



#### JOURNAL OF ORGAN TRANSPLANTATION

ISSN NO: 2576-9359

**Review Article** 

DOI: 10.14302/issn.257-9359.jot-18-2388

## Should All Living Kidney Donors Receive Donor Health Insurance? - Ethical Guidance for Evaluating Policies and Actions that Provide Financial Benefits to Living Organ Donors

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#### Abstract

This review article provides ethical guidance for determining which kinds of financial benefits provided to living organ donors are ethically appropriate. It does so by way of ethical analysis of a policy case study: the National Kidney Registry (NKR) has implemented a donor insurance program to all its living donors. Is such a policy ethically supportable, or is it an unethical practice? The article proceeds as follows. First, a framework for grounding the ethical commitments of transplant programs is defended. It is argued that this framework can be accepted by all who work in transplant medicine, regardless of differences in ethical theory preference or background. Second, from this framework two ethical principles are formulated. (1) Living donors should, as far as possible, not be worse off for donating. (2) Disincentives towards donation should be removed as much as possible. Third, issues with unethical incentives are explored: undue inducement, commodification of the body, potential decreased organ donation rates, and potential exploitation of vulnerable populations. Lastly, these ethically supportable. Financial benefits provided to donors are ethically sound if they are in keeping with principles (1) and (2), and do not cause undue inducement, commodification, decreased organ donation, or exploitation. It is ethically appropriate for transplant programs to institute as well as study such programs with the goal of serving the welfare and interests of patients, donors, and the general public.

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Keywords: National Kidney Registry			
<b>Received:</b> Sep 09, 2018 Acc	<b>cepted:</b> Dec 12, 2018	Published: Dec	: 13, 2018
Editor: Hong-Jiang Wei, Yunnan Agricultural University, China.			
www.openaccesspub.org   JOT CC-license	<b>DOI :</b> <u>10.14302/issn.257-9359.j</u>	<u>ot-18-2388</u>	Vol-1 Issue 2 Pg. no 12



### Introduction

The provision of financial benefits to living kidney donors continue to raise ethical questions. Some financial compensations provided to donors seem reasonable, but when do such benefits cross the line and become unethical or even illegal? This article has a number of goals. First, to provide an overview of what is ethically at stake when it comes to provision of financial benefits to living donors. Second, to suggest an ethical framework that can be used to think through ethical questions when financial benefits are provided to living donors. Third, to define two ethical principles that are central to transplant programs and transplant practice, which we believe guide transplant activities relating to living donors. A hypothesis that will be defended: the framework and principles stipulated in this review will be applicable to and can be endorsed by those who engage in the care of living donors. They can be used to as an ethical guide when considering financial benefits to living donors.

This review will accomplish these goals by use of a clinical case/policy example. The National Kidney Registry (NKR), the largest sharing network for kidney paired donation, considered a policy change, whereby all living donors would be offered basic life, injury, and disability insurance. Does this represent an ethical financial benefit, or should one be concerned by such a policy? How should one think through the ethical issues raised here? The goal is not to focus merely on the NKR or to address the complex issues around how post donation complications are defined. Rather, the suggested NKR policy change is used as a hypothetical case study to explore more general questions around the provision of financial benefits to donors, and to illustrate how one may navigate ethical questions that arise when considering such policies. Recall that the potential harms to living kidney donors can include medical and surgical effects of kidney removal; psychological impact of kidney removal as it relates to quality of life and various interactions with others; and the economic impact of kidney removal both direct and indirect relating to current and future employment.

### **Case Background**

The National Kidney Registry (NKR) is a voluntary network of 86 transplant centers in the United



States. NKR supports living kidney transplants using novel computer algorithms to facilitate exchanges for patients where an intended donor and recipient are either incompatible (by ABO blood group or HLA sensitization), or poorly HLA matched.<sup>1</sup> Many such mismatched pairs are connected in a chain to ensure that all intending kidney donors end up donating and all recipients receive compatible organs. Often such chains are started by a non-directed donors who come forward to donate to someone they do not know for altruistic reasons.<sup>2</sup> Since 2008, NKR has facilitated over 600 chains started by non-directed donors, with over 2800 patients receiving kidney transplants.<sup>3,4</sup> It is presently the policy of the NKR to provide donor insurance to all non-directed living donors who initiate kidney paired exchange within its network.<sup>2,5</sup> This insurance contains life insurance, disability insurance, and coverage for any injuries or complications not covered by the donor or recipient's insurance.<sup>2,5</sup>

