

Ethical Issues in Resolving the Organ Shortage: The Views of Recent Immigrants and Healthcare Professionals

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Introduction

Organ and tissue transplantation are increasingly presented as a solution for a number of serious and life-threatening health conditions. Advances in tissue typing, new generations of immunosuppressant drugs, and the refinement of surgical techniques have enhanced outcomes for transplant procedures, standardizing them as a form of therapy. These factors combined with the ever increasing human lifespan (particularly in developed countries) result in a larger number of people who would benefit by, and thus growing numbers in need of, an organ or tissue transplant. In addition, greater numbers of organs and tissues are needed for ongoing transplantation research. Yet there is a growing gap between the number of potential recipients and the number of donors in Canada and around the world.

In Canada, between 1996 and 2005, the number of transplant operations (excluding kidneys from living donors) increased by only 126, while the number of people on the waiting list increased by over 1,500. Likewise, data provided by the *Canadian Organ Replacement Register* and the American *United Network for Organ Sharing* show the number of transplant recipients in waiting increased from 49.5 per million people (pmp) in 1993 to 56.8 pmp in 2002, with the disparity between operations performed and the wait list widening by 8.3 percent.¹ Internationally, Canada's transplant rate (14

pmp) is on par with other western countries. But while Canada's rate remains above those of countries such as Australia (10 pmp) and New Zealand (11.2 pmp), it remains well below that of Spain (35-40 pmp), which has the most successful cadaveric transplant program in the world² and which many people view as the example to follow for other countries' donation programs.

Policymakers are thus grappling with how best to narrow the donor-recipient gap and increase the availability of tissues and organs for research. In the past five years, several Private Member's Bills have been proposed to address the Canadian donor shortage. The adoption of these or similar bills will make significant changes to organ procurement and to ensuring informed consent. Beyond the myriad existing ethical issues surrounding organ donation, proposed changes will introduce further ethical challenges both for healthcare professionals in this specialty area and for potential donors.

Beyond the introduction of laws directly aimed at increasing donation numbers, there is an ongoing international discussion among healthcare providers, policymakers, ethicists, and philosophers regarding other means to increase the availability of organs. At the core of the debate is the legality, ethics, and effectiveness of broadening the category of eligible donors. Procurement agencies formerly considered only persons suffering from brainstem death who had indicated during their



lifetime that they wished to donate. With the stagnating numbers of brain dead donors and the increased need for organs, new categories of persons under consideration as donors include: anencephalic newborns; non-beating-heart donors and persons revived after suffering cardiac death; executed prisoners (not applicable in Canada);³ and persons with irreversible brain damage⁴ or those persisting in prolonged vegetative states.⁵ Among these categories, donation from persons who do not respond to resuscitation is considered to be one of the most effective and efficient methods for increasing donor numbers.⁶ This mode of procurement has been called *uncontrolled donation after a circulatory determination of death* or Rapid Organ Recovery (ROR).

Attendant to the discussion of broadening categories of eligibility is the possibility of enlarging the donor pool by redefining “death.” For instance, it has been argued that while anencephalic infants have functioning brainstems, placing them in a “special category of death” could make them eligible as brain dead donors.⁷ Likewise, the concept of “imminent death” considers persons eligible due to ROR, irreversible brain damage, or prolonged vegetative states. And as researchers better understand “brainstem death,” previously accepted definitions of “death” and “dead” are called into question.⁸

Amid these debates, policymakers and healthcare professionals are attempting to address the organ shortage at a more immediate, local level. Efforts include introducing new programs such as “domino donations,” where potential recipients with non-matched relative donors are matched in sequence to other recipients and non-matched relative donors. In February 2009, Canada created the Living Donor Paired Exchange Registry, with the first surgeries occurring four months later.⁹ There are also growing efforts to raise public awareness. In Ontario, the Trillium Gift of Life’s *Recycle Me* educational program is aimed at adolescents and young adults. Since its launch in 2008, over 4,000 new potential donors have registered. Combined with these programs are recommendations for systemic shifts in organ procurement, which can involve small changes to everyday healthcare practice. In British Columbia, for instance, all persons admitted to hospital are now asked if they wish to donate their corneas upon death, a policy that has reduced the provincial cornea wait list to 14 weeks. By comparison, Alberta does not have this policy and has a wait time for corneal transplantation in excess of a year.

