COMMENTARY

Current Canadian Initiatives to Reimburse Live Organ Donors for their Non-Medical Expenses

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ABSTRACT

Living organ donors frequently incur non-medical expenses for travel, accommodation, prescription drugs, loss of income, and child care in conjunction with organ donation. Despite international precedent and widespread public support, Canada currently lacks a unified strategy to reimburse donors for these expenses. In 2005, we communicated with 78 individuals within the field of Canadian transplantation to identify which initiatives for reimbursement of living donors existed in each province. Saskatchewan was the only province in which public employees were granted paid leave for organ donation. Six provincial governments partially reimbursed travel and accommodation. At the federal level, other expenses could be partially reimbursed through an income tax credit, while the Employment Insurance program and the Canada Pension Plan provided funding for donors who become unemployed or develop long-term disability as a result of donation. Charities helped a limited number of patients in financial need through grants and no-interest loans, but funding was generally limited by contributions received. While reimbursing living donors for their non-medical expenses is considered just, existing programs only partially reimburse expenses and are not available in all provinces. Developing future reimbursement policies will remove a disincentive faced by some potential donors, and may increase rates of transplantation in Canada.

MeSH terms: Living donors; kidney transplantation; health policy; economics; costs and cost analysis

RÉSUMÉ

Les donneurs vivants engagent souvent des dépenses extramédicales (frais de déplacement et d'hébergement, achat de médicaments sur ordonnance, perte de revenus, frais de garde d'enfants) en liaison avec leurs dons d'organes. Or, malgré les précédents internationaux et l'appui généralisé du public, le Canada n'a pas de stratégie unifiée pour leur rembourser ces dépenses. En 2005, nous avons communiqué avec 78 intervenants du secteur de la transplantation au Canada afin de repérer, dans chaque province, les initiatives de remboursement des dépenses des donneurs vivants. La Saskatchewan est la seule province qui octroie un congé payé aux fonctionnaires faisant un don d'organe. Six administrations provinciales remboursent en partie leurs frais de déplacement et d'hébergement. Dans l'administration fédérale, d'autres frais peuvent être partiellement remboursés par un crédit d'impôt sur le revenu, et le programme d'assurance-emploi et le Régime de pensions du Canada prévoient des fonds pour les donneurs qui ont perdu leur emploi ou qui présentent des limitations fonctionnelles de longue durée en raison d'un don d'organe. Des oeuvres de bienfaisance aident un petit nombre de patients en difficulté financière en leur octroyant des subventions et des prêts sans intérêt, mais le montant du financement est en général limité par les contributions reçues. On considère qu'il est juste de rembourser les dépenses extramédicales des donneurs vivants, mais les programmes existants n'en remboursent qu'une partie, et toutes les provinces n'offrent pas ces programmes. L'élaboration de politiques de remboursement abolirait un obstacle de plus pour les donneurs éventuels et pourrait accroître les taux de transplantation au Canada.

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There are many, well-documented advantages to organ transplantation. For patients with kidney failure treated with dialysis, those who receive a kidney transplant live longer, have a better quality of life, and cost the health care system less (about CAN $104,000 are saved for each patient over a 20-year timeframe).[1-4] While most living organ donor transplants are kidneys (88%), living liver transplantation is life-saving, and is considered cost-effective.[5] To meet the shortage in organs from deceased donors, rates of living donation in Canada have nearly doubled over the last 10 years to 14.7 per million in 2004. Despite this, by end of 2004, 4,004 Canadians were waiting for a transplant and 224 patients had died waiting.[6] Increasing living organ donation is an important strategy to meet growing demand.

Some potential live donors express concern about the financial implications of donation.[7-9] While expenditures for medical evaluation, surgery, and hospital care are generally covered by public or private insurance, donors are often responsible for other costs, such as prescription drugs, loss of income, travel and parking costs (including the costs for a companion), post-surgery accommodation, and child care expenses.[7] Of living donors, many reported out-of-pocket expenses associated with donation, including lost income or wages (the sum of selected costs considered in one US study averaged US $867 per donor with an upper range of $28,906[10]). There is strong agreement that reimbursing donors for such expenses is just.[11,12] It is also hoped that reimbursement will remove economic barriers faced by some potential living donors, particularly those of low income, and serve to increase rates of transplantation.[13-15]

While several countries have implemented national or subnational reimbursement programs, Canada currently lacks a unified strategy to reimburse living donors for their non-medical expenses.[16,17] In 2005, we communicated with 78 individuals within the field of Canadian transplantation to identify which initiatives for reimbursement of living donors currently exist in each province and to ascertain provincial or institutional capacity to administer a comprehensive reimbursement program, should it be funded by the government.

CURRENT CANADIAN INITIATIVES

There was a consensus among our respondents that reimbursing living organ donors for their non-medical expenses was desirable; moreover, they agreed with the fairness principle that donors should not be penalized for their altruistic act of organ donation, financially or otherwise. Only a few expressed concern that awarding money to living donors could lead to the commercial trade of organs. Most respondents believed their province or institution could administer a reimbursement program, provided there was funding for additional personnel.

Canada lacked a unified strategy to reimburse living donors for incurred non-medical expenses. Notably missing was the reimbursement for lost income and lost productivity. Moreover, both governmental and non-governmental initiatives varied significantly across provinces in terms of structure and available resources.

