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## Financial and family burden associated with cancer treatment in Ontario, Canada

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**Abstract** *Goals of work:* To determine the financial and family resources burden associated with the treatment of cancer. A questionnaire was developed to determine the direct monthly “out-of-pocket costs” (OOPC), the indirect costs, and the associated perceived family burden. *Materials and methods:* A self-administered questionnaire using a quota sample from five cancer clinics in Ontario, Canada was given to 282 cancer patients (74 breast, 70 colorectal, 68 lung, and 70 prostate). Monthly OOPC were obtained for: drugs, home care, homemaking, complementary and alternative medicines, vitamins and supplements, family care, travel, parking, accommodations, devices, and others. The

questionnaire asked if OOPC for treatment were a burden, and if others took time from work to provide caregiving. *Main results:* The mean monthly OOPC was \$213, with an additional \$372 related to imputed travel costs. For those patients who responded that the burden was “significant” (16.5%), their OOPC was \$452. In the case of patients responding that their burden was “unmanageable” (3.9%), their OOPC was \$544. The survey showed that 35.6% of patients required others to take time from work and this was higher in the under-65 category. The mean number of days lost from work in the previous 30 days for these caregivers was 7 days. *Conclusions:* These results suggest the financial burden is problematic for 20% of this sample. The caregivers’ lost time from work influence this burden, and for 36% of this sample, it amounts to one third of their working days in any given month. Policies and programs to address these gaps are needed.

**Keywords** Cancer · Self-administered questionnaire · Out-of-pocket costs · Financial burden

### Introduction

In Canada, the responsibility for many social programs, including health care, is deemed to fall under provincial

jurisdiction. Health care services are delivered privately, but about 70% of the expenses come from public sector sources [16]. These provincial health care costs tend to be shared by the federal government.

The Canada Health Act (CHA) [10] defines terms and conditions which must be met by provincial plans to receive full federal funding. The comprehensiveness condition of the CHA specifies the health services (medically required hospital and physician services) on which the federal government agreed to partially fund with the provinces. At the time the CHA was put in place (1984), the majority of health services were delivered by physicians or in hospitals. That model is not as true today as care is moving outside of hospitals and to a lesser degree away from the physician's office. Those health care services delivered outside the hospital/physician and, hence, outside of the requirements of the CHA include such things as: outpatient prescription drugs, home care, complementary and alternative medicines, vitamins/supplements, devices, family support, and other direct treatment-related charges (e.g., telephone charges in hospital).

Although programs around hospital and physician services are available to all legal residents without financial barriers, it is not necessarily the case for other health programs. This raises the question regarding the balance between public and private financing and the implications of these funding choices on patient finances. In addition, the indirect costs associated with lost time from work for both patients and their caregivers have the potential to impact on a patient's perceived financial burden.

Although other literature have suggested that cancer patients' out-of-pocket costs and indirect costs can be significant [11, 12, 24], we are not aware of any literature that identifies the influence of both direct and indirect costs on patients' perceived burden in the Canadian setting. In undertaking this research, it was important to consider both the direct (generally medical services) and indirect costs (generally lost time from work), as literature has shown that, for cancer, the indirect cost burden (\$11.76 billion in Canada, 1998) is considerably greater than the direct costs (\$2.46 billion in Canada, 1998) [18].

One of the challenges in undertaking this research is in defining medically necessary care, as the variety of health services provided outside of the CHA can be viewed quite differently. These services represent a spectrum of services, some where full public funding is expected (e.g., prescription drugs), others where it is generally viewed as an individual's responsibility (e.g., complementary and alternative medicines), and yet others where the responsibility for funding is contentious (e.g., travel expenses). Hence, although some "out-of-pocket costs" (OOPC) are anticipated, one would hope that they would not become a barrier to receiving the best available care.

Some have expressed concern, especially for those in lower-income categories, regarding the impact of OOPC on patients' choices regarding treatment. Research by Dunlop et al. [8] has shown that patients of lower socioeconomic status are less likely to utilize specialist services. In addition, studies of cardiac care in Ontario have shown that those with lower incomes or less education are less likely to

receive cardiac care [2] and can also impact waiting times and survival [1]. Studies of radiation usage patterns in Ontario have shown that patients with lower incomes are less likely to use radiotherapy to treat their breast cancer [17] and less likely to use radiation as palliative therapy for cancer [13]. Although the motivations or circumstances driving these income-based differences in utilization are not well understood, it is important to be aware that they may potentially attenuate OOPC in cases where patients with limited financial means make decisions not to receive certain treatments.