These smaller shifts in practice are accompanied by numerous broad legislative measures addressing public education and the regulation and redefinition of organ procurement and its means of consent. In 2006-07 alone, six Private Member’s Bills were put forward in Ontario and two in Alberta to address organ donation at various levels. In Ontario, these included: Bill 33, which mandated teaching about organ donation in schools;¹⁰ Bill 67, which forced declaration upon receipt of a driver’s licence;¹¹ Bill 79, which involved providing a consent form to citizens receiving a new or renewed driver’s licence;¹² and the most radical, Bill 61, which would change Ontario’s current opt-in system to an opt-out, or presumed consent, system.¹³ None of these bills was passed. Likewise, in Alberta, Bill 201 proposed mandatory notification of death or imminent death of any patient to the Human Organ Procurement Exchange (HOPE) Agency.¹⁴ The bill did not pass after the Alberta Medical Association opposed it. Alberta also saw Bill 32, the *Human Tissue and Organ Donation Act*, receive Royal Assent in May 2006.¹⁵ Bill 32 was unique in that it required a medical practitioner to determine donation suitability and report it to the HOPE Agency. It also enabled minors to donate their organs, and annulled both the rights of immediate family and next of kin to negate a donor’s decision, and the rights of estranged family to decide on their relative’s behalf. To date, Bill 32 has yet to be fully enacted as the HOPE Agency awaits legal advice concerning the redefinition of family rights.

This article presents findings from a Canadian pilot-project that explored ethical issues in organ donation as they were perceived by healthcare professionals working in the area of organ procurement and by recent immigrants to Canada. Considering these findings against current debates and research regarding how best to increase donation, as well as against existing legislation and healthcare practices, the authors conclude that the very laws that policymakers believe will increase organs may in fact unintentionally drive donation numbers down.

Not Wanting to Hurt Others by the Decision to Donate

Across the board, recent immigrants spoke of not wanting to hurt or offend their family members and communities with the decision to donate their organs. Likewise, procurement staff spoke of being very



conscious of the wishes and hesitations of families of potential donors: even with Bill 32 in effect in Alberta, procurement staff, in contravention of the law, continue to let families make the final decision about organ donation. What emerged from these discussions was an understanding that the decision to donate is not reducible to a simple “yes” or “no.” (In fact, some recent immigrants informed the researchers that, when forced into a yes/no situation, for the sake of safety, many say no.) Rather, the decision to donate one’s organs is a process of building consensus, which ideally begins

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long before the prospect of death and continues to the last moments before either the organs are harvested or the body dies intact. For both recent immigrants and health professionals, the possibility of presumed consent legislation raised concerns that discussion and the final decision to donate would be the more difficult for families. According to one health professional, the recipients of organs also often require certainty of the deceased’s express desire to donate. But under presumed consent the intention to donate is no longer stated and the family lacks the guidance of the donor’s “yes.” The question of the deceased’s intention remains open. Perhaps he or she did not know? Such questions haunt families, health professionals, and recipients alike.

Connected to the desire not to hurt surviving family members was a concern for the integrity of the body. Even when they agreed to donate their organs and tissues, recent immigrants did not want their families to get the body for burial only to discover organs were missing. Some spoke of the importance of the external integrity of the body, with one participant saying her mother was adamant she could donate everything except her eyes because they are essential for the final viewing of the body. Other participants felt that anything missing from the body might distress their family members.

This was pronounced among those who expected their bodies to be returned to their native countries, and it was readily acknowledged this was related to concerns and uncertainty about the afterlife.

Throughout the focus groups with recent immigrants, what was most feared was that families would “discover something missing” from their loved one’s body. From previous incidents, such as the Alder Hey scandal in Britain,¹⁶ we readily recognize the emotional distress such a discovery can cause. However, increasingly we are seeing ethicists (e.g. James S. Taylor, Aaron Spital, & D. Micah Hester) who argue that the good from saving lives by taking organs outweighs families’ emotional distress. But do policymakers and health professionals necessarily need to choose between family distress and more available organs?