The policy takes effect when the donor leaves home to travel to the donation site, and terminates one year after any post-donation complications. It is meant to provide coverage for any losses that may be incurred through donation and not covered by other insurance policies, including travel accidents, disability, or loss of life. Medical complications are defined using the exact Medicare definition, and must be a direct result of the donor surgery. The medical complications expense benefit is \$250,000 with a \$5,000 deductible. Accidental death and dismemberment is for one year and provides up to \$1 million of coverage for accidental deaths and dismemberment. The temporary disability benefit pays \$100 per week up to a maximum of \$1,500. The permanent disability benefit pays \$5,000 per month up to a maximum of \$250,000. It is a similar insurance program that is offered by the Living Donor Organ Network through member centers. The insurance costs about \$550 per donor, which is paid by the NKR.<sup>2,5</sup>

The idea for provision of such insurance to all living donors has developed from initial work done by the South Eastern Organ Procurement Foundation (SEOPF).<sup>6,7</sup> SEOPF tracked the outcomes of living donors and extended optional insurance to cover complications to participating centers in the early 2000's, at the cost of \$550 per donor.<sup>6,7</sup> The decision to apply this





non-directed donor benefit was made by the Medical Board of the NKR after careful consideration; now called the Donor Protection Program.

### **Ethical Question**

The NKR is considering a policy change to include a wider scope for its potential living donors. The suggestion is to extend donor insurance to all living donors who donate through the NKR, rather than just to non-directed donors. Central ethical questions include whether extending insurance to all NKR donors could be considered an unethical valuable exchange or unreasonable inducement to donate, or whether such insurance would constitute unfair inducement for donors to work through the NKR rather than through other transplantation programs. Given these potential concerns, can it be ethically supported to extend donor insurance and prioritization for future transplantation to all NKR living donors? This analysis will tease out the impact of this proposed policy change within the NKR, and suggest an ethical framework for use by other transplant centers or networks that may consider similar policy changes.

### **Ethical Framework for this Analysis**

In transplantation, we are concerned with fairly distributing a scarce resource among many persons in need. We are also concerned with the interests and welfare of donors, the interests of the public, and fair stewardship of this scarce resource. To balance these various interests and to determine rules for distribution, a utilitarian approach to distribution is often utilized. Utilitarianism states that right actions (or policies) are those that lead to the greatest good for the greatest number of people. That is, policies are set to ensure that the scarce resource provides the greatest benefit to the greatest number of affected patients. This forms the basic foundation for grounding various ethical commitments and goals in transplantation. Even if one holds to another ethical approach or theory, this framework can still be recognized as applicable and foundational to transplantation.

In Medical Ethics, we are often focused on obligations owed by the clinician to the individual patient. Commonly applied Medical Ethics frameworks reflect this. For example, deontology is an ethical approach that says ethical rules describe duties and obligations clinicians owe to their patients. One such approach is that ethical rules may be derived from the inherent worth and dignity of the patient as a person. The Kantian idea of respect for persons has been very influential in Medical Ethics, and may be used to derive ethical rules and duties owed to the patient because clinicians respect the patient as a person and do not merely regard a patient as an object. Such rules include respecting the patient's right to direct their own medical care and make their own decisions, refraining from deception or dishonesty, helping patients to the best of one's ability and skill, and the like. Another well-known ethical framework is the principles framework. It recognizes four principles that describe the ethical commitments of clinicians within the clinician-patient relationship. The clinician should provide benefit, avoid harm, and respect autonomy, while also being concerned with justice. These frameworks generally focus on what is owed to the individual patient. The clinician has obligations to serve the interests of the individual patient as described by these moral rules or principles.

There may therefore appear to be a tension between commonly applied frameworks in medical ethics and the utilitarian framework we use in this analysis. We maintain that these are compatible, given the unique relationships and resource limitations that constrain transplant centers. We argue that even the deontologist or principle-based ethicist will on reflection acknowledge the validity of the utilitarian distribution framework that will be used as basis for this analysis.

