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Improving institutional fairness to live kidney donors: donor needs must be addressed by safeguarding donation risks and compensating donation costs

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Summary

The number of kidney transplants from live donors is increasing worldwide, yet donor needs have not been satisfactorily addressed in either developed or developing countries. This paper argues that unmet donor needs are unfair to live kidney donors in two ways. First, when safeguards against the risks of donation are insufficient, live donation can impair the donor's health and thus his or her fair opportunities to access jobs and offices and to function as a free and equal citizen more generally. Secondly, when the financial costs of donation are not fully compensated, operational fairness (associated with the nephrectomy event) is compromised for the donor. The donor assumes the risks of a nontherapeutic intervention – for the good of the recipient and society – and should not have to incur costs for donating. Based on a systematic analysis of unmet donor needs in developed and developing countries, context-relative measures to improve institutional fairness to live kidney donors are delineated in this paper. The identified ways of safeguarding donation risks and compensating donation costs are not merely means to removing disincentives for donation and increasing donation rates. They are essential for preserving institutional fairness in the health care of the live kidney donor.

The rise of live donor kidney transplantation

The number of kidney transplants from live donors has been steadily increasing as more patients are developing chronic renal failure. The World Health Organization (WHO) estimates that approximately 25 500 of around 66 000 kidneys transplanted worldwide in 2005 were from living donors. About 40% of the overall kidney transplants were performed in North and South America. The highest percentage of kidney transplants from live donors was in the WHO's Eastern Mediterranean and South East Asia Region (95–99% respectively) [1].

The reasons for the constant rise of live kidney transplantation are well known. The shortage of organs from deceased donors has been an ongoing crisis of transplantation since its pioneering period of 50 years ago; kidneys transplanted from a live donor survive longer than those from deceased donors and are increasingly preferred by prospective transplant recipients [2]; and live kidney transplantation is the most cost-effective treatment for end-stage renal disease.

Improvements in immunosuppression have enabled the successful transplantation of live donor kidneys not only from genetically related family members, but also from emotionally related spouses and friends and from vendors selling one of their kidneys. In addition, individuals who would have been previously excluded from kidney donation for medical reasons are now accepted as suitable donors [3].

In resource-poor settings where access to hemodialysis is scarce and the infrastructure for developing an organized system of deceased donation often nonexistent [4],

kidney transplantation from live donors is usually the only realistic opportunity for treating end-stage renal disease. Cultural objections to deceased donation also contribute to the high prevalence of live kidney donation, particularly in the Middle East and Asia. The complex constellation of medical, economic and cultural factors has resulted in an enormous expansion of live kidney transplantation around the world.

The current reality of 'transplant tourism'

Many live kidney donors are in fact kidney vendors. At WHO's Second Global Consultation on Human Transplantation in March 2007, Yosuke Shimazono (University of Oxford) estimated that 5–10% of the kidneys transplanted globally are currently related to 'transplant tourism'. Patients with sufficient resources regularly travel from one country to another to purchase a kidney (or part of a liver) from a poor person. Today, countries such as Pakistan and the Philippines are well known to permit the sale of organs to 'tourist' recipients. These countries allow their poor to sell kidneys to attain the economical gains for hospitals, physicians, brokers and possibly the lobby forces – with little regard to the unsafe, coercive and exploitative circumstances associated with these transactions [5,6].

At the same time, initiatives to dramatically increase the supply of deceased donor organs or to decrease the need for transplants through the prevention of kidney failure remain unsuccessful or rare in the 'client' countries of the West and the Far East. Because of the growing shortage of kidneys, patients on waiting lists tempt their fate in hazardous and illicit transplant procedures. Insurance companies may even propel their desperation through supporting or facilitating the purchase of a kidney outside the country of residence (e.g. in Israel).

'Transplant tourism' has become an ethical issue for transplant clinicians everywhere. Even physicians who have no part in the organ trafficking bear unwanted responsibility for the medical care of those recipients who return to their home countries after transplantation from an unknown kidney vendor. These recipients arrive at physician offices for example in Toronto and Trinidad with inadequate reports of operative events and unknown risks of donor transmitted infection or malignancy [7,8]. 'Transplant tourism' is a reality for all transplant physicians, no matter how uninvolved individually.