The health professionals interviewed described trying to reduce family distress by being transparent about the donation and transplantation process. Furthermore, they worked directly with the communities to ensure that the body is not damaged in any way that will affect death rites. To this end, they have adopted as common practice the insertion of prosthetics to replace anything removed, including internally, even if the body will be cremated. This is in line with previous research that shows donation rates increase when families are assured that donation will not affect burial arrangements.¹⁷

However, some organ donation laws negate this family involvement. Throughout the literature on organ donation, “families” are presented as the greatest “hindrance” to organ donation, with new organ procurement laws (such as Bill 32) trying to rectify this “problem” by decreasing the family’s decision-making power. Further, some organ procurement laws, such as those in Belgium, go so far as not requiring physicians to *even inform* families of the removal of organs.

Yet denying families’ direct input in the use and disposition of a deceased relative’s body not only negates the rights of the family as a social institution,¹⁸ it also appears counterproductive. Because, as demonstrated by the Alder Hey incident noted above, not involving family (i.e., doing something unbeknownst to them) affects trust in health care, and the health professionals interviewed said that having the trust of families was essential to establishing rapport in the donation process. This may reflect the contemporary healthcare context.



Rowe and Calnan argue that, as opposed to the past, trust in health care is now conditional and negotiated.¹⁹ Yet with these proposed changes to procurement laws, negotiation is removed and the ability to develop trust is negated. An unintended consequence could be to drive donation numbers down.

Having the “Donation Discussion”: Coercion or Support?

For both recent immigrants and organ procurement staff, what seemed to be desired most was negotiation. Recent immigrants wanted organ donation discussed within their churches. When faced with the possibility of donation (either from themselves or family members), they also wanted to negotiate with health professionals, particularly in determining a definition of death that was acceptable to them. This was due to the fact that, for many, the definition of “brain death” isn’t accepted. And this reservation is not limited to patients; research shows “brain” death is not even accepted by all health professionals. Even as contemporary donation laws are moving to be more inclusive of categories of death, this provision of choice for *what type of death* is not addressed.

Health professionals likewise echoed a desire for negotiation, in particular the ability to have discussion “out in the open.” For example, they felt restricted in being able to talk to people about donation outside of their clinical practice. Within their practice, some described using what they called “dual advocacy,” where an ambivalent family or even a family that has said no is asked about their rationale. Dual advocacy allows the practitioner to speak for potential recipients, telling families about the benefits to the likely donor (a child will be able to run; a mother can spend time with her children rather than be in dialysis). At times it extended to giving details about the likely recipient (location, age, direct benefits), whom they identified from the waiting lists.

Disclosure of information about recipients is illegal in Canada, however, near disclosure is not. Even so, it appears coercive and manipulative to many, and it is not endorsed by Canadian procurement agencies. Yet, for the recent immigrants interviewed, this was exactly the type of information they desire. How will their donation make a difference? Answering such questions provides a human component to something that frequently gets treated very technically and legalistically.

Communication of information was a central concern to both recent immigrants and health professionals working in the area of organ donation. It was generally felt that there was not enough information available to people *before* donation becomes a pressing issue. Further, they felt that this conversation should not be *starting* when someone is laying brain dead in a bed – it needs to be well underway before that. Even those recent immigrants who said they would not be donors themselves wanted information about donation; they knew their children might decide to be donors, and they wanted to be forewarned about the process.

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To date, various laws mandating education have tried to increase public knowledge of organ donation, as have campaigns targeting specific populations, such as the *Recycle Me* campaign. Even so, the information does not seem readily available – recent immigrants spoke about the difficulty in obtaining information about organ donation – nor does the topic seem to be at the fore of public discussion.

