

Directed Organ Donation – Ethical Considerations

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The demand for organ donors in Canada is increasing, and despite an increase in organ donors, especially living donors, many patients die while waiting for an organ transplant [1,2]. Over 4,000 Canadians are awaiting life-saving organ transplants, 75% of which are kidney transplants [2]. Within this context, should potential recipients be encouraged or permitted to solicit donations from the general public? Should living donors be permitted to direct their donors to specific recipients?

All societies must ration a limited number of health resources. The number of organs available for transplant is limited by the number of donors, both deceased and living, and our society manages this scarcity with wait lists. In this case, an 18-year old patient with end-stage diabetic nephropathy, has addressed the limited supply of organs by soliciting a kidney donation from a stranger over the internet. Not only will the donation provide potentially life-saving therapy, but it also will move forward on the waiting list everyone awaiting a kidney donation who was prioritized lower than the recipient. A kidney transplant saves public coffers \$250,000 over a five-year period, compared to dialysis [3].

Potential recipients may be best placed to encourage organ donation. They know their condition and its effect on their lives, and they stand to gain the most from successful

solicitation. However, what may be seen as a simple solution to address organ shortages is rife with ethical quandaries.

When considering the allocation of non-directed donations, a balance must be struck between the principles of distributive justice and utility. Distributive justice refers to equal treatment unless need differs, regardless of morally irrelevant criteria, such as religion, sexual orientation and socioeconomic status [4,5]; utility refers to using resources for optimal overall benefit [4]. Universal access to healthcare is a fundamental principle of the Canada Health Act of 1984 [6]. A reasonable application of these principles in the context of organ allocation results in a policy that allows access to a wait list for all those who need a transplant, and that ranks patients using a combination of need and benefit.

Donor solicitation disrupts this careful balance, as it offers significant advantage to those with better health, greater social influence and more access to financial resources.

Individuals with low socioeconomic status and those who are otherwise marginalized, by poor health, language barriers, or disability, may find it much more difficult to meet a willing donor. There is ample opportunity to misrepresent both need and benefit, deliberately to gain preferential consideration, or ignorantly due to a lack of understanding of the recipient's own prognosis. One may argue that any increase in the number of donors helps the entire wait list by treating one patient. However, those in the greatest need, who are unable to solicit a donation, sit already at the top of the wait list and therefore do not benefit. In addition, a campaign to educate the public about organ transplants and the plight of those in need is most likely to have the greatest effect on the same population as

would respond to donor solicitation: those who require little convincing to donate. Even in the absence of such a campaign, would it be reasonable to expect that if not solicited, this same subset of “near-donors” may decide at a later point to become a living or deceased donor?

A physician has a responsibility to society, to preserve the integrity of healthcare delivery and to allocate resources among those in need, as well as to his or her patient, to maximize health. While encouraging individual donor solicitation addresses the latter, it disrupts just delivery and equal access to care. However, in the absence of law [7], a donor may wish to direct his or her organ(s) to a specific recipient, regardless of the circumstances. Any organ transplant from a living donor balances autonomy with non-maleficence.

In this context, autonomy refers to the ability of the potential donor to weigh a decision to donate with full information about the procedure and without physician influence. Organ donation conflicts with the principle of non-maleficence, as does any procedure with risk. Living kidney donation carries a morbidity risk of 1.3%, with a mortality as low as 0.03% [8]. For the donor, as in blood donation, a significant psychological reward, knowing that he or she may have saved a life, often outweighs the risk of the surgery.

This psychological reward is not questioned when the donor is closely related to the recipient. A family member, for example, makes an autonomous decision to donate to save the life of a loved one and preserve or strengthen a family unit. Family members are also usually well aware of the risks to both donor and recipient in the presence and absence of

the transplant. A physician should provide complete information about the transplant, but may be reasonably assured that the donor is making an informed, autonomous decision which benefits both the donor and the recipient.

A close friend or step-sibling may be in a similar position to a family member, but does the same argument apply in the case of a potential donor who is only distantly acquainted with the recipient? An extreme case is presented, where the donor has no previous relationship with the recipient. However, if the two are part of a community such as a church group or a shared office environment, and if they connected by an announcement or a memo, it may be impossible to distinguish fairly between a relationship that would exist without the transplant and one that would not. Thus, a physician, acknowledging this ignorance, should diligently apply the same principals to each case.

When counselling a patient considering living, directed donation, a physician should thoroughly explain the transplant procedure and the associated risks. The physician should explore the patient's motivations and conduct a psychosocial screen. Though it is not possible to measure the psychological benefit of donation, it is important to determine that one exists and that the patient considers it greater than the transplant risks.

Significant psychological distress or disorder may influence a patient's decision and may increase the risk of post-operative psychological distress, and a physician may not accept a donation with such risks, on the basis of non-maleficence.

In recognition of a physician's responsibility to society, an explanation of wait lists is warranted but must be approached sensitively, as intent to influence the patient's decision violates his or her autonomy, whereas the provision of information about non-directed donation allows the patient to evaluate both options.

Given that the expected benefit to the donor is related to the benefit to the recipient, the potential donor may use the recipient's condition and prognosis to decide whether or not to donate. As discussed earlier, this information provided by the recipient to the potential donor may be misrepresented or simply incorrect. The physician needs to obtain the recipient's consent to access his or her medical records and to share them with the donor. In the absence of such consent, the physician can only encourage the donor to explore this with the recipient and caution that the possibility to misrepresent information exists.

End-stage diabetic nephropathy is a condition that typically takes decades to develop, the risk of which can be reduced by strict diabetes therapy [9,10]. A history of non-compliance and follow-up decreases long-term success of an organ transplant [11,12]. This may affect the allocation of organs in non-directed donation, where organs are prioritized according to both need and benefit. In directed donation, a patient with this information still has capacity to make an autonomous decision to donate, if he or she chooses. In the absence of information about the recipient, a physician can provide medically relevant details about the disease, but should avoid judgment, both moral and clinical, of the recipient's individualized condition.

Lastly, along with the risks of transplant surgery, the physician should discuss the implications of the relationship between the donor and the recipient. In non-directed donation, the donor and the recipient are sheltered by anonymity, from both blame and guilt resulting from complications or an unsuccessful result. This potential for blame is a risk of directed donation. Though protected by dual informed consent, significant distress from blame or guilt may arise from such circumstances, and any patient considering a directed donation should be made aware of this risk.

The need for life-saving organs far exceeds the supply of willing donors. Despite a clear benefit to individuals who successfully solicit organ donations, donor solicitation creates inequities, chief among them a lack of equal access to transplantable organs. While this practice can be discouraged, it is unethical to deny individuals with capacity the ability to make an autonomous decision to become a living donor. Within the constraints of confidentiality and non-maleficence, physicians should provide non-judgmental information to all patients considering a directed donation, with a complete discussion of the potential risks and benefits of the transplant. Following that, patients should be given autonomy over their bodies and the organs contained within.

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