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# The Rationale for Incentives for Living Donors: An International Perspective?

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**Abstract** The organ shortage has become a crisis for transplant candidates with end-stage renal disease, and a significant number of them either die while waiting or become too sick to transplant. A consequence, worldwide, has been the development of *un*regulated markets for donation; these markets have been associated with poor outcomes for both donors and recipients. In contrast, a *regulated* system of incentives might increase donation rates while also providing a benefit to donors. Criteria for an acceptable system have been proposed: protection of the donor and recipient, regulation, transparency, and oversight. Many of the concerns about the implications and impact of such a system could be answered with a clinical trial in a country (or countries) that can meet the described standards. Yet the debate about the advisability of developing such a system continues, even as the waiting lists grow and candidates die while waiting.

**Keywords** Regulated system incentives for living donation

## Introduction

The optimal treatment for patients with end-stage renal disease is a kidney transplant. Yet most countries that offer transplants have a shortage of organs. As a consequence, waiting times are long, and many accepted candidates either die while waiting or become too sick to transplant.

No single cause accounts for the organ shortage. Some countries have active living donor programs, but limited (or no) deceased donor programs. For some countries, the cost and logistics of developing a national deceased donor program can be prohibitive; other countries face insurmountable cultural barriers such as stigma associated with donation, or religious beliefs about the care of the body [1•]. Conversely, some countries have emphasized deceased donation and have not encouraged living donation. Finally, some countries have maximized (or nearly maximized) both living and deceased donation — and still have a significant shortage. A consequence of the organ shortage is that *un*regulated, underground markets for donation have developed in many countries (over many continents) [2–18].

Living donor transplants are associated with the best outcomes after kidney transplantation. In most countries, however, the financial disincentives to living donation are numerous (Table 1). Living donors not only give up a significant amount of their time, but also undertake the risks of surgery for a procedure that is of no physical benefit to them. In many countries, donors and donor candidates must, in effect, pay for the "privilege" of being a donor: they bear both the expense of traveling to the transplant center for evaluation and then, if approved, the expense of traveling to the transplant center for the surgery. Most living donors are not reimbursed for lost wages or for any other costs of donation, such as child care.

In 2006, Clarke et al reviewed 35 studies from 12 countries that looked at living donor costs. Of those studies, 17 (49 %) were from the United States, 12 from Western Europe, two each from Canada and Australia, and one each from Japan and Iran [19]. Of the living donors described, 9 % to 99 % of them claimed travel and/or accommodation costs (costs that were higher in countries with a larger land mass). In addition, 14 % to 30 % of the living donors in those 35 studies incurred costs for lost income; 9 % to 44 %, costs for dependent care; and 8 %, costs for domestic help.

A subsequent study from Australia found that the major financial concerns for living donors were the costs of testing, the extra costs associated with living in a nonurban area, and

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**Table 1** Potential disincentives for a living donor

(1) Fear of financial hardship because of:
  (a) Travel, accommodation, child care, and medication cost at the time of assessment and donation procedures;
  (b) Loss of income at the time of donation and during the recovery phase;
  (c) Loss of or difficulty obtaining health and life insurance after organ donation;
  (d) Loss of employment opportunities after organ donation.
(2) Fear of death, disability, or functional restriction. These fears encompass both short- and long-term sequelae of donation, including perceived effects on fertility and childbearing.
(3) Fear of a lost opportunity. Potential donors might prefer to retain a kidney for future potential recipients, especially children.

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**Table 2** Prioritization for supporting donor costs in the United States

| Preference Category | Income Requirements |
|---|---|
| 1 | The donor's income and the recipient's income must each be 300 % or less of the maximum per Health and Human Services (HHS) poverty guidelines. |
| 2 | The donor's income may exceed 300 % of the maximum per HHS poverty guidelines if the donor demonstrates financial hardship and if the recipient's income is 300 % or less of the maximum per HHS poverty guidelines. |
| 3 | Any donor, regardless of income or financial hardship, may be accepted if the recipient's income is 300 % or less of the maximum per HHS poverty guidelines. |
| 4 | Any donor, regardless of income or financial hardship, may be accepted if the recipient, regardless of income, demonstrates financial hardship. |

lost wages [20]. Even though Australia has a public health system, prospective donors living in nonurban areas often had no local access to the system, and consequently, underwent initial testing at a private hospital where they had to pay upfront.