The international opposition to kidney sales

There is a long-standing ethical, political and professional opposition to organ sales. The WHO has repeatedly condemned the buying and selling of organs [9,10]. The regional consultations the organization has held in the process of updating its 1991 Guiding Principles on Human Organ Transplantation revealed continued opposition to make human body parts the subject of commercial transactions [11,12]. The World Medical Association endorses the prohibition of financial incentives for providing or obtaining organs [13], and the Transplantation Society commits members to recognizing its opposition to organ sales [14]. The European Union also dismisses any kind of commercialization of the human body and its parts [15,16]. China, until now a major destination for 'transplant tourists', has recently adopted a ban on the sale of organs [17]. And the Institute of Medicine in the United States continues to 'draw[s] lines separating things treated as commodities from things that should not be treated as things "for sale"' [18].

However, the international opposition to kidney sales has also been questioned. Proponents of (multi-)nationally regulated the kidney markets believe markets would significantly lower the kidney shortage in developed countries and improve donor and recipient safety, prevent exploitation by brokers and alleviate poverty in developing countries. (The terms 'developing' and 'developed' countries clumsily pool many distinct countries with diverse cultural norms and levels of social and economic development. Despite these limitations we use this terminology because it is easily recognizable and symbolizes significant differences in the structure of healthcare, educational and other institutions that are important to this discussion.) Justice, they claim, would not be an issue because kidneys would be bought by a 'single buyer' and distributed according to customary allocation criteria. Policy debates are heavily influenced by the expectation that a regulated kidney market could be 'carefully controlled' or 'policed', as the antithesis to countries where an uncontrolled organ trade is flourishing already (e.g. in Pakistan and the Philippines).

It is a complex empirical question whether regulated kidney markets would indeed yield the intended consequences. But no matter the consequences, a regulated kidney market has significant moral costs. Its implementation delivers a social policy that expressly takes advantage of inequities between the rich and the poor. Cash payment for a kidney would especially appeal to those members of society whose opportunities for employment, education and health are already limited. Payment may also be coercive as the only alternative to providing resources for an unemployed poor family. Governments have the responsibility to shape healthcare institutions so they protect and maintain the health of all citizens and thereby safeguard fair equality of opportunity, e.g. for gainful employment [19]. A regulated market would not only exploit the existing social unfairness to

the poor, it would also exacerbate that unfairness by distributing the risks and burdens of donation unfairly within the society thus creating institutional injustices in the provision of medical care. Those concerned about fairness in live kidney donation must maintain policies of unpaid donation (i.e. without cash payments).

The worldwide need to improve fairness to live donors

Yet absence of payment does not eliminate all concerns about fairness in live donation. The frequent turn to live kidney donors – imposing on them the risks and burdens of a nontherapeutic intervention for the good of the recipient and society – is itself increasingly unfair. In most countries, health care and educational institutions could foster alternatives to live kidney donation through better prevention of kidney failure, broader access to dialysis and improved deceased donation programs. However, similar measures often rank low on political and professional agendas.

Yet irrespective of the efforts to address the kidney shortage, the international transplant community must help to shape the institutional conditions of kidney live donation as fairly as possible.

Fairness is not a norm for the interaction between individual kidney donors and recipients who in economic terms might otherwise make a 'fair deal' of compensation or follow agreed upon rules of 'fair play'. Fairness should rather unfold from a societal perspective by determining the purpose and processes of healthcare (and other) institutions in the use of kidneys from live donors. Two aspects of fairness are important for shaping institutional conditions for live kidney donation. Maintaining health and thus fair opportunity after donation, e.g. for employment, requires healthcare institutions and social security to establish safeguards against the health and economic risks of live donation. Operational fairness requires these institutions (and insurance companies) to compensate donation costs comprehensively, including those incurred by the donor. Donors who assume the risks of a nontherapeutic intervention – also to the benefit of society – should not be burdened by donation-related expenses.

