Reciprocating living kidney donor generosity: tax credits, health insurance and an outcomes registry

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Abstract

Kidney transplantation significantly improves patient survival, and is the most cost effective renal replacement option compared with dialysis therapy. Living kidney donors provide a valuable societal gift, but face many formidable disincentive barriers that include not only short- and long-term health risks, but also concerns regarding financial expenditures and health insurance. Other than governmental coverage for their medical evaluation and surgical expenses, donors are often asked to personally bear a significant financial responsibility due to lost work wages and travel expenses. In order to alleviate this economic burden for donors, we advocate for the consideration of tax credits, lifelong health insurance coverage, and an outcomes registry as societal reciprocity to reward their altruistic act of kidney donation.

Key words: kidney transplantation, live donor transplantation, policy, risk

End-stage renal disease (ESRD) is a terminal condition unless treated via dialysis or transplantation. Of the two options, transplantation is preferred by the patient and the physician because of reduced morbidity and mortality, increased quality of life and lower health care costs compared with dialysis [1, 2]. Within transplantation, donated kidneys come from the generosity of live donors (most typically friends and family) or deceased donors (donated by the families of recently deceased individuals). Given their potentially expandable supply and their excellent outcomes, live kidney donation has been the focus of many advocacy groups to increase the supply of kidneys available for donation in the USA and Europe. Recently, in the USA, the number of live kidney donors has steadily declined [3]. In Europe, live donor transplantations already make up a smaller fraction of all kidney transplants done compared with the USA—as low as 7% in Bosnia and Herzegovina [4–6]. One reason for the generally low rates may be the risks—both actual and perceived—undertaken by live kidney donors. A better response to these risks may ultimately persuade more people to become live donors and help alleviate the growing gap between donors and the waiting list.

A major consequence of live kidney donation is financial loss from travel, lodging, and even lost wages during the actual kidney donation process. Depending on the surgical approach during kidney donation, the average out of pocket cost of a live kidney donation in the USA can range from $907 to $3089—a significant cost for donors [7]. In Europe, donor costs are also an issue and have been identified as a major deterrent for potential live kidney donors [4]. As a consequence, 18 American states have implemented tax incentives to help donors recoup their losses and, in the process, attract more live donors (Table 1 lists the states and tax benefits conferred) [8, 9]. But despite their good intentions, there is no statistical difference in donation during the years before and after the implementations of these incentives [10, 11]. One reason may be that the financial carrot may be too small. For example, in Wisconsin, a family of four with a median income can claim a tax deduction of $10 000 of taxable income, but the actual cash savings amount to only $600 [11].
One part of the problem lies in the use of tax deductions, which do not allow for dollar-for-dollar reimbursements, unlike tax credits. Three states—Idaho, Louisiana and Utah—have been more thoughtful and do use tax credits—in amounts of up to $10,000 for expenses (Idaho up to $5000). However, out of pocket costs can be as high as $29,000—far greater than the tax credits in even the most generous states [12]. In Europe, some transplant centers offer reimbursement for income lost during donation, but this represents only a minority of transplant centers [3]. Such costs are not trivial as they have been shown to be a source of worry for up to 70% of actual donors [12]. In addition, out of pocket expenses are not the only risk undertaken by live kidney donors.

Donors also run the risk of having difficulty obtaining health insurance. Although the Affordable Care Act (ACA) in America now mandates insurance coverage, the future of universal health insurance is vulnerable to changing political climates. For example, the Republican-dominated, United States House of Representatives has already voted 67 times to repeal the ACA but has not succeeded with a Democrat-controlled White House [13]. With a change in presidential party, universal health coverage may be subject to repeal or revision. In an ever-changing political climate, issues of insurability are still relevant and underscore the fears of would-be donors. In one survey, 39% of transplant centers had eligible donors decline donation due to fears of future health insurance problems, 3–11% of donors actually encountered problems and another 2–14% of living organ donors continued to express concerns about insurability even after donating [14]. This risk can be reduced by guaranteeing health coverage, and it previously has been suggested that American organ donors should automatically qualify for Medicare, but this has not been implemented [15]. Another option has already existed for more than 12 years but also has been rarely utilized. The American Foundation for Donation and Transplantation provides a comprehensive insurance policy with a total benefit of $250,000 provided for only $550 [16]. The policy covers all donation-related events, yet only 4 of the 260 current transplant centers provide this service. At a minimum, this coverage should be provided to all donors as they should not be paying for donation-related adverse events.

