Removing Financial Disincentives to Organ Donation: An Acceptable Next Step?

Alexander C. Wiseman

The numbers are all too familiar, and are repeated so often in the arena of kidney disease that they start to lose meaning, becoming slightly hollow, empty, and spoken with a feeling of resignation. There are >90,000 people on the kidney transplant waiting list and this number is growing. The number of kidney transplants performed annually is only one-fifth of the waiting list overall. The mortality rate while awaiting transplant is 7% per year, and there are recent concerns that donation rates are actually falling (1). It is in this context that novel methods to increase organ donation must be considered thoroughly and thoughtfully.

A number of efforts to increase deceased donation have been implemented over the past decade to address these grim statistics. These include the expansion of donor registries at departments of motor vehicles, laws that prevent family members from reversing the stated wishes of an individual who has consented to be an organ donor, initiatives supported by agencies of the US Department of Health and Human Services to improve practices in obtaining family consent, and encouragement in utilization of older donors, as well as establishment of policies that permit utilization of organ donors who meet the definition of death via circulatory arrest rather than brain death have been widely accepted over the past decade (2,3).

Similar innovations have been made in expanding living donation. Desensitization programs have been increasingly utilized to permit blood type and/or HLA-incompatible pairs to proceed with transplantation (4). The establishment of kidney exchange networks that assist willing but incompatible (blood type or HLA type) donors to help their recipient-to-be is growing exponentially (5). Altruistic donors who wish to donate but have no particular person in mind have been gradually accepted and are now welcomed as a means to help the organ shortage and to help in the initiation of paired kidney chains (6).

With these very important advances, where are we now? These efforts thus far have been only modestly effective at sustaining, rather than dramatically expanding, organ donation (1). With this perspective, many individuals (in health care, policy making, and patient advocacy) have raised the question of whether financial incentives should be considered. The feasibility of incentive programs has been established in other countries. In Iran, for example, a system of regulated paid donation has resulted in a near-elimination of the waiting list, with the important recognition that kidney transplantation is predominantly performed using unrelated living donors (7). A cost analysis comparing expenses of dialysis and transplantation demonstrated that in the United States, a cost savings of >$90,000 could be achieved for each recipient if living donation could replace dialysis (8). The authors suggested strategies in which this savings could be utilized to support and encourage living donation (9), which was recently elaborated on in an international workgroup meeting dedicated to the subject (10).

When it comes to payment for organ donation, just because it can be done does not fully address whether it should be done (11). Ethical arguments against regulated payments for living kidney donation include the extent to which financial incentives may interfere with truly informed consent due to changes in perception of risk, the potential that lower-income individuals will be disproportionately motivated by financial incentives and increasingly placed in positions of subservience to a wealthier population, and the risk that financial incentives will negatively affect rates of altruistic donation. Interestingly, a recent survey of residents in the greater Philadelphia area suggest that lower-income individuals are more likely to be willing to donate a kidney both altruistically (without payment) or with a hypothetical incentive of $10–100,000 than higher-income counterparts, but did not find evidence that payments negatively influence an individual’s willingness to altruistically donate (12).

It is with these issues at hand that Barnieh and colleagues report a novel perspective on public attitudes toward payments to organ donors in this issue of CJASN (13). They performed a survey of Canadian citizens using a web-based questionnaire to determine if financial incentives were considered acceptable and would alter individual perceptions for both deceased and living kidney donation. The survey targeted not only health care professionals and patient groups that are tied to nephrology care but also the general public. They report a general acceptance of the concept of financial incentives for both deceased (approximately 70%) and living (approximately 40%) donors, but it is important to distinguish the type of incentive that was supported, and what type was viewed less favorably. Interestingly and importantly, very few found
reimbursement of expenses for living donors (the removal of disincentives) to be unacceptable (1.1%–5.7% within subgroups). Reimbursement of expenses and lost wages was strongly supported by a majority of respondents, whereas a direct payment was supported by <30% of respondents overall (and supported by only 15% of health care workers). For deceased donation, reimbursement of funeral expenses was most strongly supported, whereas a direct payment was again only endorsed by <30% of respondents (lower for health care professionals). When considering monetary incentives on decision making, a payment of $10,000 led 54% of public respondents who were previously unwilling to consider living donation to consider donating to a relative. When the amount of reimbursement was increased to $100,000, this number did not increase dramatically (to 62%) but an increase in willingness to donate to an acquaintance or stranger (from 6% to 16%) was noted.

Given the ethical issues at hand, and the theoretical concerns of monetary incentives negatively affecting existing altruistic living donation, is the “majority rule” identified in this survey and other surveys an acceptable milestone to test the waters of financial incentives (or at least removing financial disincentives) for organ donors? Or should we expect that a large minority of dissenters represent potential for trouble on the horizon for any proposal or pilot program that hints of financial reimbursement? On the basis of the findings of this survey, it is apparent that elimination of financial disincentives has broad support and can and should be considered. Beyond this step, the minority grows larger, reflecting our society’s discomfort (and probably reflecting our collective ethical position) and would likely result in a general backlash or “filibuster” of any proposed attempts to consider these further.

Removal of financial disincentives for living donation therefore appears to be the next most ethically accepted and logistically feasible step. Currently, a number of state-run programs and one federally funded program, the National Living Donor Assistance Center (NLDAC; www.livingdonorassistance.org), have made strides in this regard. The NLDAC provides up to $6,000 to assist with travel, lodging, and meals related to the evaluation, surgery, and follow-up for donors and up to two accompanying persons. There are income and other restrictions placed on eligibility for this reimbursement, but indeed this is a necessary and valuable program, and an important step in eliminating the financial disincentive of donating. The next step in this process would be to eliminate other financial disincentives such as reimbursement of lost wages (or potential wages) during the surgical recovery period, and to eliminate the eligibility restrictions currently placed upon these reimbursement programs. Each living donor should be treated equally and fairly, such that all donors have the peace of mind that they are not at risk of losing their job, or must use accumulated vacation and sick time, or lose the opportunity to seek employment, or are otherwise penalized for donating and undergoing the attendant postoperative recovery period. Implementation of a national health insurance system notwithstanding, donors should at a bare minimum be guaranteed adequate medical insurance coverage to cover the period of time of donor follow-up mandated by the Organ Procurement and Transplantation Network/United Network of Organ Sharing as a contracted entity of the Health Resources and Services Administration, which currently is 2 years. These disincentives can be quantified and reimbursed, and an argument could be made that this should occur regardless of the effect on organ donation. Pilot programs could be established to assess the latter, but the goodwill of living donors should be met with support and encouragement regardless of the potential upside of increasing organ donation.

The concept of removing disincentives for deceased donation is less clear-cut, because reimbursement of funeral expenses, tax credits, and so forth, although broadly supported within the survey of Barnieh et al. are not really removing disincentives and would be better defined as “gifts”. However, there are many improvements that can be made in this arena as well. Barnieh et al. report that of the Canadian public respondents living in areas with a deceased donor registry, only 56.7% were aware of the existence of such a registry. In the United States, additional improvements can be made in public education—such as a 5-minute iPod video, which increased the odds of organ donor consent by two-fold at departments of motor vehicles in Ohio (14)—and in the recognition of an individual’s choice to be an organ donor as irrefutable and not subject to authorization by the deceased donor’s family. Ultimately, the decision of the organ donor, whether living or deceased, should be respected and the donor should be provided every opportunity to give to society without absorbing more risk than the act of donation itself.

Disclosures

None.

References


Published online ahead of print. Publication date available at www.cjasn.org.