International standards for the medical care of the live kidney donor [3,20] provide a sound and widely acknowledged basis for live kidney donation. However, a closer look at current live donation practices readily reveals the worldwide need to improve fairness to live donors by addressing donor needs and assuring donor safety. The following paragraphs will show that live kidney donor needs are not being satisfactorily addressed in either developed or developing countries.

Unmet donor needs in developed countries

Safeguards for donation risks

A sufficient body of literature exists on the retrospective outcomes of live kidney donation in developed countries, yet significant prospective uncertainties remain [21]. The long-term outcome of current donors – with changing medical profiles that could increase the risks of live kidney donation – is unknown [3]. Former donors in the US are reported to be in need of kidney transplants that approximates the 1999 adjusted incident rate for end-stage renal disease in the general US population, 0.03% [22]. However, corresponding global data is missing. Long-term health risks of current live donation may be greater than previously recognized.

Although the obligation to safeguard long-term medical follow-up and access to care for donation-related health problems is widely acknowledged by transplant professionals [3], these services are not accessible to all donors, even in some developed countries. For example in the US, where 15.7% of the population was without health insurance in 2004 [23], former live donors may find themselves without follow-up and access to care. The United Network for Organ Sharing reports that only 60% of the 6-month follow-up forms are being returned and of those, 36% of donors are already lost to follow-up [22]. Similarly, although the low but realistic perioperative risk of donation-related death or disability is widely recognized [24], perioperative life and disability insurance is not routinely provided in developed countries.

Compensation of donation costs

Reimbursement of donation-related expenses and lost income is widely accepted [9,13,25] and legal in many developed countries. However, reimbursement may not be routinely accomplished. Refunding practices can vary significantly (and maybe unfairly) between different healthcare providers. Also, reimbursement of lost wages is not always comprehensive. For example, some German live kidney donors complain about disparities between normal salary and sick-pay [26].

Because the details of reimbursement are often vague and reimbursement practices remain largely unmonitored, the economic costs of donation are poorly understood. Donation-related expenses may actually go beyond the expenses recognized in common reimbursement plans. For example, incidental donation-related medical spending for postdischarge analgesics is usually not covered [27]. Costs incurred over the long term (more than 1 year after live donation) also await more detailed quantification [27]. Elevated insurance premiums or hindered access to life, disability or health insurance could consti-

tute a significant long-term cost of donation [28]. Moreover, refunding of indirect costs of donation, for example to hire caregivers or domestic help, is largely unconsidered [27]. This seems particularly unfair as women, who do much informal, nonsalaried work in both developed and developing countries, are often the ones who donate [29] or step in for a donating family member or friend [27].

Unmet donor needs in developing countries

Safeguards for donation risks

Safeguards for perioperative and long-term donation risks are particularly important in countries where access to health care is not universal. Live kidney donors from developing countries may find themselves without long-term follow-up and access to medical care for donation-related health problems. Perioperative life and disability insurance for donors may not be readily accessible in these countries, and donors may also encounter difficulty in obtaining insurance after donation. In most developing countries, there is no allocation system of deceased donor transplantation so that former live donors in need of a kidney transplant would have to turn to their family or friends – who may be reluctant to donate based on the donor's experience.

The link between health and economic risks is also stronger in countries where agricultural and physical labor prevails. Recurring back or incisional pain after donation can make it impossible to sustain heavy physical work [5,6]. Unskilled former donors may have few other job opportunities. General or donation-related disability or unemployment insurance may not exist in developing countries so that live donation is comparatively more consequential for the donor (economically) in developing than in developed countries. Moreover, former live donors risk being socially stigmatized in countries where organ trafficking is flourishing [5,6]. Access to work can be difficult for a poor donor if donation is spuriously considered a kidney sale.

Compensation of donation costs

Reimbursement of donation-related expenses and income loss is not standard in many developing countries. Moreover, laborers often work informally and without regular monetary remuneration in these countries, but reimbursement of indirect donation-related costs is rare in common refunding plans.

Furthermore, donation-related expenses can continue to burden live donors in developing countries in the long term. For example, transportation to follow-up visits can represent significant financial strain for a person living close to or below the poverty line [6]. Unless similar long-term costs are included in reimbursement plans, access even to gratuitous medical follow-up can be compromised.

