



Title: Public solicitation of anonymous organ donors: A position paper by the Canadian Society of Transplantation

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AUTHORSHIP

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Ms. Linda Wright and Dr. Daniel Buchman drafted the position statement based on the discussion. The draft was discussed among the working group members during teleconferences and was modified according to the discussions. Finally, this document was modified following the CST membership commentaries. All authors approved the final version.

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Introduction:

Worldwide, there is a gap between the supply and demand for organs. Canada is no exception. For instance, at the end of 2014, 4,514 patients (among which 3,473 were waiting for a kidney and 507 patients were waiting for a liver) were waiting for an organ. During the year 2014, 2,356 transplant procedures (1,430 kidney transplantations and 537 liver transplantations) were performed and 278 patients died waiting for an organ. During the same year, there were 553 living organ donors of which 28% had no relationship with the recipient. This high proportion is due mostly to the existence of the Living Donor Paired Exchange Registry in kidney transplantation. (1)

Given this shortage of organs, some transplant candidates are driven to find a living donor through public solicitation. Public solicitation refers to a public search for a living organ donor by a transplant candidate or representative(s). A “transplant candidate” refers to a person who is cleared for transplantation and who is awaiting transplantation. This also includes minors awaiting transplantation and their legal guardians. We acknowledge that patients not yet wait-listed for transplantation could solicit for a living organ donor. However, as with other transplantation from living organ donors, the recipient should be suitable for transplantation. Vehicles for public solicitation may include any media release such as newsletters, billboards, news stories, and appeals through community groups (e.g. religious congregations), workplaces, organ matching websites, and social media platforms (e.g. Facebook, Twitter).

In 2015, two high profile cases of media appeals for living donors have resulted in significant media attention, some positive and some negative. (2-6) The first case was the owner of a Canadian

hockey team who needed a liver transplant. He was listed for a deceased organ transplant and none of his next of kin was suitable for a living liver donation. After the public plea, hundreds of people contacted the transplant center and more than 500 completed the preliminary questionnaire. He was finally transplanted with the liver of an anonymous donor.(7, 8) The other case was the one of very young twins who suffered from a genetic liver condition. The father donated to the sicker child. For the second child, they made a public plea to find a living donor and she was finally transplanted with the liver of an anonymous donor.(9, 10)

In Canada, federal and provincial laws state that organ donation should be gratuitous and organs should not be bought or sold or deal in exchange of valuable consideration. There is no mention of public solicitation; it is therefore legal if there is no exchange of money or valuable consideration.(11, 12) Also, the living organ donor should be a competent adult and consent freely to the donation. Living organ donation should also be done in compliance with Health Canada Standards which specify that transplant centres which perform living organ donation are responsible for donor screening and testing, suitability assessment and physical exam. (13) That being said, the Canadian Medical Association, in its statement on organ and tissue donation and transplantation states that public appeals for organs should be discouraged because “they raise concerns of justice”. (14)

The above situations shed light on the fact that there is no national policy on organ solicitation. It is in this context that, under the leadership of the Canadian Society of Transplantation, the Canadian Blood Services and the Canadian National Transplant Research Program decided to work together to develop a policy and/or guidelines on this issue. We present here the

recommendations issued by an ad hoc committee composed of transplant physicians, ethicists, legal scholars and two patients.

Recommendations

Public solicitation of living organ donors raises numerous ethical issues such as fairness in the allocation of organs, privacy, anonymity, donor and recipient consent, risk and exploitation, etc. It is beyond the scope of this paper to review in details each of these issues.(12, 15-17) That being said, our committee concluded that it is ethically and legally acceptable for transplant programs to consider potential living organ donors who respond to a public solicitation provided that this is done in compliance with Canadian law and that there is no organ trafficking, monetary exchange and material rewards. The major arguments for making us conclude that it is acceptable to consider a living organ donor from public solicitation is that accepting this type of living organ donor is beneficial for all transplant patients since it adds an organ to the pool and removes a patient from the wait list, it respects donor's and recipient's autonomy and it allows patients who do not have a suitable living organ donation among their next of kin to have access to living organ transplantation. However, transplant professionals are autonomous agents and could have a conscientious objection to accept living donors from public solicitation because they find that public solicitation is unfair, it involves a "beauty contest" and that there are risks of exploitation of both donors and recipients.(17) It is therefore important that all transplant programs inform transplant candidates about their willingness to consider potential living donors from public solicitation. Transplant programs that will not consider potential living organ donors from public solicitation for directed donation should make their reasons transparent and refer transplant candidates who wish to make a public solicitation to other transplant programs that have agreed to

consider such living donors for directed donation. For transplant programs that agree to consider living organ donation from public solicitations, here are our recommendations that have to be followed in order to ensure that it meets our ethical standards.

Privacy: Transplant programs should educate transplant candidates who are considering public solicitation about the potential short-term and long-term privacy-related risks associated with public solicitation. Indeed, when a patient shares his/her story in the media to appeal for a living organ donor, he/she does not control how the information will be handled. Moreover, the transplant candidate should be informed that the media could ask for more details, even potentially negative ones (graft loss, adverse outcomes, rejection), before and after the transplantation. The issue of privacy is particularly important when the parents are soliciting an organ for their child. They have to take into account the future impact for the child of being part of public solicitation, particularly when it is widely available on the Internet.