In a more recent study of 100 prospectively enrolled living donors in Canada, the economic consequences of donation were evaluated at 3 and 12 months postdonation [21••]. The authors reported that 96 % of donors suffered economic consequences; 94 % incurred travel costs, and 47 % lost wages. The average cost per donor was $3,268 (SD, $4,704); 33 % had costs greater than $3,000 and 15 % greater than $8,000.

In the United States, the Health Resources and Services Administration (HRSA) established a grant to help remove donor financial disincentives [22]. For living donors to be eligible, the grant must be the payer of last resort (i.e., they must have no other funds from federal, state, or local government or from health insurance); moreover, both the donor and the recipient must meet strict eligibility guidelines (Table 2). To date, a total of 1,941 approved applicants have proceeded to donation; the average mean expenses for travel have been $2,767.

Most countries performing living donor transplants have not specifically looked at out-of-pocket donor costs. Sickand et al compiled a list of what many countries do and do not support [23]. In the United States, the importance of costs in the decision-making process of prospective donors can be seen in the relationship between living donation rates and the economy [24]. When the economy deteriorated in 2004, living donation rates either remained unchanged or improved among the segment of the US population with income in the top 40 %, but donation rates fell significantly among those in lower income brackets.

Other disincentives to living donation exist. In countries without universal health care, prospective donors might not have insurance to cover subsequent complications or even to pay for routine follow-up care. Often, prospective donors are concerned that donation might limit their employment opportunities; lessen their ability to change jobs, for fear of being unable to obtain health insurance; or increase their life or health insurance premiums or, even worse, lead to denial of insurance altogether. Boyarsky et al, in a single-center study in the United States, surveyed former donors to determine whether or they had difficulty either changing or initiating health or life insurance postdonation; 7 % reported problems with health insurance and 25 % with life insurance [25•].

A *regulated* system of incentives might alleviate problems for both living donors and recipients. Such a system might increase donation rates, eliminate donor disincentives, and provide an incentive to balance both the risk and the time taken. Thus, the overall rationale for considering a system of incentives is that it might increase donation, thereby saving lives and increasing the quality of life of recipients while at the same time compensating donors for their health and financial risks.

An additional potential advantage of a regulated system is that the associated increase in organ donation might decrease the current illegal business of unregulated, underground kidney markets.

## Varying Views

### Public Opinion on Incentives

To date, surveys from a number of countries—Canada, the Netherlands, the Philippines, the United States—have suggested that the public is in favor of incentives and/or would be more likely to donate if incentives existed [26•, 27–44]. In actuality, a truly universal viewpoint does not exist and may

vary between countries, just as cultures vary between countries.

## Donor Motivations

An important component of the discussion on incentives for donation is consideration of the significance of altruism. Often, opponents of incentives naively create a dichotomy between "altruism" and "incentives," insisting that all donations must be purely altruistic. (That insistence is what has led to a shortage of organs worldwide.) In reality, published studies suggest that, rather than a dichotomy, more of a continuum prevails, with mixed motives for living donation [45, 46, 47••]. For example, the three major Western religions all put high value on the saving of a life. Each has a saying similar to "the person who saves a life saves the world." Living donors with altruistic motives might also need and/or appreciate any benefits that are provided, or they might even donate, at least in part, because of such benefits and still have altruistic motives. Because of the complexities of motivations and the immeasurable value of saving a life, both the Philippines and Iran [47••, 48–53], two countries with a system of incentives in place, consider the incentive as a token of appreciation: in their system, the donor is respected and rewarded for the act of donation.

A few studies have specifically addressed the question of whether individuals would be more likely to donate if an incentive were involved. Each of those studies found that the majority of those individuals said that an incentive would not change their mind, but a significant percentage stated they would be more likely to donate. (To put this into perspective, in the United States, more than 100,000 transplant candidates are on the kidney waiting list; if only 0.03 % obtained a living donor because disincentives were removed and an incentive provided, the waiting list could be eliminated.)

## Cultural Context

All countries performing transplants have an organ shortage. Still, it is unclear whether or not a universal decision could or should be made to implement incentives for living donors. Those of us in the transplant community might all agree, in theory anyway, on certain principles, e.g., opposition to exploitation of poor and vulnerable people. Yet, within that context, cultures (including the realities of medical practice) differ from country to country, and potential solutions to the organ shortage similarly differ. Examples of cultural differences are delineated in the ethnographic work of Fry-Revere in Iran and Moazam in Pakistan [47••, 54].

