes them for donating. This model may be particularly unfair to poor donors who may not be able to afford the financial penalty associated with donating their kidney.

Fixed compensation and expense reimbursement models: There are potential advantages and disadvantages of the fixed and the expense reimbursement models. In both these models, market forces are unlikely to drive up the payments or lead donors to withhold important health information in order to donate. Under the fixed and expense reimbursement models, donors cannot adequately profit from the donation process. Thus, both these models prevent monetary inducement from being the principle reason to donate while minimizing the financial loss to the donor. One potential disadvantage of the fixed and the expense reimbursement models is that unlike the market compensation model, they are unlikely to provide a large number of donors in a short-time period.

Why the expense reimbursement model should be favored
We favor the use of the expense reimbursement model for three main reasons. First, the expense reimbursement model greatly reduces ethical concerns about undue inducement. Because none of the potential donors can have significant financial gain from donating. They will presumably choose to donate because doing so is attractive to them in some other way and altruism is likely to be a significant motivator. Because the system would not preferentially target lower income donors, risks for exploitation are reduced.

Second, although the system does not provide uniform compensation to all donors, it is standardized to ensure that all donors retain their personal financial status after donation. In contrast to the fixed compensation model, this would not create large barriers for high income donors to participate in organ donation.

Adopting the expense reimbursement model would likely require the universal adoption of the amended Family Leave Act in order to ensure adequate opportunities for organ donation. The amended Family Leave Act allows for 30 days of paid leave for donors who are federal employees (45). If private employers do not adopt the amended Family Leave Act, it will actually require financial sacrifice for donors who are not federal employees with extended paid leave. The only people who would not incur additional expenses if their time were not reimbursed would be those who are unemployed. When both lost wages and expenses are compensated for, donors will be paid unequally for the same contribution to society. However, we believe such a disparity exists because each individual has a different opportunity cost. Opportunity cost in this case is defined as the benefits (e.g. wages) lost when individuals donate their kidney. Thus, a highly paid executive may have a higher opportunity cost than a minimum wage worker.

The disparity in expense reimbursement is acceptable as long as both the employed and unemployed are eligible for life and disability insurance. Under the expense reimbursement model, the self employed could be paid a standardized daily wage. This standardized daily wage would be similar to the wages paid to those on jury duty.

There is some evidence that the expense reimbursement strategy is safe. An expense reimbursement strategy has been used for living kidney donors in Sweden with 80% of donors reporting compensation for expenses and loss of income. Long-term follow-up of these donors since 1964 has shown that donors do not regret their donation and report a good quality of life post-donation (46). These compensated donors did not have deterioration of renal function any more rapidly than what may be expected with aging (47).

Lastly, the federal law allows for the reimbursement of donors’ expenses such as travel and lodging. Title 42 of
Safeguards for Living Donors

Because the protection of donors must be paramount when introducing incentives for donation, any proposal to do so must include safeguards to protect and respect the donors. These safeguards should ensure that organs are used only for appropriate means, monitor the procurement of organs to prevent unjust practices and monitor donor outcomes.

Restrict use of organs

Any donor incentive program should ensure that the living donors are not viewed merely as a resource for transplants. All decisions to donate should be made freely and without coercion or financial exploitation. Donors should be fully informed about the risks and benefits of all procedures by persons who are not caregivers for potential recipients or paid on the basis of the number of donors obtained. To limit exploitation of poor vendors from other countries, we suggest that only permanent U.S. residents or green card holders be eligible to donate. This would help ensure proper donor follow-up and minimize donor risk in returning to a country without access to adequate post-transplant care. An exception to this residency requirement could be made for first degree relatives who are able to reside in the United States for a short-term follow-up period.

To ensure that the care of the potential donors is not compromised by the appealing possibility of a successful transplant, donors must not be asked to donate in clinically hopeless situations. Potential donors must be declared ineligible if underlying medical conditions clearly place them at increased risk of mortality or serious morbidity from complications of the procurement itself or from life with a single kidney.

Safe guards to prevent vulnerable individuals from being coerced into donation

It is possible that any individual, including a family member, could be coerced into donating a kidney. Such coercion has been described when vulnerable family members are chosen based on blood type and cross matching (32). Therefore donors should be "competent, medically and psychologically stable, and fully informed of the risks and benefits to themselves and to the potential recipient" (48). At many transplant centers both the recipient and the potential donors are informed that results of the donor’s evaluation will only be revealed to the donor. In such a situation, the donor has an easy ‘out’ by claiming that the blood type or the cross-match did not allow for donation. Transplant centers should provide committed donors with every opportunity to change their mind up until the time of the surgery itself (48). When donors choose to opt out, the medical directors should provide the potential donor with the option of being declared ‘inappropriate for medical reasons’ so that the relationship between potential donor and recipient is not adversely affected.

Every potential donor needs access to independent counsel and advice. All programs should have a donor advocate available whose sole goal is to protect donor interests as well as provide ongoing support throughout the donation and recovery period. The key to an effective advocate donor is having an advocate who is neutral to the decision of donation (49). Also the donors’ autonomy to donate despite potentially increased risk to their health should be weighed against medical judgment. Donors’ autonomy should not override medical judgment (50,51).

Monitor long-term outcome of donors using a Donor Registry

All living donors should be encouraged to participate in long-term follow-up using a National Donor Registry. As incentive to participate, members of the Donor Registry should be eligible for a national insurance plan that provides life and disability insurance for all living donors (7,52). Only a few transplant centers are offering such life and disability insurance for their living donors (7,52). The long-term follow-up must document the negative and positive medical and psychological outcomes associated with donation (49).

Through the Donor Registry, living donors would obtain life and disability insurance to compensate for any catastrophic medical expenses and long-term follow-up as part of the quality control measures of the transplant process. Such compensation for expenses of donation and quality control measures are allowed by the National Organ Transplant Act (20). This life and disability insurance ensures that donors do not incur catastrophic medical expenses as a result of donation and would ensure that donors have an opportunity to receive proper medical treatment should complications arise. Such a registry and insurance plan could be
modeled after the National Marrow Donor Program efforts in safeguarding their donors. The National Marrow Donor Program provides life and disability insurance for all live donors of bone marrow.

**Future Research**

In the future, it is important to study further the impact of the expense reimbursement model. There are several types of research that would be helpful in refining this model. First, it is critical to determine whether the expense reimbursement model will create an adequate supply of organs. The state of Wisconsin has offered such an expense reimbursement through a $10,000 state tax credit to its residents. The effect of this legislation on the number of living donors can be determined by comparing trends before and after its passage. Second, it is critical to evaluate the extent to which the offers of compensation affect the quality of donors’ informed consent. Third, it is important to evaluate the long-term psychological, economic and physical status of donors who are paid through the compensation model. Finally, it is important to study whether expense reimbursement leads to donation of a disproportionate number of ‘vulnerable’ or poor donors. Little is known about the effects and costs of reimbursing different expenses. For the present, the expense reimbursement model, coupled with a commitment to ethical treatment of transplant donors and recipients will most effectively balance the increasing need for kidney donors with adequate safeguards for living donors who make such treatments possible.

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