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Position Statement of the INTERNATIONAL TRANSPLANT NURSES SOCIETY on Financial Incentives for Organ Donation

Background

The issue of financial incentives for living and/or deceased organ donation has concerned health policy makers and professionals working in organ donation and transplantation since the 1980s. For more than three decades transplant professionals, philosophers, legal scholars and members of the public across the world have debated whether the use of incentives would increase the supply of organs available for transplant, and whether a legal incentive system would be ethically justifiable.[1-10]

The evidence from the international black market in organs and the legal market in kidneys in Iran has underpinned widespread concerns regarding coercion and exploitation of the poor, harmful health and socioeconomic outcomes for organ vendors,[6] risks for recipients of commercially procured organs,[11,12] and the negative influence of incentive programs on altruistic donation and equitable programs of organ allocation.[13] Accordingly, most countries performing organ donation and transplantation have implemented legislation prohibiting payment for organs, consistent with World Health Assembly Resolutions 44.25 and 63.22 and the World Health Organization (WHO) Guiding Principles on Human Cell, Tissue and Organ Transplantation.[14] Further, numerous national, regional and international professional societies and organizations have published position statements and policies rejecting the use of financial incentives, including The Transplantation Society,[15] the National Kidney Foundation,[16] the British Transplantation Society,[17] and others.[18] Others have specifically addressed and condemned payment for organs in the context of ethical guidelines or commentary on organ donation, including international religious authorities.[19-24] In addition more than 100 societies, including the International Transplant Nurses Society, have endorsed the 2008 Declaration of Istanbul on Organ Trafficking and Transplant Tourism, which advocates the prohibition of transplant commercialism. [25,26]

Nevertheless, proposals for "regulated markets" or "trials" of incentives for living and/or deceased organ donation are intermittently made public, most recently in the United States.[1,27,28] Some professional organizations, such as the American Medical Association and the American Nephrology Nurses Association, have published position statements tentatively supporting unspecified "trials" of incentives for deceased or living donors respectively.[29,30] Of note, many trial proposals suggest offering "incentives" that should rightly be described as payments to reimburse donors for costs incurred, rather than to provide them a financial gain. Confusion and conflation of these two distinct strategies has hampered public and professional debate, and possibly undermined advocacy of legal and ethically uncontroversial proposals to remove disincentives for donation.

Rationale

The introduction of legal financial incentives for donation may have serious implications for ITNS members and the patients they care for. ITNS members working in some countries may also be regularly confronted with the use of illegal incentives. This position statement will provide guidance for ITNS members in their professional practice and advocacy work on

behalf of ITNS colleagues and patients.

Significance and scope

This statement aims to communicate the ITNS position on financial incentives for organ donation to members, other health professional organizations, patients and the general public.

The social and regulatory impact of position statements such as this is significant in the current climate of active lobbying for the introduction of "pilot" incentive programs in the US, which in turn exerts a strong influence on policy makers and professionals internationally. Hence this proposal is developed with consideration for the global context, not merely that of the United States.

Terminology:

In the context of this position statement, the term "incentive" refers to all forms of material gain or comparable advantage offered in exchange for consent to living donation or authorization of deceased donation of organs, whereby the prospective recipient of the incentive may reasonably expect an improvement in their financial status compared with their expected status if they refuse donation.

Incentives

Incentives may consist of direct "lump sum" payments, or receipt of material "benefits" or subsidies such as scholarships for tuition, tax credits, subsidized funeral services or health insurance, when in the absence of donation the recipient would otherwise be required to pay in order to obtain such goods or services. The World Health Organization, in its commentary on Principle 5, notes, "National law should ensure that any gifts or rewards are not, in fact, disguised forms of payment for donated cells, tissues or organs. Incentives in the form of “rewards” with monetary value that can be transferred to third parties are not different from monetary payments".[14]

Removal of Disincentives

Incentives such as those described above should not be confused with interventions that merely remove disincentives to donation but which do not leave the recipient materially advantaged - financially better off - compared with their situation if donation did not occur. For example, provision of necessary travel and accommodation services for living donors or reimbursement of the costs thereof will not leave donors better off, as they would not incur these costs in the absence of donation. Similarly, provision of health or life insurance to specifically cover living donors against the medical risks associated with donation or to assure necessary follow up care is provided is not an incentive.

Payment of funeral expenses for deceased donors represents an incentive, as families would be required to pay such expenses in the absence of donation. However, any additional medical costs associated with deceased donation - such as extended duration of stay in the intensive care unit to enable donation - represent potential disincentives, costs directly associated with donation, and reimbursement or coverage thereof is not an incentive for authorization of donation.