As an illustration, the introduction of co-payments for prescription drugs has been shown to affect both utilization and outcomes. Tamblyn et al. [25], in examining the introduction of co-payments for prescription drugs in Quebec, noted that both for elderly and welfare recipients' reductions in the use of "essential" drugs occurred and were correlated with an increase in serious adverse events. Similar effects on utilization have been demonstrated in various countries, including the UK [21], the USA [14, 22], and Australia [7]. In most cases, the impact of these co-payments affect access for some populations more than others, especially those of lower socioeconomic status [3, 25] and the elderly [14, 25]. These findings might suggest that the potential for significant OOPC could have repercussions on patients' overall health, at least in the case of health services that require payments or co-payments.

In undertaking this research, we investigate where the boundaries have been drawn between what is paid for through the public purse, through other collective mechanisms (e.g., private insurance) and through what the individual pays related to direct medical costs. We hope this research will allow us to better understand how the current combination of public and private health care funding affects Ontario cancer patients' finances and the resulting impact these direct costs have on the patients' perceived burden. This research also quantifies the impact of indirect costs related to cancer in the form of lost time from work for both patients and their caregivers and its relationship to perceived burden.

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## Materials and methods

### Patient population

All outpatient cancer clinic patients more than 18 years of age receiving treatment for breast, colorectal, lung, or prostate cancer were asked to participate during a clinic visit if they met eligibility criteria. These four tumor types were selected as they are the most common and represent 56% of all cases in Ontario. It was also felt that the expenses may differ by tumor type, so limiting the types of tumors would improve our chances of detecting patterns or trends in expenditures. The eligible patients had to have been on treatment for a minimum of 30 days, be able to

read English or French (Ottawa clinic only), and be on active treatment for their cancer (those on follow-up only were excluded). Questionnaire translation was provided by the Ottawa clinic as is required for all research studies at that center; however, there were no patients who requested a French questionnaire. The pilot patients ( $n=21$ ) at the Toronto Sunnybrook Regional Cancer Center (TSRCC) were enrolled between October and December 2001. The main study patients ( $N=261$ ) were enrolled at five of the eight available Ontario cancer clinics between May 2002 and April 2003. The centers accrued their patients over a 1- to 3-month period, but start dates varied based on ethics approval. The clinics included TSRCC, Juravinski Cancer Center (JCC) in Hamilton, Ottawa Hospital Regional Cancer Center (OHRCC), Northwestern Ontario Regional Cancer Centre (NWORCC) in Thunder Bay, and the London Regional Cancer Program (LRCP). The clinics were instructed to accrue equal numbers of each tumor type with a quota of 12 patients per tumor type. Due to one clinic that declined from participation late, the quota was raised at TSRCC to compensate and reach target enrolment. All eligible patients were approached by research staff or nursing support and asked if they were interested in participating in the research. The majority of the patients agreed to participate (83.6%), with those declining being similar in mix based on tumor type, sex (56% males), and age (60.6 years).

#### Data sources

A self-administered questionnaire was used for a quota sample of patients attending cancer clinics at participating sites in Ontario. A “pilot” study was conducted initially to test the instrument for face and content validity, as well as the data gathering procedures. It was then followed by the primary study implementation in five cancer clinics across the province of Ontario, Canada. No substantive changes were required after the pilot study and, hence, after discussion with the research team, it was deemed appropriate to combine the pilot and the main study results. The evolution of this questionnaire was built to a significant degree on previous work done in the USA by Birenbaum [4] and Moore [15].

#### Questionnaire design and application

The questionnaire had 26 questions, some with multiple parts, and took the patients 10–15 min to complete. Included in the questionnaire were details on patient demographics, general health, duration of the current cancer treatment, current treatments being provided (chemotherapy, radiation, surgery, doctor visits, emergency room visits, hospitalizations, in-home nursing services, and physiotherapy services), level of insurance coverage,

employment details, perceived financial burden, and time lost from work. The questionnaire was completed by patients and/or their caregiver during their visit to the clinic. As this was a self-administered questionnaire, no information on stage of disease was captured, as it was felt to be unreliable. Although we considered requesting access to patient files to determine the stage of disease, we were at the same time concerned that this would impact on the patients’ willingness to participate.

