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Economic Consequences Incurred by Living Kidney Donors: A Canadian Multi-Center Prospective Study

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Some living kidney donors incur economic consequences as a result of donation; however, these costs are poorly quantified. We developed a framework to comprehensively assess economic consequences from the donor perspective including out-of-pocket cost, lost wages and home productivity loss. We prospectively enrolled 100 living kidney donors from seven Canadian centers between 2004 and 2008 and collected and valued economic consequences ($CAD 2008) at 3 months and 1 year after donation. Almost all (96%) donors experienced economic consequences, with 94% reporting travel costs and 47% reporting lost pay. The average and median costs of lost pay were $2144 (SD 4167) and $0 (25th–75th percentile 0, 2794), respectively. For other expenses (travel, accommodation, medication and medical), mean and median costs were $1780 (SD 2504) and $821 (25th–75th percentile 242, 2271), respectively. From the donor perspective, mean cost was $3268 (SD 4704); one-third of donors incurred cost >$3000, and 15% >$8000. The majority of donors (83%) reported inability to perform usual household activities for an average duration of 33 days; 8% reported out-of-pocket costs for assistance with these activities. The economic impact of living kidney donation for some individuals is large. We advocate for programs to reimburse living donors for their legitimate costs.

Keywords: Cost of illness, costs and cost analysis, kidney transplantation, living donors

Abbreviations: $CAD, Canadian currency; SD, standard deviation

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Introduction

Transplantation is the preferred treatment for patients with kidney failure, given the reduced risk of death (1), improved quality of life and reduced healthcare costs (2) compared with dialysis. Each kidney transplanted into a patient with end-stage renal disease is estimated to provide an additional 2–3.5 quality-adjusted life years, direct healthcare savings of $100 000 (3) and economic value of approximately $300 000 (4). Despite strategies to increase organs available for transplantation for both living and deceased donation (5–7), the need for kidneys continues to exceed their supply (8). Potential living donors and their intended recipients are concerned about economic consequences of donation (9). It has been recognized that living donors experience economic consequences during workup, surgery and convalescence. These economic consequences may be considered unfair and act as a disincentive for some donors. It has been suggested that living donors be reimbursed for their incurred expenses in jurisdictions where this is feasible (10,11).

We published a comprehensive, critical review of the existing 35 studies describing the frequency and magnitude

of expenses incurred by living donors (12); however, an accurate estimate of costs was not possible given the multiple methodological issues in existing studies, including the retrospective nature of most reports, lengthy time frames for patient recall, low response rates and incomplete capture of all relevant costs. As such the true extent and magnitude of the economic burden to living kidney donors are uncertain, highlighting the need for prospective and accurate determination of these costs (13). Given the poor health outcomes for patients on dialysis, limited supply of deceased donor organs and high costs of dialysis therapy, it is imperative that all barriers to living organ donation be identified, fully characterized and definitively addressed. Better knowledge of the economic consequences experienced by living kidney donors also informs the feasibility and conduct of emerging and existing reimbursement programs.

As part of a larger prospective multi-center study designed to determine the medical and psychosocial consequences of living kidney donation, we conducted a rigorous prospective costing study to obtain precise estimates of the expenses incurred by Canadian living kidney donors.

Methods

Economic consequences incurred were determined from participants enrolled in a multi-center prospective study designed to determine long-term outcomes in living donors. Briefly, subjects $\geq$18 years of age deemed eligible to donate a kidney to a relative or friend at one of seven Canadian transplant centers, who verbally communicated in English or French, and provided consent, were recruited prior to donation and followed post–kidney donation. This economic sub-study examined the first 100 living kidney donors enrolled who proceeded with donation and had follow-up for at least 1 year.