Federal programs

Although a comprehensive program was lacking, several federal policies offered partial financial support to living donors. The Medical Expense Tax Credit allowed living donors to claim some medical expenses on their federal tax return, including travel, meals and accommodations.[18] Those travelling smaller distances could only claim travel costs, while for over 80 kilometres, the cost of meals, accommodations, and a companion (if recommended by a doctor) could be added. For 2004, a donor could claim only expenses in excess of 3% of his net income or $1,813, whichever was less. This was a non-refundable tax credit (i.e., reduces the individual's federal income tax). Compared to those of higher income, donors with no or lower income were at a disadvantage since their tax liability is lower, compromising their ability to take full advantage of this credit.

Donors employed prior to donation could receive financial assistance under Canada's Employment Insurance (EI) program.[19] Eligibility required previous contributions to the program and 600 hours of work in the 52 weeks before taking time off. The EI program has a 'sickness benefits' component for those who cannot work due to health reasons and 'regular' benefits for people who lose their jobs through no fault of their own. An EI recipient can obtain benefits (sickness and regular) for a maximum of 50 weeks. Sickness benefits are not available before the surgery, but could be received after transplant for a maximum of 15 weeks which usually, but not always, cover the entire recovery. After this period, donors could switch to regular EI benefits for 35 more weeks if they lost their jobs, and were able to work but unable to find employment. During these 50 weeks, the maximum benefit was the lesser of 55% of average income or $413/week. Due to alternative work arrangements (part-time, no EI contributions), more than half of Canadians who become unemployed are ineligible for the EI program.[20]

If unable to work after sickness benefits, donors could use private short-term disability insurance, if available. Only 42% of all Canadian employers provide their employees with health-related benefits, such as disability insurance.[21] The Canada Pension Plan (CPP) disability benefit was available to donors whose disability prevented them from working for more than a year and who contributed to the plan. To be eligible, the physical or mental impairment must have been 'severe and prolonged.'

Provincial programs

At the provincial level, health plans covered medical costs associated with living donation, yet financial support for non-medical expenses such as travel, accommodations, lost income, or dependent care was rarely available. As of December 2005, no province had implemented a formal, comprehensive program to cover all costs. Most non-governmental initiatives were ad hoc and limited in scope; they generally lacked formal annual budgets and clear guidelines to establish need. The only provincial-level initiatives that were appropriately funded and managed were travel reimbursement programs in Newfoundland and Labrador, New Brunswick, PEI and Northern Ontario, which covered accommodations, meals and travel. These programs were not targeted to organ donors per se; rather, they provided support for general out-of-area specialty care and required physician approval. Medical expenses outside the donor's province were paid directly to the health provider.

Saskatchewan was the only province that implemented a paid leave program for public employees. In Ontario, the Trillium Gift of Life proposed extending the Family Medical Leave Act (unpaid leave, job protection) to organ donors. British Columbia was the first province to actually propose a comprehensive program for donor reimbursement that would cover all major categories of non-medical expenses, proportionally to donor's income and subject to a maximum. Planning committees were working to improve financial support for living donors in Alberta, Ontario, Quebec, and Nova Scotia.

Charity and non-profit organizations

In cases of financial hardship, social workers from transplant centres and not-for-profit organizations try to help by applying for funding on the donor's behalf. The Kidney Foundation of Canada (KFOC) is generally the first organization contacted. Although KFOC relies entirely on donations, it is often able to offer at least minimal support through interest-free loans or grants. The extent and availability of assistance varied across provinces. For example, by mid-2005, Saskatchewan KFOC had funded one living donor with $250, while the Ontario branch had given out a total of $3-4,000 over the previous two years. Occasionally, groups such as the Lions Club, Rotary or Kinsmen foundations also provided donations to particular patients. Hope Air is a national charity that helps needy Canadians fly to necessary medical treatment. Recognizing their altruistic act, Hope Air was less strict with living donors when establishing need. Respondents from Alberta and Nova Scotia particularly mentioned Hope Air as a way in which donors received travel assistance.

FUTURE DIRECTIONS

Although health care is implemented at the provincial level, we believe that national guidelines to reimburse living donors are desired to ensure uniformity of benefits across the country. Any viable program needs to be comprehensive, adequately funded, and centered on the idea that the donor should neither make any profit from donating, nor suffer any financial loss. Programs should cover – in reasonable amounts – major categories of expenses

such as lost income, travel and accommodations for donation and follow-up visits, dependent care and unpaid work, testing and outpatient medications.[7] The program will require close monitoring to ensure it is not subject to abuse, and that it is fiscally sustainable. A major obstacle in gaining policy-makers' support remains the cost of a comprehensive program. A better understanding of the direct and indirect costs incurred by living organ donors is needed,[7] and research groups can effectively inform new policies if they provide policy-makers with information in a timely way.[22] Most transplant professionals who responded to our inquiry believed their provinces have the institutional capacity to administer a reimbursement program provided there is the will to do so; the involvement of transplant centers – although desired – is presently limited by infrastructure and human resources.

To be successfully implemented, a policy solution must also be politically acceptable. At a recent national consensus conference, the transplant community agreed on the problem definition and the main course of action.[23] This should prevent policy-makers at both the provincial and national levels from perceiving change as controversial and politically risky.

Finally, formulation of comprehensive policy will be a long-term process involving steady financial commitment, public education, development of infrastructure, and continual program evaluation and knowledge exchange. The process will require strong leadership, and sufficient flexibility to motivate provincial governments to overcome jurisdictional barriers.

These efforts will help remove a disincentive faced by some potential donors, and may increase rates of transplantation in Canada. It provides donors with the social support and recognition they deserve for a truly noble and altruistic act.

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