The primary purpose of the questionnaire was to determine what portion of health care costs for cancer treatment was paid out-of-pocket in the last 30 days vs through other sources (private insurance and public coverage), as well as the impact on patient and family time from work during the same period. The patients were also asked if these expenditures were “less than other months”, “typical”, or “more than other months”. The OOPC were classified by the “type of expense” into the following categories: travel costs, prescription drugs, in-home health care, homemaking services, complementary and alternative medicine, vitamins and supplements, family care, accommodations/meals, devices/equipment, and other costs, and these categorical cost details are reported elsewhere (An examination of cancer patient’s monthly out-of-pocket costs in Ontario, Canada—by Longo et al., currently in review). Imputed travel costs were calculated based on travel distance to the clinic multiplied by the number of trips and then multiplied by \$0.43/km based on Canada Customs and Revenue Agency rates in effect in 2003. Questions on both patient’s and caregivers’ lost time from work over the previous 30 days were also captured and were used together with family income data to determine crude estimates of indirect costs. The financial burden question asked was: “How much of a financial burden are these out-of-pocket expenses?”, with the following available categorical responses: (a) not a burden at all, (b) only a slight burden, (c) somewhat of a burden, (d) significant burden, but manageable, or (e) unmanageable burden.

#### Statistical software

All analyses were performed using the statistical software Stata version 7.0 (Stata). This software has the ability to handle weighting of cases and clustering when running standard analyses such as analyses of variance (ANOVAs) and linear regressions. The procedures used generated means, standard deviations, confidence intervals, and  $p$ -values from the survey data.

#### Descriptive statistics

Information on patient demographics, treatment patterns, and level of burden for patients was captured and is presented as means, standard deviations, and ranges. Determination of

average family income for each participant, where required, was calculated as the midpoint of the family income category they chose in the questionnaire, with the value for those earning more than \$80,000/year entered as \$90,000.

#### Analyses of variance

ANOVAs were performed to identify differences in the dependent variable between different groups such as: tumor type, level of insurance coverage, education, income, and distance from the clinic. ANOVAs can be used to test differences among several means for significance without increasing the type 1 error rate. In instances where *t* tests were undertaken, a variance comparison check using a variance ratio test was used to determine if the variances were equal and the appropriate *t* test was then applied.

#### Ethics

Ethics approval was obtained from the University of Toronto. In addition, site approvals were obtained from each of the five cancer clinics involved in the study.

## Results

The patients were fairly evenly divided between male and female with 149 males of 281 patients (53.02%, one colorectal patient did not complete the entire questionnaire). The male–female mix varied by tumor type and is outlined in Table 1.

Mean patient age in the “combined” sample was 61.2 years of age. There was a significant degree of variability between tumor types, with breast cancer patients being the youngest (51.6 years) and prostate cancer patients the oldest (68.4 years), as shown in Table 1.

The patients in this study had a fairly diverse distribution related to education, with 28.7% of the sample having less than a high school education and 44.7% having at least some university exposure. The details are outlined in Table 1.

As this was a self-administered questionnaire, there are several instances where the patients chose not to answer particular questions and, hence, the full 282 patients are not available in all data fields.