The three-step micro-costing approach of identification, measurement and valuation of resources (14) was followed. Identification of potential economic consequences was determined through systematic review of existing literature (12) and iterative consultation with healthcare professionals in transplantation to identify categories and details of potential costs (Figure S1; Table S1). Measurement of resources consumed by donors was performed through two mail self-administered surveys at 3 and 12 months after kidney donation, based on the observation that the majority of costs due to donation are encountered within the first 3 months of donation, and almost all within the first 12 months. A 90-day period for self-reported productivity impairment has an intraclass correlation coefficient of over 0.80 with actual records (15), indicating that participants are likely to accurately recall expenses occurring in the 3 months postdonation. Donors reported for the predonation (including donor evaluation), donation and postdonation time periods. Follow-up telephone calls to participants were made by the central data-coordinating center for missing or discrepant data.

We identified the major cost categories relevant to living donors, including direct costs defined as resources consumed in the donation process even where a direct monetary transaction does not occur, and productivity costs including days off work with (and without) lost income, lost home productivity, as well as caregiver for convalescent or dependent care (Table S1). Workforce productivity was valued using province-specific average wage rates (Table S2). We developed a comprehensive instrument using accepted techniques to capture units of resources consumed as a result of living donation (14–16). This instrument quantified the number of units consumed in each category by donors for a full accounting of resource utilization. Collecting units consumed (e.g. capturing distance traveled instead of out-of-pocket fuel costs) facilitates portability of the results to alternate settings, as the monetary value per unit may vary depending on setting and region. Finally, we assigned each resource unit a cost using conventional costing techniques and relevant Canadian estimates (Table S1 and Supplemental Methods).

The cost incurred for living kidney donors was calculated by each cost category and in total using the average and standard deviation as well as median and range (given that cost data are frequently skewed). We determined the frequency distribution of total costs incurred by each donor. The value of lost workforce productivity where the donor did not incur lost wages was determined but was not included in total cost in the primary analysis.

Results

Among donors with at least 1 year of follow-up postdonation, 85% had complete 1-year data at the time of this analysis. The 100 living kidney donors enrolled had an average age of 45.2 years, and 64% were Caucasian women (Table 1). They were enrolled from 2004 to 2008, and all costs are expressed in Canadian dollars for this period of time. The most frequently reported household annual income category was $\geq$\$80 000; at this time, the average household income in Canada was \$71 600–\$78 500 (17). The majority of donors were from four transplantation centers in Ontario. Direct out-of-pocket costs were incurred by 94 of the 100 subjects, with highest proportion reporting cost for ground travel (94%) and nonhospital accommodation (49%) (Table 2). For donors who reported resource use in cost category of interest, the greatest average costs were observed for ground travel, accommodation and air travel (\$897, \$1759 and \$1480, respectively). When considering all donors (including those who incurred no resource use), the largest costs were for ground travel and accommodation (\$852 and \$862, respectively). In all 100 donors, average direct cost was \$1780 (SD 2504), and median cost was \$821 (25th–75th percentile 242–2271).

Work and home productivity losses occurred in over 80% of subjects (Table 3), and lost wages was reported by 47% of donors. In those who experienced loss of pay, the average number of days and income lost were 20 and \$4567, respectively; for all donors average lost wage was \$2144. Total workforce productivity loss that includes time off work with and without pay (i.e. vacation, sick leave, employment insurance) for all donors was \$6729 (Table 4).

Approximately 45% of donors directly experienced economic consequences attributable to living kidney donation (out-of-pocket costs, lost pay, but excluding home productivity costs) that were less than \$1000 (Figure 1). However, 20% incurred costs between \$1000 and \$3000, 34%

