Canada's organ shortage is severe and getting worse

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Features

Chroniques

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En bref

LA TRANSPLANTATION D'ORGANES HUMAINS VITAUX SAUVE LA VIE de quelque 1500 Canadiens par année, ou l'améliore de façon spectaculaire. Ces interventions délicates, qui ne sont plus expérimentales, évitent aussi au système de soins de santé des millions de dollars de frais d'hospitalisation, de dialyse et autres. Or, malgré l'appui général de la population, le Canada enregistre un des taux les plus faibles de dons d'organe et de transplantations au monde.

At times of flood, fire or famine, Canadians are justifiably proud of their generosity, their willingness to give a helping hand to others in desperate need. A hand, yes. But a heart when they no longer need it? Or a kidney, a lung or a liver?

In one of those puzzling Canadian paradoxes, a 1994 Angus Reid survey found that 77% of adults would donate their organs after death and 58% had signed donor cards. So why is Canada's actual donor rate among the lowest in the industrialized world, lagging far behind the US and many European countries? In 1994, Canada's per capita organ-donation rate was 44% lower than Spain's, the acknowledged world leader.

Canada's mediocre donation rate has a direct and measurable impact on the transplantation program. By the end of 1996, 2829 Canadians were waiting for donations of vital organs; at any time, approximately 5% of them were in the most critical phase of end-stage organ failure. Between 1992 and 1996, 587 people are known to have died while awaiting a transplant.

In the 39 years since Canada's transplantation program was launched with the transfer of a kidney between identical twins at Montreal's Royal Victoria Hospital, the procedure has evolved from frontier science to mainstream medicine.

In 1996, 29 major adult and children's hospitals from Halifax to Vancouver performed 1557 of the procedures, 62% of them involving the kidney (cadaveric, live related, live unrelated or in combination with a liver or pancreas). Other organs transplanted were 352 livers, 166 hearts, 69 lungs (single and double), 4 heart/lung combinations and 2 pancreata.

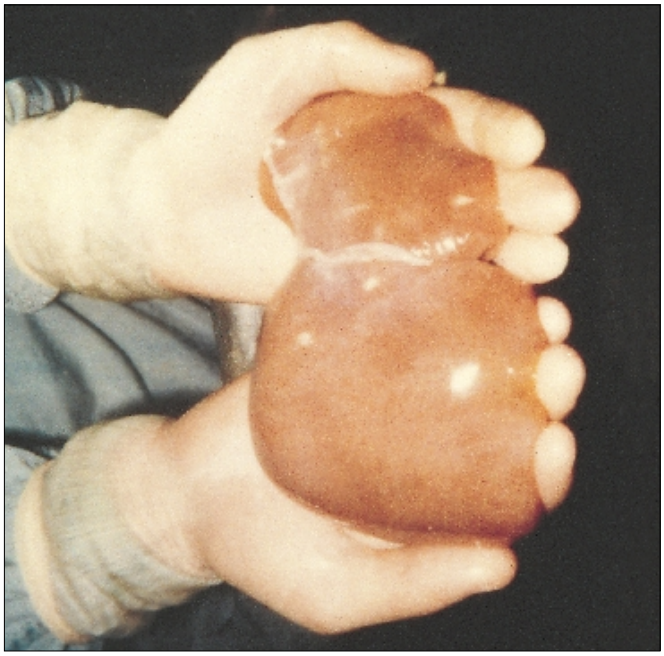
Despite these successes, the total number of transplants appears to have plateaued, rising only 9% over the previous 3 years. In fact, 6 fewer procedures were performed in 1996 than 1995. By comparison, the waiting list for organs grew by 33% between 1993 and 1996.

This growing gap between supply and demand is understandably troubling for transplant professionals, advocacy groups and desperately sick patients. The reasons for the gap are generally known; it's just that solutions remain elusive.

Still, there is room for optimism. Canadian governments have demonstrated a new level of commitment to the principles of organ exchange. The spending is not yet there, but at least an attempt to coordinate and enhance a highly fragmented system is now under way. Moreover, there are plenty of success stories, at home and abroad, that are even now pointing the way toward a better Canadian system.