Expenditure reimbursement and guaranteed health coverage do reduce the risk undertaken by live kidney donors, but they may not be enough to completely reassure a potential donor to donate. For example, in Sweden and the UK, all organ donors are reimbursed for their expenses and lost wages during the process and are already provided universal health care through the government, but a shortage of donors still exists [14, 17, 18]. The persistence of the waitlist is representative of additional barriers to donation. Traditionally, these risks have been minimized to avoid deterring potential donors and may be one reason why guaranteed health insurance has not been universally provided to donors [15]. However, acknowledgment and appropriate compensation of these risks may be necessary to move forward.

For example, although the risk of dying from a donor nephrectomy is exceedingly small—0.03%—and not significantly different from a matched cohort of nondonors, the risk of major and minor complications are 6 and 22%, respectively [19, 20]. Known risks—and possible deterrents—for donors include hypertension, kidney failure, especially among blacks and Hispanics, gestational hypertension and preeclampsia [19–23]. The increased risk of kidney failure is noteworthy as Muzaale et al. have shown in an American cohort: the approximate cumulative incidence of ESRD 15 years after donation being 30.8 per 10,000 for donors and 3.9 per 10,000 for matched nondonors [23]. Similar findings were seen in a Norwegian cohort [22]. Even though the increase in ESRD is small, the fear of developing it may be larger. Not informing donors and not systematically tracking all outcomes does not help address the fears potential donors may have.

Donors are not always aware of these risks because not all centers disclose them to the patients, and when risks are disclosed there is a large variation in what is discussed in both American and European centers [4, 24]. Finally, there is a dearth of long-term follow-up data on the medical risks of a donor nephrectomy, which may take 25 years or more to develop. Consequently, long-term medical risks cannot be accurately assessed [15]. Long-term data are especially scant in certain donor subgroups, like African Americans and the obese [19]. Given the lack of knowledge and the absence of a national registry, we echo the creation of a registry—a recommendation that has been voiced by others [18]. Tracking of the long-term outcomes will improve our understanding of them and improve counseling of future donors. In countries where many obstacles to donations have already been removed, like Sweden and the UK, the creation of a registry may provide additional information needed to assuage undecided potential donors.

When potential donors do find out about these risks, it may not be from their nephrologist, but from a major newspaper.

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**Table 1. Tax benefits for kidney donation by state within the USA**

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<thead>
<tr>
<th>State</th>
<th>Maximum tax incentive and amount</th>
<th>Purpose</th>
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<tbody>
<tr>
<td>Arkansas</td>
<td>$10,000 tax deduction</td>
<td>Travel, lodging and lost wages</td>
</tr>
<tr>
<td>Connecticut</td>
<td>$10,000 tax deduction</td>
<td>Travel, lodging and lost wages</td>
</tr>
<tr>
<td>Georgia</td>
<td>$10,000 tax deduction</td>
<td>Travel, lodging and lost wages</td>
</tr>
<tr>
<td>Idaho</td>
<td>$5,000 tax credit</td>
<td>Any donation-related expense</td>
</tr>
<tr>
<td>Iowa</td>
<td>$10,000 tax deduction</td>
<td>Travel, lodging and lost wages</td>
</tr>
<tr>
<td>Louisiana</td>
<td>$10,000 tax credit</td>
<td>Travel, lodging and lost wages</td>
</tr>
<tr>
<td>Minnesota</td>
<td>$10,000 tax deduction</td>
<td>Travel, lodging and lost wages</td>
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<td>Mississippi</td>
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<td>Rhode Island</td>
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documenting the adverse outcomes experienced by a previous donor. In recent years, prominent American news agencies, including the Chicago Tribune, the National Public Radio, The Washington Post, The New York Times and the Los Angeles Times, have featured donors who have subsequently endured unfortunate consequences, including the loss or denial of health insurance, the loss of employment and chronic pain, not to mention, excessive out of pocket costs, among other things [25–29]. The repetition of poor outcomes in the media may be contributing to the documented overestimation of risks by would-be donors [30].