**Table 1** Study population: demographic characteristics by study sample and tumor type

Demographic characteristics	Main sample ( <i>n</i> =261)	Pilot sample ( <i>n</i> =21)	Total ( <i>n</i> =282)	Breast cancer ( <i>n</i> =74)	Lung cancer ( <i>n</i> =68)	Colorectal cancer ( <i>n</i> =70)	Prostate cancer ( <i>n</i> =70)
Age	61.5	56.3	61.2	51.6	64.1	63.1	68.4
Age range	26–87	38–75	26–87	29–78	39–81	26–85	51–87
Male	142	7	149	2	33	44	70
Female	118	14	132	72	35	25	0
Treatment duration, (days)	326.8	355.3	328.8	424.4	218.6	327.7	339.5
Education, <i>n</i> (%)							
Elementary	21 (8.1)	0 (0)	21 (7.5)	1 (1.4)	6 (8.8)	6 (8.6)	8 (11.4)
Some HS	58 (22.2)	2 (9.5)	60 (21.3)	10 (13.5)	23 (33.8)	14 (20.0)	13 (18.6)
Complete HS	65 (24.9)	7 (33.3)	72 (25.5)	17 (23.0)	18 (26.5)	20 (28.6)	17 (24.3)
Some university education	35 (13.4)	6 (28.6)	41 (14.5)	14 (18.9)	7 (10.3)	14 (20.0)	6 (8.6)
Complete university education	52 (19.9)	5 (23.8)	57 (20.2)	21 (28.4)	8 (11.8)	10 (14.3)	18 (25.7)
Post-graduate	27 (10.3)	1 (4.8)	28 (9.9)	10 (13.5)	5 (7.4)	5 (7.1)	8 (11.4)
Missing	3 (1.2)	0 (0)	3 (1.1)	1 (1.4)	1 (1.5)	1 (1.4)	0 (0)
Income (\$)							
0–19.9K	30 (11.5)	0 (0)	30 (10.6)	7 (9.5)	9 (13.2)	6 (8.6)	8 (11.4)
20–39.9K	67 (25.7)	3 (14.3)	70 (24.8)	13 (17.6)	20 (29.4)	17 (24.3)	20 (28.6)
40–59.9K	45 (17.2)	6 (28.6)	51 (18.1)	13 (17.6)	9 (13.2)	16 (22.9)	13 (18.6)
60–79.9K	27 (10.3)	6 (28.6)	33 (11.7)	11 (14.9)	6 (8.8)	9 (12.9)	7 (10.0)
80K+	48 (18.4)	3 (14.3)	51 (18.1)	21 (28.4)	7 (10.3)	12 (17.1)	11 (15.7)
Missing/do not know	44 (16.9)	3 (14.3)	47 (16.7)	9 (12.2)	17 (25.0)	10 (14.3)	11 (15.7)

## Perceived financial burden for patients

The results showed that more than 20% of the patients perceived the financial burden to be significant or unmanageable (Table 2).

An analysis of variance of total costs vs burden was statistically significant ( $p=0.005$ ) but did not have a strong predictive value ( $R^2=0.080$ ). Individual costs categories vs burden were statistically significant for “prescription drugs” ( $p=0.000$ ,  $R^2=0.1051$ ) and “vitamins and supplements” ( $p=0.0045$ ,  $R^2=0.0555$ ), but no other cost category showed statistical significance. The descriptive statistics between total costs and burden, shown in Table 3, confirm that mean OOPC were higher for patients who perceived a significant or unmanageable burden than for other patients. The aggregate mean monthly OOPC for all cancer patients was \$213 with an additional \$372 related to imputed travel. For patients who responded that the burden was “significant” (16.5%), their reported mean OOPC was \$452 and their imputed travel cost was \$353. For patients whose burden was “unmanageable” (3.9%), their reported OOPC was \$544 and their imputed travel cost was \$324.

It was noted that, in a few cases, the patients with relatively high OOPC considered their burden to be low (three cases more than \$1,000); however, in all of these cases, the average family income was greater than \$60,000 per year. Some patients with low OOPC conversely perceived their burden as significant or unmanageable (19 cases under \$100); but most had considerable expenses for travel and parking, and they tended to be lower-income earners.

An analysis of the percentage of monthly family income by burden category was undertaken (Table 4). Only actual incurred costs were used in this analysis; imputed travel costs were omitted as they did not necessarily represent OOPC during that month. An analysis of variance between income and burden showed a strong relationship ( $p=0.000$ ) with an  $R^2$  of 0.134. This analysis shows a clear relationship between percentage of monthly income and perceived burden as patients with “no burden” spent 3.9% of their income and those with an “unmanageable burden” spent 20.8% of their income on OOPC.