The deontologist and principlist are concerned respectively with rules and principles that govern patient-practitioner relationships and protect the interests of the individual patient. However, when it comes to transplantation of scarce human organs, we are confronted with many patients who are competing for said organs, and living donors whose interests must also be protected. In trying to secure and protect the interests of individual patients when deciding how to distribute this scarce resource, the deontologist and principlist will try to serve the interests of each individual patient fully as required by their Medical Ethics frameworks, but will fall short because of the restricted nature of the resource. What we end up with is a utilitarian type distributive system, which seeks to serve





the interests and welfare of all those competing patients and donors to the maximal degree possible. It allows the clinician to fulfill obligations owed to the most patients and to the greatest extent possible. The utilitarian guiding principle used in this report will be that transplant policies should seek to maximize the interests and welfare of the most people, including the kidney recipient, the donor, the program and its professionals, and the public.

# Two Important Ethical Principles in Support of Compensation and Donor Protections

The transplant center must serve the interests of the most patients and donors possible to the maximal extent possible, given the inherent resource-limitations in transplantation. From this ethical basis, two ethical principles can be stipulated regarding protection of living donors. In contemporary clinical practice these principles are widely accepted in the transplant community, even if they are not explicitly stated, and are part of the guiding principles of transplant programs.

## 1) Living Donors Should, as far as Possible, not be Worse off for Donating

In clinical practice this means that the harms associated with donating a kidney should be minimized or mitigated as far as is possible. This idea can be justified in a number of ways: (a) If donors come to harm or suffer financial setbacks because of donating, it decreases the welfare of those donors with negative consequences for affected donors, their families, and the public. (b) Donation related harms and financial setbacks would make people less likely to donate and have a negative impact on the donation process, patients needing transplants, and consequently the broader public. (c) It is in keeping with obligations of harm avoidance or non-maleficence central to medicine, which can be grounded in any of the approaches to bioethics.

Donors must accept various risks when agreeing to donate, and harms cannot always be avoided. A central tenet for those obtaining informed consent from donors is to outline reasonable expectations of risk so that donors have the necessary information to support their decision to donate. In clinical practice harm to donors should be avoided or minimized so that donors are no worse off for donating. When it comes to financial matters, this means donation should be a financially neutral event for the donor.<sup>8</sup> Transplant programs should strive towards ensuring that donors are not financially penalized or that they do not fall behind due to kidney donation.

## 2) Disincentives Towards Donation Should be Removed as far as Possible

The idea of removing disincentives to donation (and particularly financial disincentives) have been advanced by several authors.<sup>8,9,10,11</sup> The principle of removing disincentives can be justified in at least two ways. (a) Disincentives present barriers to donation, and are likely to decrease organ donation rates. They should therefore be removed to prevent their negative effect on organ availability for those waiting for transplants. (b) Disincentives generally are negative or harmful things that may befall donors. Such harmful things affect the welfare of donors negatively, and should therefore be removed.

# Ethical Arguments: When is a Financial benefit Unethical?

Authors usually distinguish between compensation and financial incentives as different forms of payment to living donors.<sup>12,13</sup> Compensation is usually thought of as money paid to make up for a loss or to reimburse costs. This could include reimbursement of travel expenses or hospitalization costs.<sup>13</sup> Incentives are financial benefits given to encourage donation, and does not focus on merely replacing what was lost or reimbursing costs associated with donation.<sup>12,13,14</sup>

There is an ethical and legal distinction between compensation and incentives as defined above. Legal and ethical norms tend to support compensation; financial payments for donation related costs are permitted by American law.<sup>13,15</sup> Incentives can be more ethically complex and problematic, and appear to be inconsistent with American jurisprudence.<sup>15</sup> Financial incentives are explicitly forbidden in the NOTA legislation which regulates transplantation. The law does allow financial payments to cover "expenses of travel, housing, and lost wages incurred by the donor".<sup>15</sup> Financial incentives may therefore place transplant programs and donors at legal risk. This would have substantially negative effects for said transplant programs, their patients and donors, and cannot be





ethically supported under present legislation.

Apart from the issue with present legislation, there are generally four arguments offered to show why financial incentives are thought to be ethically problematic.

# 1. Undue and Unreasonable Inducement in the Decision to Donate<sup>13,15,16,17</sup>

The argument is that if incentives are provided, it may induce people to donate who would not otherwise do so. In a sense, the incentive interferes with the voluntariness and freedom of the decision to donate and holds sway over the person that influences their ability to provide informed consent. In addition, it is often thought that the greater the benefit or payment, the greater the risk of unreasonable influence over the decision to donate. Even if incentives increased short term donation rates, they would not serve the greater interests of all. If the freedom of people to choose are undermined, their interests are compromised.

