

Fragmented organ donation programs hinder progress

Comparisons of international organ donation rates, systems, policies and practices often suggest most developed nations are playing chess, while Canadians are playing checkers.

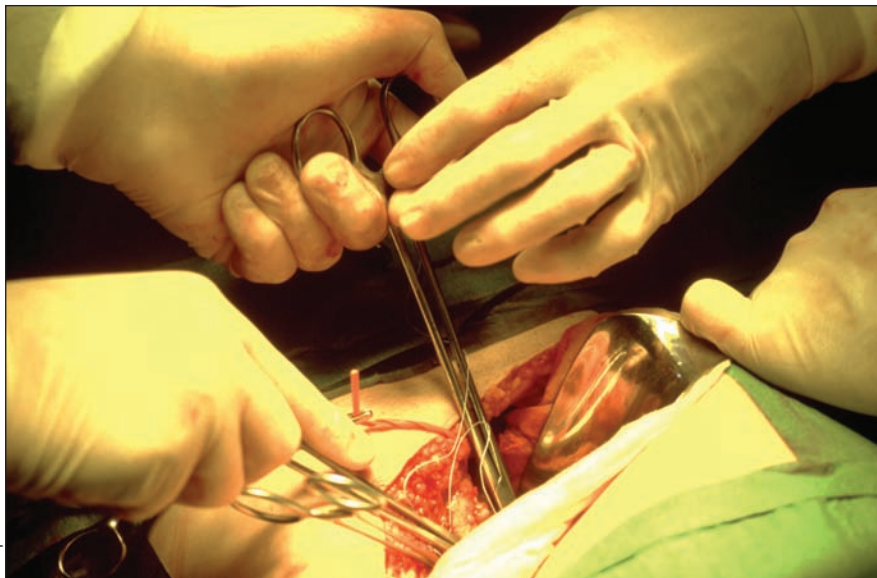
So varied are the nation's transplant programs that it's impossible to characterize national practice, other than to say it's quintessentially Canadian; a reflection of the fractured jurisdiction over health care.

As transplant physician and Canadian Society for Transplantation President Lori West notes: "It's the eternal divide in Canada. It isn't a system. It's grown and developed and evolved as provincial transplant organizations. It hasn't evolved as a system at all, so it's not surprising that it's very different from province to province."

Canada's low organ donation rates "may be partly because of our lack of a coordinated, central kind of response to take new ideas and move them forward quickly among provinces," the University of Alberta professor of pediatrics, surgery and immunology says. "That's why many of us agree that if we had some national agency of some sort . . . we might be able to take some of these ideas that gain success in other countries and apply them to our own populations more quickly and more efficiently."

But Canadian Council for Donation and Transplantation (CCDT) Chief Executive Officer Kimberly Young argues that Canada's organ donation rate compares favourably to other nations, and the system isn't in need of structural reforms.

Other countries use different denominators for determining donation rates, so crude international comparisons aren't methodically valid, Young argues. "We certainly have pockets of excellence in Canada that have as high a rate, or higher, from their reporting and their review of medical records."



Canapress

Some experts say a Canada-wide organ registry is needed; others disagree. Here, surgeons perform a mother to daughter kidney transplant.

According to the Canadian Organ Replacement Registry, Canada's crude donation rate for deceased donors in 2005 was 12.8 per million population, well below that of countries like Spain (35.1), Estonia (26.5), Belgium (22.8), US (21.5) and Italy (20.9), as projected by the International Registry maintained at the University of Barcelona.

Living donations in Canada are rising, however, and now tally 15.6 per million.

But there are significant regional variations in deceased and living donation rates. Deceased donations range from 5.1 in Manitoba to 17.9 in Quebec. Living donations range from 7.0 in Quebec to 19.9 in Alberta.

Some 3974 Canadians were waiting for an organ transplant on Jan. 1, 2006, compared with 2592 in 1995. Some 275 Canadians died waiting last year. There were 1904 transplants last year, compared with 1542 a decade earlier.

There are also significant provincial variations in wait times for transplants. A recent study of 7034 dialysis patients (*CMAJ* 2006;175[5]:478) found people under 40 waited a median 8 years in Ontario for a new kidney, compared with 3 in Alberta.

In the face of those rates, variations and wait lists, a number of issues and options have surfaced on the organ donation horizon, including:

Creation of a national registry and mechanism for allocating organs, similar to the US United Network for Organ Sharing (UNOS)

Canada does not have a nation-wide wait list, allocations, or mandatory organ sharing for priority cases (after taking into account factors like the risk of ischemia in cases where an organ is needed on the other side of the country). The London Transplant Program maintains a list of "status 4" urgent cases, disseminated weekly. There's also some sharing among programs, although no one keeps formal statistics on frequency and many say it's quite limited. The cardiac transplant community seems the most advanced, with a voluntary agreement that gives preference to urgent cases under a status system. The liver community may adopt a similar agreement. There's little, if any, kidney sharing, ostensibly because dialysis allows provincial programs to keep most recipients alive while waiting.