The effort is worth while on several levels. Apart from the hundreds of lives saved every year by transplantation, many hundreds more patients experience a vastly improved quality of life, free from the drudgery of dialysis and unending trips to the hospital.

Leanne McDougall, diagnosed with tetralogy of Fallot, had been in and out of hospital more than 50 times since her first open-heart surgery at age 13. "Just be-



Liver-transplant surgeons have developed a refined informal sharing process, along with standards and eligibility criteria

fore my transplant [in 1989], if I had a shower in the morning, I had to go back to bed for 3 or 4 hours just to get enough energy to come downstairs and make coffee," recalls McDougall, 45, of Gatineau, Que. Today she swims and rides her bike, and has even walked a marathon. "It wasn't until I had a healthy heart in my chest that I realized how my life had been affected and how little I could do."

Many donor families also derive substantial benefits from the act of giving. "Donating Phillip's organs has given us a reason why he had to die," says Teresa Cassidy, whose youngest child died of a burst cerebral aneurysm in 1987. "It made us proud of what he did in death."

The retired nurse recalls her shocked incapacity to accept the 23-year-old's death, even though her husband and 6 surviving children were already considering organ donation as a means of coping with the tragedy. "I was the medical person in the family but I never thought of it," Cassidy admits. "All I was thinking was, 'What could they do to save him?' And then I thought, we have something that somebody needs and we can't use it. So how can you refuse?"

Donations can save more than lives — kidney transplants in particular have been found to save money. The cost of a new organ and subsequent maintenance is estimated at $50 000 over 5 years. Dialysis would cost roughly $250 000 over that period.

As rational and persuasive as such arguments may sound, Canada's organ shortage is severe and getting worse. Moreover, it can be traced simultaneously to the demand and supply sides of the equation.

Organs are retrievable only when brain death has occurred and the body continues to be carefully ventilated and maintained for blood circulation. At most, only an estimated 3.7% of hospital deaths fit that definition. Increasingly, moreover, organs are being rejected because of suspicions of HIV or hepatitis B infection. And Canada's aging population is having an impact on the number of potential donors. Older people tend to drive more cautiously in safer vehicles and take fewer risks, generating a declining number of head-trauma patients suitable for organ retrieval. And, while older people are more likely to experience brain death by stroke or cerebral hemorrhage, this cohort is less likely to embrace the modern, high-tech notions of organ exchange.

On the other hand, as people live longer, the chance of needing a replacement organ grows. With improvements in immunosuppressive drugs and general medical care for the elderly, the eligibility criteria for replacement organs have been liberalized. Older recipients, even those with systemic diseases such as diabetes mellitus, are now routinely considered for renal transplants. In some centres, early pre-emptive kidney transplantation is encouraged to avoid the chronic poor health and health and social costs associated with long-term dialysis.

Given those demographic realities, 3 courses of action are available: expand the donor pool, plumb more thoroughly the depths of the existing pool, and ensure that every available organ is used in the most effective way. With varying success, most jurisdictions are pursuing some or a combination of these objectives.

Canadians seem more ethically at ease with restricting the donor pool to brain-dead patients. Even so, it is estimated that only a fraction of potential candidates are identified and their survivors approached for consent. To make the most of a pool limited to perhaps 1200 to 3000 brain deaths annually, Canadian physicians are considering organs (especially livers) donated by older people. The oldest donor on record at Ontario's Multiple Organ Retrieval and Exchange program was 92.

Many provinces have tried campaigns to encourage residents to sign donor cards, but results have been mixed. Perhaps in explanation, one British study reported that a 6-month campaign generated a 42% increase in kidney donations, but a 1-month campaign had no effect.

BC is piloting a more direct approach, asking people renewing their driver's licences to specify whether they would be organ donors. In the event of death, a computerized registry is used to notify hospitals.

But preparing people for the prospect of organ donation and actually getting grieving families to sign the documents are entirely different things, and many organs are lost to the system between the hospital and grave. Dr. Anita Molzahn, dean of human and social development at the University of Victoria, found in a survey of 831 physicians that although 95% strongly approved of organ donation, a

staggering 57% conceded they didn't want to get involved, for reasons of time, potential liability, perceived conflict of interest or the excessive emotional demands of the process.