## 2. Some Things are too Valuable to Sell – Commodification of the Human Body<sup>13,17,18</sup>

The argument states that not everything should have a financial value, and not everything should be sold in markets. Placing a financial value on things that are intrinsically valuable cheapens them and should not happen. For example, freedom is of incalculable value; it would not be ethical to allow someone to sell their freedom. Related to this argument is the idea that a gift of a transplant organ is a different kind of interaction than selling an organ. The first is a gift, an altruistic act, one where one person helps another because of moral considerations. The second is a commercial transaction, reducing the participants to buyer and seller, or to businessperson and customer, which is argued to be the wrong motivation for donating or receiving an organ. It changes the type of interaction, and necessarily changes the relationship and obligations that exist between the parties.

# *3. Some Potential Donors would not Donate, Leading to Decline in Donation Rates*<sup>13,14,17</sup>

The argument is that providing incentives would change the nature of the interaction from an altruistic action between equals to a business transaction. This would lead to a moral repugnance among some potential donors, who would then decline to donate. These ideas are based on the theoretical work of Richard Titmuss, who compared the altruistic blood donation system in the UK with the financially incentivized blood donation system in the US.<sup>19</sup> He argued that providing financial payments to blood donors would decrease blood donation rates and quality. The central idea is based on crowding out theory, an economic theory which states that certain altruistic behaviors will decrease if incentives are added.<sup>20</sup> Allowing payment for altruistic gifts and acts changes the meaning of these acts, leading to a paradoxical decrease in such acts. Essentially, the psychological value and goodwill an altruistic donor places on their decision to donate would be lost, making donation less likely. A 2008 economic study provided some evidence for Titmuss' conclusions; in this study financial payments significantly decreased the amount of female blood donors due to a crowding-out effect.<sup>21</sup> A concludes "limited 2013 meta-analysis evidence suggests that Titmuss' hypothesis of the economic inefficiency of incentives is correct".22 The concern is that something similar could happen with financial incentives relating to kidney donation. Donation rates would decrease, and the psychological and goodwill benefits to donors would decrease.

# 4. The Risk of Taking Advantage of the Poor and Marginalized<sup>13,13416,17</sup>

Those who are lower on the socio-economic spectrum may perceive an even greater inducement to donate when incentives are introduced. Some have argued that the poor are especially vulnerable to unreasonable influence caused by financial inducements, and that their autonomy with regards to donation is substantially affected by financial incentives.<sup>16,17</sup> Studies done in developing countries where organs can be exchanged for money show that many poor people sell organs to cover debt or costs of living, often purely for economic reasons.<sup>16,22</sup> In many cases, the money received does not ultimately alleviate the financial need that motivates donation, and the donor is often worse off.<sup>17,23</sup> The fear is therefore if incentives are introduced, the poor and vulnerable will be at risk of exploitation; the organs of the poor will be used to benefit the rich, while the poor will not get an equal benefit in return.





These arguments have remained persuasive to many, and exchanging valuable considerations for organs therefore remains illegal. Some authors have argued that they are mostly theoretical or conceptual based in normative and arguments, ethical argumentation, and have not been extensively empirically tested.<sup>12,13</sup> These authors suggest that studies should be done to determine the empirical validity of these arguments.<sup>12,13</sup> The need for transplant organs is great, they argue, and if incentives can raise donation rates without compromising important interests of living donors, it would be justified. Studies done in the black market in developing countries do not necessarily reflect what would happen in a regulated incentive system in a developed country. Also, surveys in the United States suggest that smaller payment amounts could encourage donation without being perceived as an undue inducement.<sup>24</sup>

It is therefore controversial to what extent incentives can be consistent with the ethical obligations of the transplant program. At the very least, we can state that any incentive that is likely to lead to unreasonable inducement, commodification of the body, decline in donation rates, or exploitation of the vulnerable is ethically problematic. Financial benefits provided to donors should therefore be scrutinized carefully to see whether such benefits are out of bounds.

## Is it a Compensation or an Unethical Incentive? Applying these Considerations to the Suggested NKR Policy Changes

Extending donor insurance to all donors clearly provides a financial benefit to donors. The insurance provides coverage for possible complications and harms directly associated with the act of donation. It is therefore an avenue for managing possible donation associated harms and losses that are not financially provided for in another way. The goals of donor insurance therefore seem onsistent with removing disincentives to donation, and ensuring that donors are as far as possible no worse off for donating.