An aggregation of the lower burden responses (none, slight, and somewhat) mean percent of family income

**Table 2** Patient response to “financial burden” question

Perceived level of burden	Frequency	Percent (%)
None	77	27.6
Slight	75	26.9
Somewhat	70	25.1
Significant	46	16.5
Unmanageable	11	3.9
Total <sup>a</sup>	279	100.0

<sup>a</sup>Three patients did not answer the burden question

**Table 3** Total 30-day out-of-pocket costs (excluding travel) by level of burden

Perceived level of burden	N (%)	Mean (\$)	SD (\$)	Range (\$)
None	73 (29.9)	77.31	174.84	0–1303
Slight	66 (27.0)	197.42	424.31	0–2990
Somewhat	57 (23.4)	186.75	250.13	0–1108
Significant	37 (15.2)	452.19	944.99	0–5230
Unmanageable	11 (4.5)	544.18	684.13	8–2000
Total <sup>a</sup>	244 (100)	213.26		

<sup>a</sup>There were 38 patients with missing cost data and/or burden data

(5.8%) vs the higher burden (significant and unmanageable, 16.3%) shows a statistically significant difference ( $p=0.001$ ) in the percentage of monthly income spent on OOPC for cancer. It should be noted that those reporting a significant burden had similar characteristics with those with an unmanageable burden and, hence, grouping them together is justified. As an example, the OOPC, when reported as a percentage of monthly income, suggests these two categories have similar financial implications (15.0 and 20.8%, respectively). In contrast, the other burden categories report OOPC of 3.9 to 7.6% of monthly income.

The results also showed that patients with unmanageable burden were mostly females (10 of 11), on chemotherapy (10 of 11), and under 65 years of age (10 of 11) and had reported a family income of less than \$50,000 per year (seven of nine). Of those indicating a significant burden, 26 of 46 were female, 35 of 46 were on chemotherapy, 31 of 46 were under 65 years of age, and 25 of 38 had a family income under \$50,000 (some respondents did not provide information on the amount of their family income). We did not show any relationship between clinic distance and OOPC (excluding travel) or burden, although a relationship between travel costs and clinic distance does exist. In addition, no relationship between level of insurance coverage and perceived financial burden was shown.

The data also show that while 36.7% of patients with income below \$20,000 identified the burden as “significant

**Table 4** Total 30-day out-of-pocket costs excluding imputed travel as a percentage of family income by burden

Perceived level of burden	N	Mean (%)	SE (%)	Range (%)
None	59	3.93	1.88	0–112.32
Slight	56	6.30	1.14	0–48.38
Somewhat	51	7.58	1.40	0–51.98
Significant	31	15.00	4.14	0–119.52
Unmanageable	9	20.83	6.66	1.6–66.05
Missing income and/or cost data	73	NA	NA	NA
Total <sup>a</sup>	279			

<sup>a</sup>Three patients did not answer the burden question

or unmanageable”, only 9.8% of those with family income of more than \$80,000 did so (Table 5).

Lastly, looking at patients’ perceived burden by age category, it appears that those under 65 years of age are almost twice as likely to report the burden as “significant or unmanageable” (age <65, 25.8%; age >65, 13.2%).

#### Time lost from work for patients and their caregivers

We speculate that perceived burden may take into account both actual monetary expenditures and lost income as patients and their caregivers are forced to take time off from paid employment. Many of the cancer patients in our study (211 of 282) were not working, but what is not clear is whether or not this was voluntary, involuntary, permanent, or temporary departure from work. Of those that had worked in the past 30 days, the mean lost time from work was 12.6 days. Moreover, many caregivers ( $n=100$ ) also lost time from work; they averaged 7.0 days off work over the previous 30 days. What is also noteworthy is that 59.6% patients who perceived a high-cost burden had caregivers take time off work, significantly more than the 29.7% in the low burden category.

A crude estimate of lost income was undertaken and revealed that patients and their family lost on average of \$101 per day of work missed. This conservative estimate assumes that all family members contributed equally to family income. Using this figure, 35% of patients had family members losing more than \$700 in income over 30 days, and in addition, for the 20% of patients that were working, they lost an average of more than \$1,270 in income over 30 days. This assumes that caregivers are family members in the same dwelling as the patient and that their time off was without pay. We noted that 38% of the patients that took time off work did so without pay, hence, the assumption of time off without pay regarding the caregivers may be high; but employers do not generally cover sick leave as generously for caregivers as they do for those who are ill.