Table 1: Characteristics of living kidney donors

Variable	N = 100 donors
Age at time of donation, mean (SD)	45.2 (9.5)
Female, n	71
Race/ethnicity, n	
Caucasian	90
Asian	3
African Canadian/American, Black	2
Other	4
Married prior to donation, n	74
Family income prior to donation (CAD), n	
<15 000	2
15 000–29 999	6
30 000–49 999	22
50 000–79 999	21
≥80 000	48
Relationship to recipient	
Sibling	38
Parent	16
Son/daughter	14
Spouse/partner	12
Friend	4
Other	15
Transplant center, n	
Edmonton	11
Halifax	8
Hamilton	11
London	34
Toronto (St. Michael's)	12
Vancouver	11
Winnipeg	13
Province of residence, n	
Alberta	11
British Columbia	11
Manitoba	12
Nova Scotia	4
Ontario	59
Prince Edward Island	1
Out of country (USA)	1

One donor is missing age, gender, race and annual household income.
All respondents were English speaking.

experienced costs >$3000, with 15% of those incurring costs >$8000. The average out-of-pocket costs and lost wages for living donors was $3268 (median $1282) (Table 4). In sensitivity analysis, mean home productivity cost was estimated at $5521.

Interpretation

To our knowledge, this is the first study to prospectively and comprehensively capture and value the economic consequences experienced by living kidney donors. While there is considerable variation between donors in what costs are encountered and their magnitude, the vast majority of living kidney donors directly experienced substantial economic consequences, with an estimated average value of costs of $3268 for all 100 Canadian living

Table 2: Direct economic costs for 100 Canadian living kidney donors

Cost type	Cost category	Description	Number of patients (n = 100)	Units	Median (25th–75th percentile) units[1]	Costs $ (in patients reporting outcome)[1]		Costs $ (all patients)[2]		
						Average (SD)	Median (25th–75th percentile)	Average (SD)	Median (25th–75th percentile)	Average (SD)	Median (25th–75th percentile)
Direct										1780 (2504)	821 (242–2271)
	Travel	Ground travel	94	# Return trips	10 (6–16)	897 (1048)	512 (216–1187)	852 (1040)	486 (194–1080)		
		Air travel	3	# Return trips	3 (1–4)	1480 (1108)	2065 (203–2173)	44 (299)	0 (0–0)		
	Accommodation	Nonhospital accommodation	49	# Overnight stays	6 (3–11)	1759 (2567)	1094 (547–2007)	862 (1995)	0 (0–1090)		
	Medication[3]	Pain medication or antibiotics	4	Drugs taken (yes/no)	N/A	40 (28)	40 (20–60)	1 (6)	0 (0–0)		
	Medical	Out-of-pocket medical expenses related to tests, appointments or hospital stays	22	Expenses incurred (yes/no)	N/A	152 (247)	60 (40–150)	30 (123)	0 (0–0)		

[1]Considers only those donors who reported the resource use.
[2]Considers all donors (n = 100) in denominator (one donor experienced exceptional circumstances [out of country donor with 3-month stay] and these costs were excluded).
[3]Medication includes only patients who paid for medication out of pocket, and some or all of the cost of medication was not reimbursed. Note that 30 out of 100 donors reported requiring medication. Two out of four donors are missing cost of medication.

Table 3: Economic outcomes for 100 Canadian living kidney donors

Cost type	Cost category	Description	Number of donors reporting the outcome	Number of days (in donors reporting outcome)	Number of days (all donors)	Costs $ (in donors reporting outcome)[1]		Costs $ (all donors)[2]			
				Median (25th–75th percentile)	Median (25th–75th percentile)	Average (SD)	Median (25th–75th percentile)	Average (SD)	Median (25th–75th percentile) Cost	Average (SD)	Median (25th–75th percentile)
Indirect	Lost wages									6729 (6259)	6572 (1048–9081)
		Time spent away from work (with loss of pay)	47	20 (5–44)	0 (0–14)	4567 (5111)	3273 (850–7484)	2144 (4167)	0 (0–2794)		
		Time spent away from work (without loss of pay)	68	38 (14–53)	15 (0–46)	6898 (5448)	6659 (2288–8522)	4558 (5753)	2517 (0–7816)		
	Housework and dependent care									5233 (5196)	3345 (838–8557)
		Days unable to perform usual household activities (estimated cost)	83	33 (14–60)	23 (6–56)	6597 (5053)	5763 (2445–9780)	5453 (5231)	3977 (1116–9014)		
		Number of days requiring assistance or care (reported out-of-pocket cost)	8	7 (6–12)	0 (0–0)	372 (800)	53 (0–125)	23 (202)	0 (0–0)		

[1]Considers only those donors who reported the resource use.
[2]Considers all donors (n = 100) in denominator.