A national strategy to improve donation rates and donor management practices, similar to the “Breakthrough Collaborative” initiated by the US Department of Health and Human Services.

Ontario and Quebec are informal partners in the US program, and the Western provinces hope to establish a pilot collaborative soon. But insofar as Canada has anything like an agency promoting coordination and harmonization, it's the CCDT, an independent non-profit corporation, established in 2001 and given roughly \$18 million over 5 years to provide advice to the Conference of Deputy Ministers of Health. It has undertaken 7 studies: definition and determination of brain death; donor management models; highly-sensitized patients; paired exchange; public awareness; diverse communities and religious faith; and most recently, donation after cardiac death (*CMAJ* 2006;175[8 suppl]:s1-24). CCDT recommendations aren't binding and, consequently, implementation has been predictably checkerboard.

Many believe there's a need for a national registry and allocation system.

Donation after cardiac death (DCD)

Although now widely practised in the US and several European nations, there have only been 3 cases in Canada, all in Ontario, and initiated at the behest of a donor's family. Only Ontario's Trillium Gift of Life Network has formally adopted DCD as official policy, although Quebec is on the cusp of doing so and several others will likely follow suit. Ontario has also developed rapid response units (some 20 ICU-trained nurses) to help hospitals implement DCD. Trillium President Dr. Frank Markel says early returns in New England suggest DCD could increase organ availability by 30%, a substantial hike given that organs are now obtained only from people suffering brain death (just 1.4% of all deaths).

Presumed consent

Currently, people can “opt in” to donate after they die by either signing the form on their driver's license, or through the explicit consent of surviv-

ing family. Presumed consent works on the principle that everyone's a donor unless they've specified otherwise in advance. Variations of this practice exist in Europe. Austria has the harshest form, placing those who decline to donate at the back of the line in the event they need an organ. Ontario rejected presumed consent on the grounds that Canadian society isn't ready, but Markel says the province is considering the notion of “first person consent,” i.e., automatically harvesting organs when a donor card has been signed. Canadian practice has traditionally been to leave the final decision to families.

Mandatory hospital reporting of ICU or emergency department deaths

The US passed “routine notification and request” legislation last January. Ontario requires reporting by 12 Type A hospitals and will add 9 this fall. BC, Manitoba and New Brunswick have similar tiered requirements (by hospital size, with different reporting criteria in differ-

ent jurisdictions), and Alberta has legislation in the works. Most take an educational, rather than a punitive approach. Ontario has achieved a 70% compliance rate and is considering mandatory reporting for all potential tissue (as opposed to solid organ) donors. Some Ontario hospitals have adopted voluntary reporting policies when potential donors demonstrate certain clinical triggers, such as specific scores on a coma scale.

Incentives for donation

The US Organ Procurement and Transplantation Network and UNOS are examining options like reimbursing donor's funeral expenses; medical leave for donation; priority access for previous donors in the event they need an organ; and even, issuance of a medal of honour. France requires donor reimbursement for travel and accommodation costs, and the UK permits such reimbursements, including lost wages. The state of Pennsylvania has launched a pilot project to

provide \$300 toward funeral expenses of deceased donors. BC has a pilot program to reimburse living donors for “reasonable expenses” (such as travel for tests, appointments and hospital admissions, accommodation or medications after discharge) up to \$5500. The CCDT will soon release a report on incentives, and Ontario is creating a green ribbon task force on the issue.

Given the variations and vagaries in policy and practice, many believe there's a need for a national registry and allocation system, as well as some form of oversight agency, analogous to the Canadian Blood Services.

West and the CST's cardiac group believe both are necessary, although she quickly adds the association itself hasn't adopted an official policy. Markel says a national wait list for highly-sensitized patients (like many women as a result of pregnancy) would be valuable but surmises that a national oversight agency won't fly because of jurisdictional wrangles.

CCDT council member Dr. Sam Shemie says the advisory body isn't interested in becoming a national oversight agency but when its mandate expires next March, it may have an interest in maintaining separate national registries for highly-sensitized patients and paired exchanges between living donors from different provinces. “We're not there to enforce or interfere with the provincial organ procurement organization's role,” says the Montreal Children's Hospital pediatric critical care physician.

Young contends more debate is needed before moving to a national system. “There's one key thing for us. We don't want to replace what's already working well, and nobody wants to pay for things twice.”