Writing about the differences in informed consent practices in Iran (versus developed countries in the Western world), Fry-Revere notes that physicians respect the concept of informed consent. But, in part because of physician shortages, they feel that, if they took the time to answer all patient and family questions, the "process of treatment would get bogged down" and they would not be able to see as many patients in 1 day; in fact, some patients "might not be seen in time and some might not be seen at all" [47•• p.48].

Writing about kidney donation in Pakistan, another developing country, Moazam makes similar comments about informed consent [54 p. 25]. In that culture, patients trust that physicians will respect them and will make the right decision for them. Importantly, Pakistan has very limited resources for dialysis, and physicians often need to decide who to accept (versus deny) for dialysis [54 p. 91]. Those who are accepted most often must pay for dialysis; and, the vast majority of the population cannot pay for long-term dialysis. In this context, Moazam notes that "patients are perceived as powerless in the face of life-disease" and that "each patient is seen as deserving of a cure [whose] vulnerability is seen as compounded in instances where none of their family members are willing to donate a kidney." Accordingly, physicians and other members of the health care staff feel "an ethical duty" to such vulnerable patients "to come to the rescue." Moazam points out that "the staff begins with the premise … (that) an autonomous decision is unlikely by patients and their family members" and therefore (the staff) "do not travel the path of noninterference paved with intellectual detachment and information provided in a dispassionate manner." Instead, they "interfere actively in the lives of patients and their families as they attempt to ferret out donors; they reason, but they also prod, push, control, and threaten [54 p.111]."

Moazam gives examples of physicians and other staff members telling family members that, unless someone steps forward to be a living donor, dialysis will be stopped. In contrast to their Western medicine counterparts, the encounters of Pakistani physicians with their patients and families are "colored by a Pakistani ethos of relationships and duties." They would consider as "alien concepts" the following principles, so common in developed countries: "compassion without emotional investment, a concern for the patient uncoupled with personal engagement and a focus on the rights of individuals: [54 p. 121]".

### *Unregulated Experience*

To date, the experience with incentives for donation has mostly occurred in the context of *un*regulated, underground markets, which have developed worldwide. As a result, it is unknown how many such transplants have been done; one estimate is 10 % of all transplants worldwide [2]. Also unknown are statistics on donor and recipient outcomes after such transplants. In these unregulated, underground markets, prospective donors are often poorly informed, inadequately screened, not allowed to change their minds, given little postdonation care and no follow-up, and are often not even rewarded with

the incentive that was promised [3–14]. In general, reports from the countries that have underground markets indicate that many donors regret their participation; unknown is whether or not any donors from the same countries feel that they benefited. As well, because of poor donor screening, recipients often develop serious infections; some have reportedly returned to their home countries without any information about their immunosuppressive protocol or their immediate posttransplant course. Even worse, recipients have often arrived with concomitant acute rejection and infection [15–17, 55, 56].

An additional problem with these unregulated, underground markets is that the kidney recipients have generally come from two populations: (1) wealthy citizens and (2) foreigners who can afford to travel and pay the market price. Citizens who cannot afford the market price are left to die. Ethically, serious concerns should and do arise about the rich buying from the poor, both within and between countries.

Two exceptions to this general negative experience must be noted: in the Philippines and in Iran. Both of these systems have some element of regulation.

*Philippines* Underground, unregulated markets have been reported from the Philippines. However, a hospital in Manila receives government funds to facilitate kidney transplants for individuals who could not otherwise afford one. Within this specific system, a government-approved program allows "gratitudinal gifts" to nonrelated donors. These gifts can include health and life insurance, reimbursement for lost income, an educational plan, and job placement. Although the numbers are small, Manauis et al reported that living donors in Manila benefit from having improved socioeconomic status [48].

*Iran* Two bodies of literature, both emanating from within Iran, offer conflicting accounts of the Iranian system. One, represented by Ghods et al, suggests that the incentives system, although not perfect, has had a positive result for both recipients (Iran does not have a long waiting list for kidney transplants) and donors (they benefit from donation and have no regrets) [48–53, 57, 58]. The other body of literature, represented by Zargooshi et al, asserts that the system does not work, that living donors are treated badly, and that they regret proceeding with donation [59, 60]. For those of us outside Iran, knowing where the truth lies is thus difficult.

Recently, Fry-Revere traveled to Iran in an effort to understand better and describe the Iranian system [47••]. While there, she visited different areas of the country and concluded that "one static system" does not exist in Iran; rather, "regulations, guidelines, and practices governing transplantation have evolved over time" and "implementation can vary considerably from region to region" [47•• p. 212]. She noted that the Iranian parliament approved the formation of nongovernmental organizations (NGOs) to work with kidney disease patients and (incentivized) prospective donors, in order to help "depersonalize the process and standardize procedures." Those NGOs also function as charities to help raise funds to provide to living donors.