In research published in February, Molzahn found troubling gaps surrounding doctors' knowledge of brain death, particularly the legal and ethical rules that surround it. Indeed, the mean score on 12 knowledge-testing questions was 68.3%. The same proportion of respondents said they felt comfortable identifying organ donors.

But even if the doctor has the knowledge and the will to request organs, hospitals, especially smaller ones affected by cutbacks and restructuring, are finding it increasingly difficult to see the benefit of maintaining a body for 2 or more days so that another hospital, province or country can get an organ.

In response, Quebec now requires hospitals to refer potential donors to the provincial organ procurement agency, but reimburses referring and organ-retrieving hospitals to a total of $5000 per donor. This policy is credited with boosting the donation rate by 53% between 1992 and 1993.

BC has created a provincial organization responsible for all organ retrieval. A specialized team travels the province collecting organs and bringing them to 1 of 3 transplant hospitals.

Sometimes, people just can't accept organ donation

A profound dichotomy between medical and lay perceptions of organ transplantation may help explain chronic organ shortages in developed nations, an American medical anthropologist says. "Donation requests are best understood as encounters across cultures," notes Dr. Donald Joralemon of Smith College in Northampton, Mass.

Physicians and other transplantation advocates see the process as a recycling of unneeded body parts to prolong someone else's life. However, the ordinary human response, developed over centuries of social conditioning and ritual, is to see the body and its full complement of organs as the manifestation of an individual, dead or alive.

"If I consent [to organ donation], I have tacitly accepted that my body is an assemblage of replaceable parts, that my 'self' is anatomically reducible to neural activity, and that when brain activity ceases, 'I' no longer exist," Joralemon argues.

Indeed, Canadian transplant experts spoke of the "myths" and "taboos" that continue to plague the procurement process, even in the enlightened '90s. People fear, for instance, that consenting to donation will cause a premature termination of life support. Many who believe in an afterlife want their loved ones buried whole. Some fear that the deceased's body will be mutilated, or that an individual may lose his or her identity by receiving another person's organs.

According to Pat Sherbin, a spokesperson for Ontario's Multiple Organ Retrieval and Exchange Program, many people say they don't want their loved one to suffer any more pain, even after death. Others claim religious objections, even though a survey of all major faiths found the practice acceptable, either as a matter of personal conscience or to save another person's life. Still, Joralemon says organ-procurement professionals continually face the "dissonance" between the medical conceptions of donation and those held by the family.

This, he says, explains the medical establishment's preference for the term "gift of life" to describe the surgical removal of organs during a moment of personal tragedy. Joralemon calls the use of this appealing term a "cultural suppressant" to overcome the powerful natural resistance to such a request, analogous to the use of immunosuppressive drugs to prevent graft rejection.

Rather than dismiss this rejection instinct as misguided and uninformed, medical practitioners ought to understand and accept it, and find ways to accommodate it, Joralemon says.

He proposes the creation of special hospital settings for the declaration of brain death and associated rituals. As well, families would be assured of adequate time for mourning, even if it jeopardizes the retrieval of some organs, and there would be reconsideration of the "default assumption" that donation is anonymous. "It could be that facilitating, rather than discouraging, donor-recipient contact actually would add a social dimension to the gift, and thereby promote altruism."

Parent Muriel Houde of Chalk River, Ont., feels deeply hurt that of the 5 people who received organs from her 19-year-old son Dustin, only one ever responded to her letters. "I guess I thought, well, if I hear from these people, I know they're OK and that I've done a thing that's going to change the lives of all these people." Houde feels medical staff should impress on organ recipients how important it is for donor families to know their selfless gift was worth while.

Kim Gibb Young, a coordinator with the Canadian Association of Transplantation, says the transplant community recognizes that some people have a hard time making such contact. Recipients may feel guilty that they longed for years for an organ, knowing that somebody has to die for them to get it, and others may fear that they didn't deserve a gift of such magnitude.