Improving institutional fairness to live kidney donors: a proposal

The previous paragraphs make clear that healthcare institutions and social insurance do not meet live kidney donor needs satisfactorily in both developed and developing countries. Insufficient safeguards against donation risks infringe upon the fair opportunity of former live donors. Inadequate compensation of donation costs conflicts with the operational fairness surrounding the nephrectomy event.

How can we improve fairness to live kidney donors and address donor needs more comprehensively? A structured list of donation risks and donation costs systematically presents measures for improving fairness to live kidney donors (Table 1). At the same time, the fairness perspective excludes cash payments for kidneys and other significant incentives for live donation, be they financial (e.g. tax deductions, stipends for education) or nonfinancial (e.g. asylum, citizenship, pardoning). These measures lead themselves to unfairness by being compelling to poor 'donors' primarily and unbalancing the risks and burdens of donation within the given society.

What is appropriate and fair must be examined by each country with involvement of local stakeholders. In most developed countries, the health and economic risks of donation are safeguarded by general health and social insurance. Improving fairness under these circumstances would primarily require closing the existing gaps in routine health and social insurance and reimbursement programs. In most developed countries this implies establishing temporary life and disability insurance on a routine basis and refining reimbursement plans, for example by including compensation for lost productivity surrounding the donation event.

Although principally transferable, these measures may be neither appropriate nor primary in developing countries. For example, it is conceivable that temporary life-insurance can be life-threatening for donors in resource-poor settings. Priorities may also be different in countries where access to health care is not universal or essential health care does not protect from impoverishing out-of-pocket expenses. Safeguards against the health risks of live donation are often insufficient under these circumstances, and introducing insurance for long-term follow-up and care of donation-related health problems is paramount for addressing donor needs more comprehensively.

It is important from a fairness perspective that insurance for donation-related health care would not be equiv-

Table 1. Elements of improving institutional fairness to live kidney donors. What is fair and appropriate needs to be determined in relation to particular contexts.

Costs or risks related to…	Suggested measure(s)
Donation	Comprehensive reimbursement or replacement of incurred expenses for arranging and effecting the pre-, peri- and postoperative phases of the donation process (e.g. long-distance telephone calls, travel, accommodation and subsistence expenses) lost income lost home productivity (e.g. expenses to hire caregivers or domestic help in relation to donation) incidental medical expenses (e.g. postdischarge analgesics) expenses incurred by other individuals (e.g. family and friends) in supporting the donor
Physical and psychological health	
Perioperative mortality	Temporary life insurance for donation-related death (insurance sum according to local circumstances)
Perioperative morbidity	Temporary disability insurance for donation-related disability Insurance for perioperative follow-up and care for donation-related health problems
Long-term morbidity	Insurance for long-term follow-up and care for long-term donation-related health problems (if necessary, including reimbursement for related transportation expenses) Job (re-)education programs or disability/unemployment insurance in case of donation-related job loss
Social stigma and discrimination	Official certificate to prove donation has been unpaid and state-of-the-art, possibly in combination with a token of societal recognition Explicit non-discrimination legislation regarding donor access to jobs, offices, insurances, etc.

alent to basic health insurance as some suggest [30,31]. Insurance benefits for live donors should be primarily determined with reference to donation-related health costs and include long-term medical follow-up, care for donation-related health problems and, depending on the patient's vulnerability, care for a limited number of non-donation-related clinical conditions. Solidarity justifies that some rescue means are made available to treat former donors with certain grave medical conditions or to protect them from impoverishing health expenses. Confined non-donation-related coverage would have to be determined according to particular contexts, ideally in line with larger efforts to achieve or broaden access to essential health care (for example the Fund for Protection form Catastrophic Expenses in the Mexican Seguro Popular [32,33]).

Rewarding live donors – and some propose also their families [31] – life-long basic health insurance would make live kidney donation a precondition of access to health care for those suitable to be a live donor, but not for all citizens. This would further expose the inequities in health whereas healthcare institutions should safeguard health and thus fair opportunity of all citizens [19]. One should not have to 'earn' insurance. Making access to healthcare dependent upon kidney 'donation' for some – usually those with already limited opportunities – would create significant institutional injustices.