Donation Must Remain a Gift

One thing that did appear not to be up for discussion was the belief that *donation must remain a gift*. That recent immigrants in the study did not support compensation models appears to contradict some research that claims financial incentives can increase donation.²⁰ The “no compensation” model is currently supported by Canadian law, which states that bodies are not property and one cannot buy, sell, or bequeath one’s body. One can donate one’s body to science or for organ and tissue donation, but one cannot leave one’s body (or any parts thereof) to a specific person. Rather than being private property, the body is part of the common good and, as our participants suggest, the community should have input into how it is treated.



However, Canada is increasingly challenged by the idea of the body as commodity. For example, physicians are now faced with the question of how to treat “transplant tourists,” persons who leave Canada to buy organs. For someone who goes elsewhere and contravenes a basic tenet of Canadian law (that bodies are not owned), do they, upon their return, have the same rights to services (i.e., treatment for complications associated with the foreign transplant surgery) that we provide to persons who undergo transplant surgery within the country? We are also seeing increased debates about body ownership and, through recent laws, greater restriction on families’ right to control relatives’ bodies. We cannot ignore the prevalence of the international sale (legal and illegal) of organs, and we are increasingly seeing the patenting of human genetic material (for example, Decode Iceland) and life forms such as the “Harvard mouse.”

Connected to this, then, is a discussion of what it means to be Canadian. The pressure placed upon Canadians by the international sale of organs, the patenting of living material, the commercialization of health and the pressures of privatized health care all bring into question what Canadian values should be.

For our immigrant participants, however, it was abundantly clear: *to institute presumed consent is un-Canadian*. Though the Canadian public at large may be debating what is and is not acceptable to Canadian society, the recent immigrants of our study had a very clear, strong sense of what it meant to be Canadian, and this extended to Canada’s treatment of organ donation. The recent immigrants felt that the adoption of presumed consent would not respect individual difference – a cornerstone of Canadian society. Further, such an adoption would not acknowledge the very real situation which many of them have lived: not knowing the language, not knowing the law, and not understanding the culture or language of health care. For them, presumed consent is a policy that forces a choice and, in doing so, is disrespectful of individuals and communities; thus it is essentially *un-Canadian*. Canadian attitudes towards organ and tissue donation were described in terms of openness to individual and community differences and to genuine support of personal decision making. This seems belied in proposals that will make an affirmative pro-donation decision a given unless a citizen recorded his or her opposition to it.

The health professionals interviewed, for the most part, appeared uncertain and unclear in their understanding of new immigrants’ perspective on organ and tissue donation. They described recent immigrants who were receiving organs but could account for few who donated them. They wondered about the role cultural differences played in donating but could not share specific examples. (Cultural aspects of Aboriginal peoples’ perspectives on donation were more familiar, but this was not the focus of this pilot study.) An interesting question was raised by one professional: Could it be that there are few minority donors simply because physicians do not ask them? This participant thought physicians may be hesitant to inquire about donation because they did not trust their own sensitivity to relevant cultural issues or to overcoming language barriers. When in doubt, it is easier to abstain (or to say no, as some of our new immigrant participants suggested).

Integrating a multicultural perspective into our healthcare system is one area where Canada – explicitly and proudly multicultural as it is – needs further work. As A. S. Daar says: “understanding cultures ... must not be seen as a tool to overcome resistance, but as one of many factors to consider in delivering health care to individuals and communities.”²¹ We must pay particular attention to understanding and working with alternative decision-making methods. Our healthcare system largely follows traditional bioethics, which values personal autonomy; therefore the role of community in the organ donation decision can appear problematic. While the need for cultural safety in healthcare environments is embraced as an important goal, programs designed to promote it are often lacking.

Conclusion

As we consider how best to increase organ donation the world over, we face the pressing issue of a lack of healthcare resources. The question has to be asked: Is *increasing organ donation* where our efforts and funding should be going? We lack even basic support for the needs of new immigrants. We have persons with mental illness being released to the streets because there is no transitional housing. Our long-term care facilities are underfunded and understaffed. Yet we focus on increasing the number of available organs for transplant in operations that routinely cost hundreds of thousands of dollars. In pushing for more organs, will we be funnelling even more of our limited health care funds to



“high-tech care,” as one professional with transplantation team experience put it, due to “the tyranny of urgency.” The question of how to increase organ donation is with us – we cannot ignore it or pretend it is not under debate – but we must consider this question within the larger context of health care and the general wellbeing of the population, including new immigrants. Is our most urgent need more organs?

