Pushing the envelope on organ donation

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In June 2007 a Dutch television station broadcasted a program in which a terminally ill patient interviewed three potential candidates in order to select one of them to receive her kidneys.\(^1\) The choice of recipient was to be made on the basis of the contestant’s history and profile, as well as based on conversations with their family and friends; viewers were also able to add their input via text messages. As expected, medical professionals and politicians were outraged when the program was aired. Soon after, it was revealed that the show was a hoax intended to raise awareness about the shortage of organ donors; the donor was in fact an actress, while the three potential recipients were genuine. Even though the impact of the program on the public and on government policy is difficult to assess, it does bring to our attention the fact that there is a significant worldwide shortage in the supply of donated organs for those in need.\(^1\) In fact, just like most other developed nations, Canada has been unable to keep pace with the demand for organs. This issue of organ shortage is worth exploring in order to be able to make conclusions about the causes and possible solutions.

The Situation in Canada

In order to assess the extent of the problem in Canada it is important to review some of the available statistics. For instance, 4,195 Canadians were on wait-lists for organ transplants on December 31, 2007\(^2\) compared with 3974 people on Jan 1, 2006 and 2592 people in 1995.\(^3\) Only 2188 transplants were performed in 2007\(^4\) and 193 Canadians died waiting for an organ transplant in the same year.\(^2\) Moreover, according to the Canadian Organ Replacement Registry, Canada’s cadaveric donation rate for deceased donors in 2005 was 12.8 per million inhabitants, which falls well below the rates in countries like Spain (35.1), Estonia (26.5), Belgium (22.8), Italy (20.9) and the United States (21.5) as projected by the International Registry maintained at the University of Barcelona, Spain.\(^3\) On the bright side, living donation rates in Canada are rising and currently stand at 15.6 per million inhabitants. Nevertheless, there are significant regional variations in deceased and living organ 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.\(^3\) There are also significant provincial variations in wait times for transplants. In fact, a recent study of 7034 dialysis patients found people under 40 waited a median 8 years in Ontario for a new kidney, compared with 3 years for those in Alberta.\(^5\) Hence, not only does Canada have a shortage in organs, the nation also possesses a very fragmented system that has led to regional variations in organ donation rates as well as provincial variations in wait times for transplants.

One of the problems of the Canadian system is that less than half of the organs that could potentially be transplanted are actually harvested. There are a number of reasons for the inefficiency including the fact that in many cases the family members of an individual are simply not approached for consent. In addition, there is no concerted effort and little resources allocated to educate Canadians about the benefits of organ donation.\(^4\) However, the main problem with the Canadian system lies in the presence of many fragmented organ donation programs that are so varied that it is difficult if not impossible to characterize national practice in Canada as a whole.\(^3\) The existence of many organizations and programs that vary from province to province is a
“reflection of the fractured jurisdiction over health care”. In fact, it has been suggested that Canada’s low organ donation rates maybe be partly due to a lack of a coordinated and centralized approach to dealing with the issue.

New Developments

In recent months there have been attempts by both federal and provincial governments in Canada to make policy changes that will reduce the shortage of organs available for transplantation by attempting to decrease the fragmentation and improve the coordination and communication amongst the provinces. In fact, one very recent positive development with regards to organ donation in Canada was an agreement reached in August 2008 between the federal, provincial (except Quebec) and territorial governments to develop an “integrated national organ donation system”, including national oversight and allocation mechanisms for all donated organs and tissues. Prior to this initiative, Canada was the only developed country without a national transplant system, which has resulted in a significant variation in organ donation rates across the country and a lack of equal access to life-saving transplants. Under the new funding arrangement, the Canadian Council for Donation and Transplantation (CCDT) has merged with Canadian Blood Services, which has expanded its mandate and operations to include organ and tissue donation and transplantation. While the fragmented provincial transplantation agencies will continue to run independently, more effort will be put into improving the co-ordination amongst the different agencies.