Suppose then that the entire professional structure is ready, willing and able to support organ retrieval. In Canada, where the principle of voluntary consent governs organ donation, the next obstacle may be the surviving family members, especially when the deceased left no specific instructions.

"The most important thing is to understand brain death," explains Liz-Anne Gillham-Eisen, organ-donor coordinator in Ottawa. "They have to be able to grasp that the brain is dead and unless that is clear to them, they can't conceive of donating."

The explanation may be the most important thing; it's also the toughest, especially for doctors who moments ago may have been fighting valiantly to save the patient's life. The University of Victoria's Molzahn found that nearly 50% of physicians found it hard to explain brain death to families and 45% did not know how to refer potential donors to procurement agencies. This unease contributes to the chronic shortage because 75% of families asked to donate loved ones' organs give permission.

In a survey of 831 physicians, a staggering 57% conceded they didn't want to get involved with organ donation.

On Father's Day 5 years ago, Muriel Houde of Chalk River, Ont., lost her 19-year-old son, Dustin, in a car accident. The young man was rushed to the Ottawa Civic Hospital, but there was no hope.

"My husband found it really hard to walk out of that room," Houde says now, "because the machines were still breathing. Just before we left, Dustin squeezed my husband's hand, and he looked at the doctor and he said, 'He moved.' And she said, 'It's just reflex.' But you walk away wondering. I think, for him, he remembers that last moment."

For people like the Houdes, Gillham-Eisen goes out of her way to explain, to demonstrate, to walk people through the respiratory, pupil and other tests that prove a brain has ceased to function. She helps them understand that brain death is irreversible, then leaves the family time to comprehend and grieve.

This dedication seems to work. In each of the past 3 years, the Ottawa transplant coordination team has consistently achieved among the highest rates of organ donation in the province. Indeed, any jurisdiction that gets serious about organ retrieval and distribution can usually chalk up impressive improvements in its donation and transplant rate.

In just 3 years, Spain brought its donor rates from 14.3 to 21.7 per million population, among the highest in the world. It introduced a national system of organ sharing and designated donor coordinators, usually doctors, in 118 of the country's hospitals. (Canada's donor rate is roughly 14.8 per million population. — Ed.)

In the US, organ-procurement organizations (OPOs) have piloted some innovative programs. In one case, members of minorities approach other minority families about organ donation. In some jurisdictions, the success rate is so high that the proportion of minority donors exceeds their proportion in the population. US studies have also demonstrated that greater investment in OPO programming and staff training, hospital development and public education pays big dividends.

The BC Transplant Society (BCTS), established in 1985 as a comprehensive health organization, oversees every facet of organ procurement, transplant, follow-up care and research in the province. The model, a publicly funded insurer contracting for the delivery of private services according to best price and quality, is unique in Canada. Between 1985 and 1993 the transplantation rate has increased from 35 to 193 grafts per year. And, because of economies of scale, the cost of transplants was cut by one-third.

What about the rest of the country? A federal, provincial and territorial working group examined Canada's transplantation system in 1995–96 and found it wanting. In fact, there was no definable "it" — Canada is unique among advanced nations in having no national presence in this critically important field.

Instead, totally distinct systems are in place across the country, at widely divergent stages of evolution, and there is no formal sharing mechanism to ensure the neediest Canadian — not the one lucky enough to live close by — always receives the next available organ. Indeed, in 1995 the median waiting time for a liver ranged from 21 days in Vancouver to 135 days in Toronto.

The working group's report recommended no new national body, but called for the urgent formation of greater cross-Canada collaboration. It called for a national system of track organs and prospective recipients. The report, which is now in the hands of Canada's deputy ministers of health, also urged the development of uniform standards for safety and efficiency in procurement, allocation and transplant programs. It noted that liver-transplant surgeons have developed a refined informal sharing process, along with standards and eligibility criteria, that would serve as a useful template for greater collaboration.

And finally, to overcome provinces' inherent reluctance to share among themselves, the document proposed a system for mutual reimbursement for the expense of identifying and maintaining donors and retrieving the organs.