The national government in Iran provides a monetary incentive to living donors (which equals about a third of the average individual income), 1 year of health insurance, and, for men, an exemption from the country's 2-year military service requirement [47•• p. 51]. In many regions, donors receive more than 1 year of health insurance not only for themselves, but also for their families; in some regions, donors can come back indefinitely to their recipient's clinic for health care postdonation. In addition to these benefits, matched donors and recipients can also negotiate an additional benefit (often the equivalent of 1.3 times the average individual income). In parts of the country where are able to raise money, they provide any negotiated additional donor benefit for recipients who cannot afford it; in reality, for most donors throughout Iran, the benefit is provided by the NGOs (Sigrid Fry, personal communication). The NGOs also pay for all the testing before donation and for all donor travel expenses. Foreigners were initially accepted in the system, but the process has now been restricted to Iranian citizens. Throughout her travels, Fry-Revere interviewed donors, recipients, and administrators. Although she did encounter some donors who felt cheated and mistreated (most often feeling that they should have been paid more), "most did not regret their donation" [47•• p. 91].

*Comment* Both the isolated setup in the Philippines and the more general one in Iran suggest that developing an acceptable regulated system of incentives might be possible in other countries. Both the Philippines and Iran are working to improve their programs; nonetheless, in both countries, negotiations between donors and recipients persist and are often ethically problematic. In the Philippines, access to transplants is generally limited to the wealthy; the situation in Iran is less clear.

## An Acceptable *Regulated* System?

A fully regulated, government-sponsored system of incentives for donation could minimize the inequalities and abuse that have been reported in unregulated, underground markets. The arguments in favor of such a system have been presented in detail [61–79, 80••]. Such a system would feature full donor evaluations and acceptance criteria similar to the current evaluations of prospective living donors in the United States and other Western countries (United States and other Western countries are cited as examples because the author is familiar with their systems); provision of the incentive by the

government (or a government-approved agency), so that all donors would receive something of equal value; anonymity between donors and recipients; allocation of the kidney to the number-one candidate on the waiting list (similar to the allocation algorithm for deceased donors currently in place in the United States and other Western countries), so that all transplant candidates on the list have an opportunity for a transplant; and full protection for donors and recipients.

Each system would be limited to individual countries (or areas such as Eurotransplant that share organs); only that country's citizens and legal residents would be able to participate. Each country/system would need to determine possible incentives. First, all donor disincentives (e.g., lack of health insurance, costs of traveling to and from the transplant center, and lost wages) should be eliminated. A menu of choices for the incentive could be offered, because different things might be of value to different donors. In 2012, an international group met in Manila to discuss criteria by which a plan of incentives for living donation could be judged to be acceptable. Conclusions were summarized, and outlined in a manuscript prepared by the participants and other interested parties [80••]. Four crucial elements were stipulated for an acceptable system: protection of the donor and recipient, regulation, oversight, and transparency. "Specifically, (i) the donor (or family) is respected as a person who is able to make choices in his or her best interest (autonomy); (ii) the potential donor (or family) is provided with appropriate information to support informed decision making (informed consent); (iii) donor health is promoted at every step, including evaluation and medical follow-up (respect for person); (iv) the live donor incentive should be of adequate value (and able to improve the donor's circumstances); (v) gratitude is expressed for the act of donation [80•• p 308]."

In terms of protection, the risk for living donors should be similar to the risk for currently accepted donors in the United States and other Western countries. In addition, in such a system, donors should benefit in a way that would improve their own or their family's life: "For this to be acceptable, the donor must be fully informed, understand the risks, understand the nature of the incentive and how it will be distributed, and receive the benefit. There must be follow-up and an opportunity to address any wrong doing" [80•• p308]. In terms of regulation and oversight, all aspects of the process must be clearly defined for outside review (both national and international). Clearly defined policies must be established and implemented for follow-up, outcomes determination, and detection and correction of irregularities. Consequences must be defined for entities within the system that do not adhere to those policies.

In terms of transparency, it must exist throughout the process, so that both national and international observation is possible. Principles of an acceptable system have been formulated (Table 3), and guidelines for its development suggested (Table 4).