The initiative is further aimed at creating and managing three electronic registries: the Urgent Status Registry to ensure patients most desperately in need of organs are treated first, regardless of where they live; the Living Paired Exchange Registry to facilitate the donation of organs such as kidneys and lungs by living donors; and the Intent to Donate Registry to coordinate the various provincial programs that allow potential donors to give their consent to donate organs when they die. The creation of these registries will not only reduce the

fragmentation in our approach to organ donation, it will also provide us with much needed data and evidence to allow us to better evaluate our progress. In addition to the national organ-sharing network that will be created, there will also be efforts directed at standardizing consent policies and creating nationwide wait lists for all available organs. Mandatory organ sharing and other requisite elements of a national organ donation and transplantation program will be phased-in over a number of years.

Alternative options

At the present time, Canada utilizes an “opt-in” approach to organ donation. An individual needs to give consent by signing an organ donation card, or explicit consent needs to be obtained from surviving family members before a person’s organs can be used after their death. This approach to organ donation has proven to be suboptimal when it comes to harvesting organs to give to those in need. In fact, Canada possesses a legal framework that does not promote organ donation.

An alternate strategy would be a “presumed consent” (opt-out) approach, whereby everyone is presumed to be a donor unless they have specified otherwise in advance. There are two main variations of this policy that have been utilized in some European countries. For instance, Spain, a world leader in organ donations, has managed to achieve the highest organ donation rate in the world by implementing a policy of “soft” presumed consent whereby relatives may opt-out for a dying patient. In addition, the Spanish government invested heavily in educational campaigns and “transplant support teams” who provide emotional support to bereaving families, helping decrease refusal rates. Since the implementation of the “soft” presumed consent approach in Spain in 1990, donation rates have doubled to their current level of 35 per million. Another variation of this policy is the “hard” presumed consent policy seen in Austria where relatives may not opt-out for a dying patient. In addition, the Spanish government invested heavily in educational campaigns and “transplant support teams” who provide emotional support to bereaving families, helping decrease refusal rates. Since the implementation of the “soft” presumed consent approach in Spain in 1990, donation rates have doubled to their current level of 35 per million. Another variation of this policy is the “hard” presumed consent policy seen in Austria where relatives may not opt-out for a dying patient. This approach began in Austria in 1982, and since then, their donation rate has quadrupled to 25 donors per million.
rejected the presumed consent approach on the grounds that Canadian society “is not ready”; however, it is difficult to say whether or not the government has the right to judge if the people are or are not ready for a new approach to organ donation. Still the Ontario government is not sitting idle and is considering the idea of “first person consent”, whereby an organ is automatically harvested when a donor card has been signed, with no consideration for the opinion of the donor’s family.

As effective as presumed consent appears to be, however, simply changing organ donations laws and regulations will not solve Canada’s shortage of organs. What is needed in addition to changing the laws is a significant shift in attitudes toward organ donation. In Spain for instance, considerable emphasis is placed on organ donation awareness. There is special funding and training provided for transplant teams, who are responsible for working with grieving family members to explain the situation and explain to them the value of organ donation. Furthermore, the general public needs to be educated about the importance of signing their organ donation cards, and about the many lives they can save if they choose to do so. Without such a system of education and counseling for grieving families, a presumed consent law will not live up to its potential.

In addition to presumed consent, there are a number of other strategies that can possibly be implemented to address the shortfall in donated organs. These include monetary incentives for those who signup to be a donor. For instance, making an offer to the family to reimburse the donor’s funeral expenses. Other incentives could include providing priority access for previous donors in the event they need an organ.

Conclusion and Future Outlook

All in all, Canada has had a dismal record when it comes to organ donation and that must change sooner rather than later because the demand for organs has been growing over the years. The federal and provincial governments have taken some positive steps in recent years to try to improve the situation; the most significant step has been the plan to develop an integrated national organ donation system, including national oversight and allocation mechanisms for all donated organs and tissues. However, more needs to be done to correct the current state of affairs. This could involve amending the current laws and regulations pertaining to organ donation, educating the public and raising awareness about the importance of organ donation, as well as providing incentives for those who agree to donate their organs. Until such time we can only look with admiration towards countries such as Spain, which has become a world leader when it comes to organ donation.

References