Table 4: Total costs incurred for living kidney donors

Scenario	Average cost $ (SD)	Median cost $ (25th–75th percentile)
Donor costs[1]	3268 (4704)	1282 (205–4619)
Estimated home productivity cost[2]	5521 (5287)	4462 (1222–9014)
Total workforce productivity cost[3]	6729 (6259)	6572 (1048–9081)

Considers all donors (n = 100) in denominator.
[1]Donor costs = out-of-pocket costs + lost wages.
[2]Home productivity determined using provincial wage rates.
[3]Includes time off work with and without pay.

donors in this study. We also identified a wide variation in costs incurred in both overall costs as well as costs in the categories examined. While a large proportion incurred costs valued at <$1000, one-third of donors experienced a large economic burden in excess of $5000 or $10 000 as a result of donation.

We (10), as well as others (18), have advocated for reimbursement of incurred expenses on both the principle of fairness, as well as eliminating a potential barrier or disincentive to living kidney donation. The economic consequences enumerated here are not trivial, and the context in which they occur is worth noting. Biological relatives and spouses make up the majority of living donors, who may be burdened financially by the burden of the chronic illness of end-stage renal disease. Further, living kidney donation leads not only to better quality and quantity of life for recipients but also to substantial net healthcare cost savings estimated at $100 000 (3). It is counterintuitive to allow economic penalties to occur to living kidney donors when programs are attempting to heavily promote this activity that results in health improvements and healthcare resource savings.

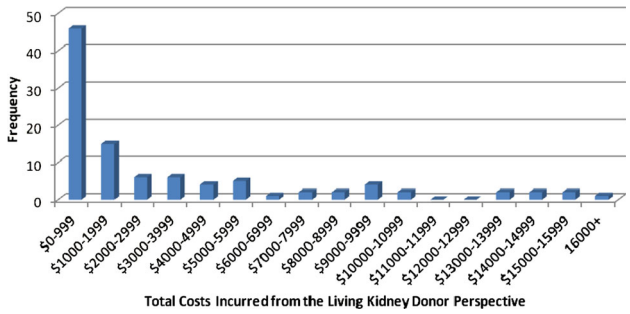

Figure 1: Frequency distribution of total costs incurred from the living kidney donor perspective. 25th percentile: $205; median: $1282; 75th percentile: $4619. Average (SD): $3268 (4704). Five donors incurred 0 costs. Excludes home productivity costs and time off work where no pay was lost. One donor experienced exceptional circumstances (out-of-country donor with 3-month stay) and these costs were excluded.

Several living donor reimbursement programs have emerged in Canada since our study began, and while this is an important step forward, the conduct of new and existing programs can be informed by this study. We are aware that many of these programs have caps in place for reimbursement by cost category and overall in an attempt to maintain sustainability, with caps often of ~$5500 per donor. While our data indicate that this is sufficient for the majority of donors, there are a proportion of donors who experience costs that exceed these caps. While sustainability is a critical consideration, it is not equitable that donors who incur higher costs should be penalized. Examples of these scenarios encountered in this cohort include individuals unable to obtain time off work with pay, or an out-of-country donor who was required to stay near the transplant center for almost 3 months postdonation and incurred high costs due to this. We would argue that all reasonable costs as a result of living kidney donation be reimbursed, without penalizing those in whom circumstances lead to a greater magnitude of these costs.