Anonymity: In Canada, deceased organ donation and living altruistic donation are anonymous acts. In organ donation following public solicitation, there is one-sided anonymity since the donor knows the identity of the potential transplant candidate but the potential transplant candidate does not know the identity of the donor. The transplant candidate and potential living organ donors should be educated about the potential challenges associated with one-sided anonymity such as imbalance of information and power, risk of unwanted requests (e.g. money, relationships and rewards) and risks of recipient exploitation by the donor. Also, the ability to guarantee anonymity for a living donor from public solicitation may be reduced when the campaign for the living donor is public and highly publicized.

Even though anonymity is a requirement before the transplantation, some transplant centers could accept and/or may facilitate some contact post-transplant. There is however some risk of unwanted requests, harassment and exploitation while allowing post-transplant contact. Prior to the donation, both the transplant candidate and the living organ donor from public solicitation should be informed of and agree to the transplant program's policy on contact post-transplant.

Informed Consent: In living organ donation, the informed consent of the donor and transplant candidate is of paramount importance. In this section, we discuss the specific issues related to living organ transplantation from public solicitation for the donor and the transplant candidate.

Living Donor: Living donors from public solicitation should be informed, as any other living donors, about the risks, the benefits and the process of living organ donation. Relative risks of different donation options should also be discussed with living donors from public solicitation (e.g. living liver donation is less risky when the recipient is a child rather than an adult). In cases of public solicitation, consideration should be giving to informing the potential living donor that his or her options include donation of a kidney or partial liver to (i) the intended transplant candidate; (ii) a transplant candidate in more urgent need or one ranked higher by local allocation algorithm; (iii) the national waiting lists such as the Canadian Blood Services Kidney Paired Donation program (kidney) or local paired donation programs(18); (iv) another transplant candidate either now or in the future; (v) no transplant candidate, and withdrawal from the evaluation process. Potential solicited living donors should also be informed that a public solicitation campaign could contain misleading information on the recipient.

The transplant candidate: The transplant candidate should be informed about the potential risks and benefits of receiving an organ from an anonymous directed donor (privacy and anonymity issues).

Living organ donor's assessment: Potential solicited living donors should be evaluated according to standard criteria for living donation.(19-21) All potential living donors must meet the accepted medical, psychosocial, legal and informed consent criteria established by the transplant program.(22, 23) Donors from public solicitation should not receive preferential treatment nor be processed more rapidly than other living organ donors, nor should the number simultaneously undergoing workup exceed what is usually done in the transplant program. In the case of liver transplantation, the medical needs and pace of failing health of the transplant candidate are factors that could influence the speed at which any living donor is worked up, regardless of whether it is a directed or public solicitation donor. However, donor safety and the time required to obtain fully informed consent are the most important factors determining the pace of donor workup.

With public solicitation, there is always a possibility of a surge of potential living organ donors following a highly publicized campaign. It is therefore important that transplant programs that evaluate living donors from public solicitation have adequate resources (manpower, material, tests, etc.) to process surges in public solicitation living donors' applications within the usual assessment times. It is the responsibility of the transplant programs to screen potential living donors and decide who should be evaluated. The decision to prioritize one living donor from public solicitation from another should be based on medical criteria. We encourage each transplant program to develop a surge plan with input from patients, physicians, health care professionals and administrators. This

surge plan should be made public for patients, physicians, staff and the public.

Public solicitation living donors' follow-up: As with any other living organ donors, we recommend that transplant programs who accept living donors from public solicitation offer long-term follow-up to prevent and address medical or psychological complications related to the donation.

Conflict of interests: To avoid professional and organizational conflicts of interests, individual transplant clinicians, transplant programs, and healthcare institutions should refrain from initiating and leading individual public solicitations for organs.

Patient and public involvement and engagement in the development and the revision of this policy: Transplant patients, transplant candidates and the public should be actively engaged in the development and revision of policy on organ donation and public solicitation. Patients should be engaged given that they have an experiential knowledge of living with a chronic disease, waiting for organ transplantation, looking for a living organ donor, etc. Moreover, the results of this policy on organ donation and public solicitation will directly impact patients. (24) Finally, the public also needs to be involved in this process given everyone is a potential living organ donor and public trust is important in organ donation. Two patients (one kidney transplant patient and one liver transplant patient) were actively involved in the discussion and development of these guidelines.

Research recommendations: Given that public solicitation is a new phenomenon and that there is a paucity of empirical data on this phenomenon, we encourage conceptual and empirical research on this issue. Here are some future avenues of research: (i) stakeholders' perspectives and

experiences on public solicitation; (ii) the magnitude of this phenomenon; (iii) the psychosocial profile of solicited living organ donors and patients who solicit and (iv) the outcomes for transplant candidates and their potential living organ donors.

Conclusion

In conclusion, in Canada, it is legal and ethical for transplant programs to consider living organ donors from public solicitation when certain conditions are met. Transplant programs should however be transparent about their attitude towards solicited living organ donors. Transplant programs that refuse to consider these donors should refer these patients to another center which agrees to consider them. It is important that issues of privacy, anonymity and informed consent of both the donor and the transplant candidate be discussed and addressed. Living organ donation from public solicitation offers numerous future avenues for research given the paucity of empirical data on the topic. Finally, this policy will need to be reviewed in the future based on transplant programs' and patients' experiences as well as empirical data from research.

The working group

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