The insurance policy costs \$550 per donor, and as such is not an extraordinary amount, nor is it paid directly to the donor. Rather, an insurance benefit is provided that would only cover donation related complications. The potential for unreasonable inducement seems quite small. Insurance is an effort at harm mitigation and reduction of financial loss, rather than providing valuable exchange for the organ. Given these considerations, it does not appear as if there is any risk for creating a business transaction or placing a price tag on a kidney.

The risk of exploitation of the vulnerable appears minimal, as those who are poor will not be financially better off after donation. The policy is meant to remedy donation related risks and losses, and not offer financial inducement. It may replace financial losses, but the insurance does not generate new income. In addition, the usual process for donor evaluation will remain, which includes an additional set of safeguards against exploitation. In particular, the Independent Donor Advocate, a required participant in the living donor evaluation and informed consent process at all transplant centers, will be present to monitor possible exploitation. It therefore seems unlikely that donor insurance would lead to exploitation of vulnerable and marginalized patients.

One possible concern some may raise is that availability of donor insurance through the NKR may provide incentive for donors to work with NKR rather than other paired exchange networks who do not offer such insurance. This concern does not hold up to scrutiny, since donor insurance is aimed at removing donation disincentives and mitigating donation related losses. If one transplant program offers an injury or loss management program when others do not, it is not

unfair or unethical for donors to prefer that program. For example, if one transplant program introduces innovative surgical procedures that have evidence based lower complication rates and/or better outcomes for donors, it is very reasonable that donors would choose that program. On the contrary, one can argue it would be incumbent on other transplant programs to consider implementing similar procedures if they are shown to improve donor outcomes. Similarly, if the NKR implements a program that aims at removing disincentives and mitigating donation related risks, it would be incumbent on other programs to consider such practices.





## Other Considerations – Considering Cost and Unintended Effects

Extending insurance to all donors would incur costs to the program. It could represent a substantial financial investment, given the amount of paired exchanges facilitated by NKR. The increase in cost may well be justified by the ethical goals of removing disincentives and ensuring donors are not worse off for donating. However, it would be important to consider whether there are other means by which these same goals could be reached at less cost. Simply put: is the donor insurance the best use of the program's resources, or are there other ways in which the program can remove disincentives and compensate donors at a lower expenditure? A notable alternative use for such funds would be reimbursement for lost wages. Such reimbursement would also aim at removing disincentives towards donation and ensuring that donors are no worse off, while potentially increasing donation rates. Is this a better use of the program's financial resources, or should both benefits be considered? The lost wage coverage is currently being evaluated by the American Society of Transplant Surgeons.<sup>25</sup> Keep in mind that any increase in costs should not place the kidney paired exchange program at financial risk or compromise the program's other activities. Such actions would be against the ethical goals of the program. Admittedly, our paper focuses on laws and practices in the USA, but the purpose of our paper was to outline the ethical principles that can be applied when decisions involving financial transfers to donors are made. These principles are universal.

Finally, should any of these compensations be offered, the impact and cost-effectiveness of these interventions should be studied. In this way any unforeseen effects can be detected early, and permit appropriate changes in policy. Furthermore, by studying the policy and its effects valuable data can be generated that can provide guidance for other transplant programs who are considering similar compensation policies. Underlying any programmatic financial considerations should be the goals of doing more kidney transplants, removing more patients from dialysis, while leaving donors no worse off for donating, thereby reducing healthcare expenditures. This results in a net gain for society in general.

### Conclusion

This review provided tools that can be used to address ethical questions regarding financial payments to living donors. A framework to ground and analyze the ethical obligations and commitments of transplant programs was described: namely, to serve the interests of the greatest number of stake-holders to the maximal amount possible. This framework was used to defend two principles that should govern all policy and actions that affect living donors, as far as possible: (1) Living donors should not be worse off for donating, and (2) Disincentives towards donation should be maximally reduced. Reasons why incentives may be problematic were reviewed, and it was concluded that any ethically sound financial benefit should not be an undue inducement, should not commodify the body, should not decrease donation levels, and should not exploit the poor or vulnerable. These considerations can be used to evaluate financial benefits offered to living donors, as was demonstrated by use of a case study. The ethical framework and principles defended in this article can be used to analyze any future policy proposal at a transplant center regarding financial benefits paid to living donors.

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