There are limitations of this study. First, there may be recall bias for participants. We attempted to minimize this by utilizing a short recall time frame of 3 months (15) during the time when most losses would occur, and requesting identification of units of resources to minimize the cognitive burden of calculating costs. This also allows portability of results to different jurisdictions where the cost per unit (hotel night, airline travel) may differ. Second, these data are reflective of participants enrolled in a larger observational study, and it is not clear that results would be generalizable to all donors. For example, it is surprising that donors traveling by air would have a median of three round trips, although air travel was reported by only three donors. Further, Canada is geographically large and many donors may travel longer than in more densely populated areas. However, study inclusion criteria are broad, and donor characteristics are similar to typical living kidney donors in Canada. Third, economic consequences may be greater for living donor paired exchange, where travel distances may be greater and the donor frequently brings a support person; this practice was nonexistent in Canada during the study enrollment period. Finally, medical costs were not considered as Canada has a single payer universal healthcare system. Incurred costs may be higher in other jurisdictions, which may be a critically important consideration (19) given the recommendations of lifelong medical surveillance of living kidney donors for adverse medical consequences, such as hypertension. Currently in Canada recommended practice is follow-up at 4–12 weeks and 1 year, followed by annual follow-up with a medical practitioner (20); other jurisdictions such as the Organ Procurement and Transplantation Network mandate follow-up for 2 years. While we do not have data from our study on these costs beyond 1 year (or other cost related to disability or death that rarely occur with living donation), we support provision of short-term and long-term medical insurance for living kidney donors.

While uncertainty exists regarding the optimal method of valuing and reimbursing lost home or workforce productivity, we adhered to accepted practice. First, we used average provincial wage rates to determine cost, not actual wage rates. For reimbursement purposes, it is not clear if actual wages should be reimbursed, or if a standard wage rate or set stipend should be provided. Potential benefits of a stipend are that it would compensate home productivity losses without requiring measurement, may mitigate unfairly undercompensating nonemployed donors (which in our sample were primarily female—the predominant gender of donors), and may particularly serve those with little or no home productivity support. Due to poor response we do not have actual wages, and argue that the main purpose of reimbursing lost wages is to prevent financial hardship in a sustainable fashion. As some donors may have a very high income, reimbursing actual income may not be feasible or desirable. From an economic perspective nonpaid labor (such as home productivity) has real value, which a set stipend may address, if allowable by interpretation of existing legislation. Second, we examined the value of time off work that did not result in a loss of wages to the donor in scenario analysis. We are aware of many donors who use sick leave, vacation time or employment insurance to avoid lost wages. Arguably donors should not have to utilize these privileges, which have quantifiable economic value, for the act of donation, but retain them for their intended use or to utilize when required at a future date (e.g. retain the ability to take future sick leave due to unrelated reasons). Finally, we did not include the value of home productivity, as the true economic value of this activity is not clear. If lost home productivity is valued in the same manner as workforce productivity, the mean and median values are $5233 and $3345, respectively. However, if these activities are assumed by other household members, this may be an overestimate. Further, from a strictly economic perspective, this has a nonzero value; it is not commonly used or advocated for in donor reimbursement programs, despite the fact that is of real value.

In conclusion, we present the first high-quality comprehensive prospective assessment of the economic consequences in 100 Canadian living kidney donors from seven centers. Economic consequences are frequent and nontrivial, with a sizable proportion of donors experiencing significant costs. These results further support the development of donor reimbursement programs and can be used to guide their implementation.

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Disclosure

The authors of this manuscript have no conflicts of interest to disclose as described by the *American Journal of Transplantation*.

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Supporting Information

Additional Supporting Information may be found in the online version of this article.

Figure S1: Cost categories for living kidney donors.

Table S1: Direct and indirect costs incurred by kidney donors, unit of measurement, valuation method and valuation sources.

Table S2: Average wage rate per Canadian province (July 2008).

Supplemental Methods