**Table 3** Guidelines for an acceptable incentives system (Manila meeting, 2012)

(1) Each country implementing a system of incentives should have a legal and regulatory framework for the process;

(2) The process and outcomes must be transparent and subject to government and international oversight;

(3) The incentive should be provided by the state or state-recognized authority;

(4) The incentive would be of similar value for all donors;

(5) Allocation should be performed by a single recognized system using a predefined and transparent algorithm, so that all on the list have an opportunity to be transplanted;

(6) The incentive should be limited to citizens and legal residents to ensure adequate follow-up, to determine whether or not outcomes are similar to today's conventional donors, and to prevent travel from one country to another for the purpose of incentivized donation.

(Modified with permission from: Working Group on Incentives for Living Donation, Matas AJ, Satel S, et al: Incentives for organ donation: proposed standards for an internationally acceptable system. Am J Transplant. 2012 Feb; 12(2): 306-312) [80••]

Tremendous debate continues about the value versus risk of such a system. As this debate goes on, the waiting list keeps growing longer. In the United States, more than 100,000 candidates are waitlisted for a kidney transplant alone (Organ Procurement and Transplantation Network [OPTN] data

**Table 4** Additional guidelines for an acceptable incentives system

(1) A clear and transparent process must be implemented for providing information about risks to the donor, for ensuring that the donor understands the operation and its risks, and for obtaining donor consent.

(2) A thorough donor screening evaluation must use defined (and widely available) protocols, including well-defined and transparent criteria for donor acceptance.

(3) A fixed "incentive" must be offered, so that all donors (in any one country) receive equal value.

(4) Donors and recipients must be limited to citizens and legal residents of the country, to help ensure long-term donor medical care and follow-up.

(5) The donation must remain anonymous, with no contact between donors and recipients.

(6) Each donor must understand the need for long-term follow-up and must consent to follow-up.

(7) A well-defined and transparent method must be established to follow donors and study outcomes postdonation, including the following:

(a) Studies of the impact of incentivized donation on the number of deceased and living donors, on the number of transplants (covering all organs), and on the waiting list and waiting time for a deceased donor transplant;

(b) Comparisons of short- and long-term outcomes (including quality of life) of incentivized versus conventional donors;

(c) Studies of whether the incentive had an impact on the donor's life.

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accessed July 21, 2014). Since 1988, a total of about 119,000 transplant candidates have died while waiting; since 1999, currently, more than 6,000 transplant candidates have died *each year* while waiting. At the same time, more than 44,000 transplant candidates have been removed from the waiting list after becoming too sick while waiting even to be able to accept a graft.

Opponents to a regulated system argue that some countries would not be able to implement one, and therefore, any regulated system should be prohibited worldwide. The consequences of such a blanket prohibition are severe, including a shortage of organs, death of transplant candidates while waiting, disincentives to living donation, and development of underground, unregulated markets. No doubt, cultures — and the potential for successful regulation — vary between countries. But unregulated markets have developed even in countries prohibiting incentives for donation. At the same time, we have every reason to believe that countries in Western Europe, as well as Australia, Canada, Japan, New Zealand, and the United States (and, likely, others) would all be able successfully to establish a regulated system as described above.

One way to assess the value of incentives would be to do clinical trials. To date, we have no data on outcomes after establishment of an acceptable regulated system of incentives. Proponents of incentives argue that a trial would determine whether or not any of the opponents' concerns are realistic. The trial would have two major goals: (1) to determine whether donation rates increase and (2) to determine donor outcomes. If the trial were to show increased donation rates but poor donor outcomes (in terms of health, psychosocial or social issues, any regret) as compared with conventionally accepted donors, the system would be unacceptable. Without such a trial, the debate and discussion will go on endlessly, while potentially ideal transplant candidates deteriorate and often die while waiting.

## Summary and Conclusions

In summary, the worldwide transplant community needs to take seriously the following realities: (1) the lack of effective regulation regarding living donation is dangerous to donors and recipients; (2) a significant number of transplant candidates are either dying while waiting or becoming too sick to transplant; and (3) experience has shown that unregulated, underground markets do not protect donors and recipients. Much of the debate about the potential value of a regulated system could be resolved by a clinical trial. Clearly, such a trial needs to be done in a country (or countries) that can develop acceptable systems, as defined by the principles outlined above.

If the government or its designated agency cannot provide full protection of both the donor and recipient, regulation, transparency, and oversight, then, at least in that country, a regulated system should not be considered. But in countries that have maximized conventional organ donation, continue to have a significant organ shortage and can meet the criteria outlined above, a clinical trial of incentives should be considered .

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**Compliance with Ethics Guidelines**

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