**Table 5** Patients’ perceived level of burden, by income

Income (\$)	None/ somewhat	Significant	Unmanageable	Total S/U percent (%)
0–19.9K	19	6	5	36.7
20K–39.9K	58	12	0	17.1
40K–59.9K	40	9	2	21.6
60K–79.9K	25	7	1	24.2
More than 80K	46	4	1	9.8
Do not know/ missing	34	8	2	22.7
Total <sup>a</sup>	222	46	11	20.4

<sup>a</sup>Three patients did not answer the burden question

#### Other results of interest

The average duration of treatment for the patients in this study was just less than 1 year (329 days). The range of treatment duration was just under 30 days to a high of 3,880 days (10.6 years). The patients described their last 30 days OOPC as “less than usual” 13.5% of the time, “typical” 51.6% of the time, and “more than usual” 23.3% of time, with 11.6% stating they “did not know”. The data showed that 59 patients did receive some home care paid for by the government. However, 35% of the patients overall used unpaid caregiver assistance, with 44% for those under 65 years of age needing such help. The questionnaire was completed by patients alone (78.7%), caregiver alone (3.3%), or both (18.0%).

Some data validation was attempted to determine if patient reports were consistent with insurance claims. Privacy issues unfortunately prevented us from attaining patient level data. However, aggregate insurance data and patient data were consistent, suggesting that approximately 90% of drug costs and 66% of costs of devices were covered for those with private insurance. We were unable to validate data on lost time from work.

#### Discussion

This research suggests that a sizable minority of cancer patients find the burden of OOPC to be significant or unmanageable, even in a health care environment where much of the care falls within the public funding envelope. We speculate that both direct and indirect cost elements play a role in perceived burden, as other cancer research has provided evidence that both of these cost elements contribute to patient costs [11, 12, 24]. As one might expect, our results also show that expenditure, as a percentage of income, is greatest for those with low income, a finding consistent with that in other cancer research [11]. Finally, the limited literature that does exist on cancer patients’ OOPC is mostly in a predominately private, for-profit health care environment (most of which are US data), so this research also adds to our understanding of the financial impact when the majority of care is funded publicly (as is the case in Canada).

We had speculated that direct monthly OOPC is only part of the reason some patients find the financial burden troublesome. The support for this speculation is based on an assumption that, as a cancer patient’s health deteriorates, they are also less able to continue paid employment leading to loss of income just as their “out-of-pocket” health costs are occurring. Moreover, it often falls on family members to help with household and personal support tasks normally undertaken by the patient in addition to support related to their treatment. Most cancer patients in the study did not report any paid employment during the 30-day period of study. While for some (particularly seniors) this may reflect

the fact that they were not in the paid workforce even before their illness, others have likely experienced a 100% loss of employment income. For those who worked over the previous 30 days, income losses were less than 100%; nevertheless, the data suggest that even family members may lose one third of their potential workdays in any given month to assist in patient care.

We identified that patient care needed at home is likely a cause of this lost time from work for family members. For many cancers, acute care and palliative care fortunately tend to be fairly limited in duration, and in these cases, publicly funded home care coverage is typically not a problem. The real issue is likely to appear in cases where the cancer more closely resembles a chronic condition, and in these cases, the patients are likely to exceed the allocated public funding limits in Ontario resulting in: out-of-pocket payments, family members assuming the caregiver role, or decisions to forego the caregiving support. The average duration of treatment for the patients in this study was just less than 1 year, a time period that exceeds coverage for most publicly funded home care programs currently in place.

Although some patients did receive home care paid by government, we still found that 35% of patients overall used unpaid caregiver assistance, with 44% of those under 65 years of age needing such help. The average loss of more than 7 days in the past 30 days (generally 22 work days in a month) or a third of their workdays to assist their family member/friend with their care is considerable. It appears from this research, in the cases where family members provide support, that public home care was not provided, suggesting either that it was not available or not appropriate or that the patients did not know how to access such care. This raises important issues about the OOPCs particularly for cancer patients with prolonged illnesses.