Others argue a national agency would likely yield higher donation rates through standardization of organ management practices and improved donation education programming, particularly for front-line physicians.

There's still “extensive” variation across Canada in the way potential donors are identified and families are approached, and few jurisdictions provide doctors with instruction about best practices, says Fides Coloma, president

of the Canadian Association of Transplantation, which represents front-line health care professionals like nurses and organ procurement coordinators.

There must be far more physician awareness of their role in organ donation, adds Dave Smith, president of the Canadian Transplant Association, which represents organ recipients. “Are doctors saying: ‘you know what, we have an organ donor here,’ or do they just steer clear of it? Why don’t we make ‘the ask’ a mandatory thing in a doctor’s routine?” — Wayne Kondro, *CMAJ*

DOI:10.1503/cmaj.061256

Cardiologist’s privileges restored after 4 years

A Nova Scotia bylaw ensures that when a physician’s privileges are suddenly varied the review process takes no more than 30 days. For Halifax cardiologist Dr. Gabrielle Horne that process has taken 4 long years.

On Oct. 8, 2006, the Capital Health board of directors reinstated all Horne’s privileges, which were suspended in October 2002 amid accusations that she endangered patients, conducted unethical research and failed to be collegial. That reinstatement, says Acting CEO John Malcom, turned solely on a procedural issue.

The 8-member board determined that Capital Health jumped the gun in using the emergency privileges variation in the provincial Medical Staff disciplinary Bylaws.

“The decision reinforces that [district health authorities] must enforce fairly and use procedures effectively,” Malcom notes.

The decision also states that “Dr. Horne has a considerable history of difficult relationships with doctors in a supervisory position to her. Further, the Panel readily accepts that the Administration had reason to ... try to correct Dr. Horne’s behaviour.”

That conclusion is uncalled for, unsupported by evidence, and outside the scope of the board’s decision, say Horne and her lawyer. Ron Pizzo.

The board ended the hearing on the grounds that the largest district health authority on the East Coast had overstepped its bounds and that is all that should have addressed in its decision, says Pizzo.

“The board said there were some problems with collegiality. ... In legal terms, those are gratuitous comments.”

Those comments are especially unfair to Horne, he adds, because she doesn’t get to answer the charges by calling witnesses in a formal hearing.

Horne says she will be taking the health authority to court. “I have to have compensation for what I have been through, and I would like the research project restored,” she says.

She also wants the courts to send a strong message. “You can’t just end a physician’s career with the stroke of a pen and not give them due process,” says Horne. “You can’t hold people hostage for 4 years.”

Horne’s research, which was approved by the QEII ethics board, focused on new ways to repair heart muscle damaged by myocardial infarction. In October 2002, Horne, the assistant professor of medicine and biomedical engineering at Dalhousie University and staff cardiologist at the Queen Elizabeth II Health Sciences Centre (QEII), was accused by a colleague of endangering patients, unethical research and a lack of collegiality.

The QEII responded by blocking her access to patients and charts and she was informed she could not continue with her research project until those concerns were addressed. The source and specifics of those concerns were never publicly revealed.

For her part, the award-winning clinician-researcher is glad the ordeal is almost over. “I’m thrilled that I have my privileges back finally,” she says, “[but] I did not like the way that the board went about it.”

That feeling is shared — vehemently — by the Canadian Association of University Teachers (CAUT), which went so far as to establish an independent inquiry into Horne’s case 2 years ago.

“We are appalled by what the Capital District Health Authority board has done,” says James Turk, CAUT’s executive director. “It’s good news for Dr.



Courtesy G. Horne

Horne wants her day in court.

Horne on the one hand, but rather than apologizing to her and entering into discussions as to how they can compensate her, instead they condemn her.”

As a Dalhousie Clinical Research Scholar, 70% of Horne’s time was protected for research. Despite subsequent clearance from an internal medical committee at the QEII and a signed settlement agreement with the health authority’s former CEO, Horne has not been able to carry out her work since being suspended. She had to shut down her research lab and let her staff go.

Fortunately, says Horne, she has not been alone. “I just would not have my privileges back today if it were not for the work of the medical staff, the university, the faculty association and CAUT.”

In 2004, 120 doctors from Capital Health walked for 15 minutes in the rain to a meeting at Dalhousie University (the health authority would not let them meet in the hospital) to discuss Horne’s situation. That meeting ultimately led to a new medical staff association and a meeting with the minister of health to express concerns about what was happening to the Halifax cardiologist. Staff doctors launched their own investigation and recommended, in December 2005, that Horne regain her full privileges.

For its part, CAUT launched an independent investigation into what it saw as issues of academic freedom and research interference related to Horne. — Donalee Moulton, Halifax

DOI:10.1503/cmaj.061244