Review of the key issues:

Living Donation

1. Removal of financial disincentives to living donation

Potential or prospective living organ donors may be discouraged or prevented from donating due to the financial costs that may be associated with screening, organ procurement and/or follow up care (see **Box 1**).[31,32] In the United States it is estimated that many living organ donors from low-income households incur travel costs of $2767 and lost wages of $2784, and prospective donors who do not complete donation may incur travel costs of $1077.[33]

There is widespread consensus that removal of such disincentives is ethically acceptable, and would ideally represent best practice for living donors by protecting donors against financial harm and reducing inequities in access to living donation opportunities.[34] Some countries have implemented programs seeking to address some of the financial disincentives to living donation, including Australia[35] and the United States,[33,36] but many do not.[37] The World Health Organization, the Declaration of Istanbul and numerous professional society position statements encourage efforts to remove disincentives to living donation[14,17,19,22,25] and international research has demonstrated public support for interventions that would address the costs potentially associated with living donation.[38,39]

Box 1 - Potential costs incurred by prospective living organ donors

- Medical:
  - Medical and psychosocial evaluation and care during screening and organ procurement, medications, treatment in the event of complications and routine post-donation follow up care
- Travel and accommodation:
  - For donors (and potentially family members) to attend medical appointments and undergo organ procurement
- Employment:
  - Loss of wages during time off work
- Social
  - Costs of childcare, care-giver replacement or assistance, or other service providers required to replace the donor in their home while they are unable to perform their customary household duties or caregiver duties
- Insurance
  - Health and/or life insurance costs where insurance is required to protect the donor against future events that may occur as a result of undergoing organ donation, or where the costs of routine or pre-existing insurance premiums are increased following donation

2. Provision of financial incentives to living donors

Most proponents of incentives rely on two core empirical claims: (i) that a legal program of incentives for living donation would result in an overall increase in supply of organs for transplantation;[40] (ii) that in a legal program, the harms associated with illegal organ markets could be avoided.[5] Proponents may additionally argue (iii) that individuals have a right to sell their own organs;[41] (iv) that provision of incentives represents a fair reward for donors; [42] (v) that incentives are a form of compensation addressing potential disincentives to donation such as "pain and suffering" to which a financial cost is less readily attributed.[3] Incentive proposals are often framed by the claim that incentives are *necessary in order to save lives*, that is; in the absence of incentives, there will be insufficient motivation for donation, and hence insufficient supply of organs to meet demand for transplantation, resulting in deaths that could be avoided if incentives were introduced.[43]

- *Estimating the impact of incentives on organ supply*

It is plausible that, in some countries, the offer of sufficiently large incentives for living donation may increase the supply of - at least - kidneys for transplantation, as has been the case in Iran, where a legal market was introduced in 1988.[44] However, it is also plausible that in other countries - especially those with well-established altruistic donation programs and social welfare systems - incentives may be less effective in recruiting donors. Potential organ donors are likely to be more susceptible to financial incentives in countries with high rates of poverty and limited social support systems. Further, there is evidence that where organs may be purchased, potential living related donors are significantly less likely to donate, as has occurred in Iran.[45] Commercialization of living donation may also exert a negative influence on altruistic deceased donation by compromising public trust in the integrity of donation and transplant programs and by undermining societal recognition of donation as an ethically praiseworthy act.

- *Estimating the efficacy of regulation in preventing harm*

Like the impact of incentives on organ supply, the ability of hypothetical regulated incentive programs to successfully prevent the harms associated with illegal organ markets remains a matter of speculation. In countries with sufficient resources to enforce regulations and closely monitor incentive programs, it may be possible to reduce the risks of coercion and exploitation of donors, through enhanced procedures for obtaining consent and ensuring donors received promised payment of a sufficiently large incentive. It may also be possible to reduce the risk of poor health outcomes associated with organ selling in the black market through screening and routine provision of free follow up care.

Nevertheless, use of financial incentives will place the burden of donation predominantly on poorer members of society, undermining the justice inherent in altruistic programs in which all members are encouraged to donate and efforts are made to promote equity in access to transplantation for all. Further, the physical and psychosocial risk profile of the potential paid donor population is likely to differ from that of current altruistic donor populations.[46] Increased risks of poor psychological outcomes for paid donors, for example, may be less easily detected during screening. Psychosocial risks are particularly concerning given the probability that stigmatization of paid donors noted in black markets is likely to persist despite legalization of incentives, as has occurred in Iran.

Although the risk of coercion of paid donors may be reduced through careful consent procedures, the commercialization of donation creates increased opportunities for coercion of the poor. The use of organs as collateral for loans could be prohibited, but financial pressures may nonetheless compel individuals to donate an organ in return for payment despite their preference not to do so.[2]

- *Minimizing risks and pursuing evidence-based solutions to the organ shortage*

In short, even in the ideal circumstances of hypothetical incentive program proposals, serious ethical concerns remain. In this context, the argument that incentives are necessary to save lives plays a critical role in garnering support for incentive proposals. Yet, there are numerous strategies of proven efficacy in increasing donation and preventing premature loss of life from organ failure which are not ethically controversial. Among these, removal of barriers to living donation has been clearly identified as a strategic priority.[33,34]