These results also suggest that the lost income may have had a larger financial impact than the direct OOPC identified in this research and that the combined effect of lost income and increased expenditure can be problematic for a sizable minority of cancer patients. We speculate that the low incidence of home care and homemaking expenditures by the patients in this study (reported elsewhere; An examination of cancer patient's monthly out-of-pocket costs in Ontario, Canada—by Longo et al, currently in review) indicates the significant role that the patients' families play in cancer care, especially when the cost of professional health care may prove to be prohibitive for those in the lower-income categories.

#### Limitations and future research

As indicated earlier, this sample was taken from five cancer clinics and looked at the four primary tumor types in Ontario. The methods used in this research did not include an evaluation of patients treated outside of the cancer

clinics or of patients with other types of cancer. Hence, it cannot be determined if costs would have been higher or lower and whether those costs would be in the same categories as was seen in this study. We also did not consider other financial factors that can impact on the patients' available disposable income including such things as mortgages, education expenses for family members, and personal debt.

It does appear, however, that any cancer treatment that requires aggressive chemotherapy by definition requires a significant expense related to prescription drugs, and in this regard, we would expect that the gap identified in this research would be found in the other indications as well. Demographics can also play a role, as some cancers tend to have a younger population and, hence, are more likely to have uninsured or underinsured individuals. Testicular cancer and Hodgkin's disease that tend to have a much younger age of onset are two examples not evaluated in this research and could prove to be cases more problematic than the population examined in this research.

The fact that we did not capture information on stage of disease means that we are unable to determine if this factor significantly influences expenditures. This is one of several factors that are likely to create variability in cost data. Literature has shown that the costs associated with care for lung, colorectal, breast, prostate, and bladder cancer patients tend to be highest in the first 6 months after diagnosis and in the last 12 months before death with the time in between being significantly less expensive [19]. It is likely that the patients were recruited throughout the life cycle of their illness in this study and, hence, significant variation in health care resource use should be expected and may have significant impact on their OOPC as well as on the perceived financial burden. Some of the costs, being episodic in nature, will clearly be captured early in a patient's treatment while others will be captured later in the course of treatment. These factors make it more difficult to clearly elucidate the factors that determine those patients most at risk for significant financial burdens.

Finally, surveying patients has some inherent challenges in terms of its ability to obtain reliable information, although the literature is mixed with some suggesting it is quite good [9, 20, 26] while others have suggested otherwise [5, 23]. Although we attempted to verify some of the data related to prescription drugs, privacy issues resulted in a very limited validation although it was supportive. Data on patients' lost time from work was also not verified due to privacy issues, and its accuracy is, hence, a further limitation of this research.

#### Policy implications

In Ontario, there are a number of programs designed to assist patients with high financial burdens related to health. They include special means tested drug funding programs

(Trillium), healthcare funding programs for patients with work-related illnesses (Workplace Safety and Insurance Board), and special healthcare funding for persons who are out of work (Ontario Works). Our results do not clearly determine, but might suggest, that patients are not always able to take advantage of these programs. Whether those patients with high financial burdens were unable to acquire assistance because of qualification criteria, lack of awareness, or other reasons cannot be determined from this research but is worthy of further investigation.

As some patients have a high financial burden, it suggests that the current demand for supportive services may exceed the supply, whether provided by family, charitable organizations, or through cancer clinics. Any gap in level of support services available through cancer clinics is clearly going to fall onto the caregivers, and this research suggests this gap is significant. One factor that impacts on the perceived burden can be related to psychosocial distress which has been shown to be as high as 43% in lung cancer patients [6]. Hence, one could ask if there is an opportunity to minimize these perceived patient burdens through more extensive supportive care programs.

We believe that the loss of one third of a caregiver's income to deliver necessary services at home contributes greatly to a patient's perceived burden. In January 2004, the Federal Minister of Health announced a \$1.5 billion grant to cover supportive leave for families delivering end-

of-life care for up to 6 weeks. This will address the needs of many of the patients who identified their family members as losing approximately one third of their workdays to support them. However, 6 weeks is only a fraction of the time needed to deal with most of the common cancers that have treatment cycles of 4–6 months and often have a follow-up treatment that will carry on for years.

These results suggest that the boundaries of health care can spill over into or be influenced by other welfare programs like those associated with income replacement. It raises the question of whether policymakers should consider the influence of programs outside of the Ministry of Health when evaluating the comprehensiveness of publicly funded healthcare for illnesses like cancer.

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