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Endnotes

- 1 V. C. McAlister & K. Badovinac, “Transplantation in Canada: Report of the Canadian Organ Replacement Register” (2003) 35 *Transplantation Proceedings* 2428.
- 2 *Ibid.*
- 3 See John Crawford, Lisa Manchanda & Nick Pace, “Transplantation Ethics” (2007) 3 *The Foundation Years* 66; Robert A. Sells, “Ethical Issues in Transplantation” (1994) 8 *Baillière’s Clinical Gastroenterology* 465.
- 4 Crawford, Manchanda & Pace, *ibid.*
- 5 Sells, *supra* note 3.
- 6 James M. DuBois, “Increasing Rates of Organ Donation: Exploring the Institute of Medicine’s Boldest Recommendation” (2009) 20 *The Journal of Clinical Ethics* 13.
- 7 Crawford, Manchanda & Pace, *supra* note 3 at 66.
- 8 See T. S. Huddle *et al.*, “Death, Organ Transplantation, and Medical Practice” (2008) 3:5 *Philosophy, Ethics, and Humanities in Medicine*, online: *Philosophy, Ethics, & Humanities in Medicine* <<http://www.peh-med.com/content/3/1/5>>.

In their editorial of this issue dedicated entirely to exploring death and organ donation, Huddle *et al.*, citing recent research, point out that better understanding of brain and body function leads

many to conclude that “brain-mediated bodily integration does not offer a reason to suppose that brain dead patients are really dead” (at para. 4).

- 9 See Canadian Blood Services, Organ & Tissue Donation and Transplantation, “First Cross-Province Domino Kidney Transplant Surgery Successfully Completed,” online: Canadian Blood Services <<http://www.ccdt.ca/english/home.html>>.
- 10 Bill 33, *Education Amendment Act (Organ Donation Education)*, 2d Sess., 38th Leg., Ontario, 2005.
- 11 Bill 67, *Organ and Tissue Donation Mandatory Declaration Act*, 2d Sess., 38th Leg., Ontario, 2007.
- 12 Bill 79, *Trillium Gift of Life Network Statute Law Amendment Act*, 2d Sess., 38th Leg., Ontario, 2006.
- 13 Bill 61, *Trillium Gift of Life Network Amendment Act*, 2d Sess., 38th Leg., Ontario, 2006.
- 14 Bill 201, *Human Tissue Gift (Notification Procedure) Amendment Act*, 2d Sess., 26th Leg., Alberta, 2006.
- 15 Bill 32, *Human Tissue and Organ Donation Act*, 2d Sess., 26th Leg., Alberta, 2006.
- 16 During a 30-year period, over 54,000 organs and tissue samples, predominantly from children, were retained by various hospitals without knowledge or consent on the part of relatives. It was only in 2001 that the full extent of this was revealed in an investigation by England’s Chief Medical Officer.
- 17 See W. DeJong *et al.*, “Requesting Organ Donation: An Interview Study of Donor and Non-Donor Families” (1998) 7 *American Journal of Critical Care* 13; Laura A. Siminoff *et al.*, “Factors Influencing Families’ Consent for Donation of Solid Organs for Transplantation” (2001) 286 *JAMA* 71.
- 18 Mark R. Wicclair, “Ethics and Research with Deceased Patients” (2008) 17 *Cambridge Quarterly of Healthcare Ethics* 87.
- 19 Rosemary Rowe & Michael Calnan, “Trust relations in health care – the new agenda” (2006) 16 *European Journal of Public Health* 4 at 4.
- 20 Sells, *supra* note 3.
- 21 A. S. Daar, “Cultural and Societal Issues in Organ Transplantation: Examples from Different Cultures” (2000) 32 *Transplantation Proceedings* 1480 at 1480.