- *Considering the global impact of incentive proposals*

Of note, the ideal conditions conceived by incentive proponents are unlikely to prevail in many countries, making effective regulation of legal incentive programs problematic. Evidence from the Iranian experience supports the claim that the harms of the black market will not be avoided by legalization.[5,44,47] Overturning the established international consensus that financial incentives for living donation should be prohibited, through legalization of incentives in a country such as the United States, is likely to result in a rapid change in policy in less developed countries such as those that have previously struggled to combat organ trafficking.[48,49] While incentive proposals are often conceived as a domestic concern, the evidence of legal and illegal international travel for transplantation and the declared willingness of some policy makers and incentive advocates to endorse international trade in organs means that such proposals must be considered in the context of globalization of healthcare services. The opening of legal markets in organs across the world is likely to result in systematic outsourcing of organ donation to societies that suffer not from a surplus of organs, but a shortage of income earning options. In this setting, regulation of legal incentive schemes is unlikely to be effective, and exploitation, inequity and harm to organ vendors and transplant recipients will undoubtedly ensue.

Deceased Donation

1. Provision of financial incentives to families authorizing deceased donation

The provision of incentives to families authorizing organ procurement from a deceased relative is often portrayed as less ethically problematic than offering incentives to living donors. However, families may be economically vulnerable at the time of a relative's death, and offering a financial incentive in return for authorization for donation may be exploitative.[49,50] Incentives may place families at risk of social stigma and psychological harm, especially where a genuine reluctance to approve donation is overcome by financial necessity. Incentive offers also introduce potential conflicts of interest in end-of-life decision making for family members and potential organ donors. Although careful oversight of donation programs may protect against corruption, public trust in the integrity of the determination of death and end-of-life care providers may be undermined.[50]

Research in the United States reveals that where an individual has previously registered their preference to donate, few families decline donation,[51] thus registries play a key role in increasing authorization rates for deceased donation. In a recent Canadian study, 89% of public respondents who indicated they would not join a deceased donor registry were unwilling to join in return for payment.[39] There is well-established evidence for strategies known to improve rates of family authorization for deceased donation.[52,53] In contrast, there is at best limited evidence of success from the Saudi Arabian experience of incentives for deceased donation.[54]

Trials of incentives for living kidney donation (LKD)

The introduction of trials of incentives for LKD has been repeatedly proposed in the United States as necessary to evaluate the impact of incentives on supply of kidneys and to determine if the ethical concerns of incentive opponents are borne out in a regulated market. Trials are portrayed as a compromise by market proponents: offering a scientific method to objectively resolve the continued ethical debate, and allowing for the possibility of returning to the status quo - prohibition of incentives - if the results of trials prove incentives ineffective in increasing kidney supply, and/or if the impact of incentives is sufficiently harmful to outweigh the benefits of an increase in supply. However, trials pose three key concerns, in addition to those cited above, with regards to incentives for living donors:

1. If incentives prove unsuccessful and/or if the harms of incentives are found to outweigh the benefits, successful restoration of the prohibition on incentives may be difficult;

2. Any such trial would constitute a clinical trial, and as such should be subject to rigorous ethical and scientific review. As yet, incentive trial proponents have declined to share a detailed plan of a possible trial. Details of eligible participants, magnitude and method of delivery of incentives, the scale and duration of the trial, how success would be evaluated, and what measures would be taken to mitigate against negative outcomes are lacking.[49] In the absence of such information, it is impossible to evaluate the merits of hypothetical trials, which must be considered, for example, in the light of existing evidence concerning risks of living nephrectomy for prospective participant populations.[46]

3. Given the risks of incentive trials, and the limited evidence to suggest they will prove successful, it seems unwise to invest in inevitably complex, lengthy and controversial "pilot studies" of incentives, when there are numerous strategies of proven efficacy, legality and ethical value that have yet to be fully implemented such as comprehensive removal of financial disincentives to living related donation.

ITNS Recommendations

ITNS endorses the recommendation of the World Health Assembly and the Declaration of Istanbul that financial incentives for living organ donation be prohibited, as they pose unacceptable risks to potential donors and vulnerable communities across the world, undermine efforts to promote equity in donation and transplantation, and may endanger the progress achieved through best practice in altruistic donation programs.

ITNS endorses the World Health Assembly recommendation that financial incentives for authorization of organ procurement from deceased persons should be prohibited, recognizing that the next of kin may be vulnerable to harm including exploitation and coercion, and concerned that payment of incentives would undermine public trust in the process of deceased donation.

ITNS further strongly supports the recommendation of the World Health Assembly, the Declaration of Istanbul and other professional organizations that greater efforts be made to remove financial disincentives to living donation, so as to improve supply of organs for transplantation and reduce inequities in access to living donation.

ITNS rejects proposals for the trial of incentives for living donors, due to the fact that a number of evidence-based strategies of proven efficacy in increasing organ donation have yet to be implemented and should be prioritized, and that although trial risks may be reduced in a highly regulated environment, the legalization of trials in developed countries may exert a negative influence on policy in practice in countries with less capacity for effective regulation.

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