In the absence of universal access to essential health care, live donor insurance should be confined to the donor and cover only donation-related health conditions. Of course the ascribing of a malady to donation has to be carefully defined. Conflicts are foreseeable when a former live donor seeks care for a clinical condition that turns out to be unrelated to donation and therefore ineligible for treatment. These conflicts and the need to assess clinical conditions and the treatment in relation to kidney donation could significantly strain the relationship between patients and physicians. Insurance for donation-related health conditions will also lead to some added bureaucracy as the donor will need access to a medical advocate in order to prove the validity of his or her claims. Completing the necessary paperwork may be more difficult for less educated donors, and administrative costs for proving the relation to donation could be so high that fixed compensation might seem more pragmatic. However, social workers and transplant coordinators could assist less educated donors with the completion of medical claims in the follow-up visits of the donor at the transplant center. The reason not to have a cash payment has been discussed in more detail above.

Nonetheless, in countries where access to health care is not universal, pointing out the difference between basic health insurance and specific donor insurance for donation-related health problems is crucial for striving towards a just health system. Our proposal is not intended to resolve the need for a just health system for all citizens. But it does underscore that in countries without universal access to health care those who are likely to donate often do not have health insurance; therefore, it also emphasizes that access to general health care should not be dependent upon kidney 'donation' for poorer members of society.

Addressing donor needs becomes more extensive in countries where healthcare institutions and social security are fragmentary and/or financially deprived. Job (re-)education programs to safeguard donation-related work loss, for example, would be important where disability or unemployment insurance is limited or does not exist. And in countries where uncontrolled kidney markets flourish and vendors are stigmatized or discriminated against, an official certificate that attests to an unpaid donation – possibly in combination with a token of societal recognition – or legally enforced nondiscrimination of donors would address important donor needs.

Finally, fairness requires addressing donor needs unconditionally. Donation-related life, disability, unemployment or health insurances should not be dependent upon the willingness to participate in long-term follow-up [34,35]. Obtaining prospective data on the long-term outcome of live kidney donors is urgent [21], but donors should not be coerced into participating in research.

Improving institutional fairness, not reducing disincentives or creating incentives

The proposed measures borrow on elements from existing reimbursement and insurance programs for live donors. They also include ideas that have been suggested to increase live kidney donation rates by reducing disincentives for donation [30,31,34–37]. Increasing the willingness to donate is the prevailing rationale for reimbursement of donation-related costs and the provision of specific donor insurances. In contrast, our proposal is intended to make the conditions of live kidney donation fairer for today's donors. Whether or not addressing donor needs more comprehensively will boost donation rates remains to be determined. Irrespective of that outcome, we must shape the institutional conditions of kidney donation as fairly as possible.

Practical challenges

We recognize the proposal's practicality remains to be elaborated and scrutinized. The difficulty of specifying a comprehensive list of donation-related events and the disadvantages of added bureaucracy have already been mentioned above. Assigning concrete responsibilities for the provision of donation-related services – in particular in the long term – will be another practical challenge. Ideally, institutional fairness should be based on institutional power to implement fairness. But the source of funding for donation-related services may well have to be private charitable organizations in resource-poor countries (at least partially). And finally, the most daunting question is: who can force countries to implement institutional fairness to live kidney donors? Consensus initiatives from professional societies, for example The Transplantation Society and the International Society of Nephrology working in collaboration with the WHO, can bring the care of the live donor to the attention of the ministry of health of each country.

Conclusions

Institutional fairness to live kidney donors has been largely unaddressed in developed and developing countries that have established programs of kidney transplantation. Providing safeguards for donation risks and compensation for donation costs are not merely means to removing disincentives for donation and increasing donation rates. They are essential for addressing donor needs and for preserving the purpose and processes of healthcare institutions: protecting and maintaining the health – and thus fair opportunity – of all citizens, including live donors.

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Authorship

ASB provided the first draft of manuscript with important intellectual input from FLD. FLD revised subsequent versions of the paper.

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