In Europe and America, most live donors have a relationship to their recipients in some way. Donating a kidney does involve risk, but it also stands to benefit the donor if they know the recipient. The benefit derived in donating a kidney may be in the emotional joy of watching a loved one regain their health or a more practical benefit in having a family member return to their role as a parent or breadwinner. For these donors, the benefits outweigh the risks, because they have a pre-existing relationship with their recipient. Those donating a kidney to someone who they truly do not know comprise <4% of all living donors in the USA and an almost non-existent percentage in Europe [4]. Those who donate to strangers represent a very small percentage of live donors regardless of location [31].

For those with ESRD and who do not know a potential live donor, they are dependent upon the kindness of a stranger for a live kidney donation. Unrelated, non-directed donations occur at a rate of <4% of all donations and may be the result of a prohibitive cost–benefit ratio. In order to increase the number of live donors, policy makers should focus on two groups: potential donors who have a pre-existing relationship with the recipient but are currently unwilling to donate due to the current risks and those who do not know their recipient and have no reason to undertake additional risk, especially for someone they do not know. Tilting the scale in favor of donation may be accomplished by appropriate compensation of risks in the form of tax credits.

Tax incentives represent a compromise between the status quo and a commercial market for organs. In the USA, the National Organ Transplantation Act prohibits ‘any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation’ [32]. All European countries have similar laws prohibiting the sale of organs. These laws are written to prevent the commercialization of organs and the exploitation of the poor but do not restrict the appropriate compensation of live donors for any real or perceived risks involved in the donation process. The passage of existing tax laws is representative of their growing acceptance as a possible motivator for potential organ donors. However, the net financial benefit has proven to be too small and does not even address all the risks undertaken by organ donors. In addition to compensating donors for out of pocket costs and providing guaranteed health insurance, we believe that policy makers should pass laws giving live kidney donors higher tax credits over multiple years as a form of risk compensation. For example, $1500 tax credit per year for 10 years is a net benefit that has previously been determined to be appropriate for risk compensation [33]. The distribution of tax credits over several years or even decades minimizes the potential of impulsive donations and the exploitation of an individual at any given point in his or her life. The poor are least likely to be exploited because they have little to no tax burden to begin with and the benefits of tax credit are non-transferrable. This tax incentive will also appeal to higher income families, who already have lower rates of live donations [11]. The actual value of the tax credit and the number of years they are in effect can be titrated until the increase in live kidney donors has plateaued. Total tax credits of up to $94 000 can be used and still offer savings to taxpayers, although such high amounts are likely neither necessary nor recommended. Tax deductions and inappropriately low amounts of tax credits should also be avoided.

Conclusion

Tax credits have the potential to overcome the risks that may have previously deterred would-be donors from donating. However, the costs of not implementing tax credits are enormous to patients and society. Patients who do not receive a live donor transplant are left to depend on dialysis, and the 5-year survival rate of ESRD patients on hemodialysis is a dismal 35%. Of those who survive while on dialysis, only 10% are able to maintain employment or school enrollment. From a financial perspective, taxpayers bear the burden of substandard care for ESRD patients by paying an additional $52 000 per hemodialysis patient compared with each transplant recipient annually in the United States. The need for more donor kidneys cannot be understated and efforts should be made to expand the supply of both deceased and live donor kidneys.

Kidney failure creates an enormous burden on taxpayers and patients in the USA and Europe. Dialysis provides inferior therapy when compared with a transplant with a living kidney. We cannot reasonably expect more live kidney donors to donate without acknowledgment and compensation of the risks they undertake. In summary, many of the adverse outcomes of donating a kidney can be mitigated through several solutions:

(i) All donors should receive lifelong health insurance that covers all donation-related events.
(ii) Donation-related expenses should be reimbursed through tax credits, not tax deductions, and not be capped at such low amounts.
(iii) The known and unknown risks of medical complications over the long-term should be tracked and fully disclosed to every donor and compensated through additional tax credits over time.

Risk compensation is appropriate and has the potential to attract otherwise fearful donors. Future discussions of increasing the supply of kidneys should include risk compensation if we truly want to eliminate the waiting list.

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Conflict of interest statement

None declared.
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