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ORIGINAL ARTICLE

Understanding the full breadth of cancer-related patient costs in Ontario: a qualitative exploration

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Abstract

Objective This research informs existing work by examining the full scope of out-of-pocket costs and lost income, patients' private insurance behaviors, and their overall management of finances during their cancer treatment. The intent was to gain a deeper understanding of patient circumstances and the related costs.

Methods Participant qualitative interviews were conducted in person during outpatient clinic visits or by telephone and were recorded between June 2011 and July 2012. Interviews were transcribed verbatim and subjected to a descriptive qualitative analysis. The research team collaborated early in the process (after three subjects were enrolled) to develop a preliminary coding framework. The coding framework was modified to incorporate additional emerging content until saturation of data was evident. Transcripts were coded using the qualitative software NVivo version 9.0.

Results Fifteen patients agreed to participate in the study and 14 completed the interview (seven breast, three colorectal, two lung, and two prostate). Consistent with existing published work, participants expressed concerns regarding expenses related to medications, complementary/alternative medicines, devices, parking and travel. These concerns were exacerbated if patients did not have insurance or lost insurance coverage due to loss of work. Although many acknowledged in hindsight that additional insurance would have helped, they also recognized that at the time of their diagnoses, it was not a viable option. Previously unidentified categorical costs identified in this study included modifications to housing arrangements or renovations, special clothing, fitness costs and the impact of an altered diet.

Conclusion We confirmed the results of earlier Canadian quantitative work. Additionally, cost categories not previously explored were identified, which will facilitate the development of an improved and more comprehensive quantitative questionnaire for future research. Many patients indicated that supplemental health insurance would have made their cancer journey less stressful, highlighting existing gaps in the government funded health care system.

Keywords Out-of-pocket costs · Cancer · Insurance behavior

Introduction

Limited published research exploring cancer patients' out-of-pocket costs (OOPC) for cancer and treatment-related services has been undertaken in Canada. Especially absent are more in-depth investigations on the nature of these costs and the impacts they have on patient's overall quality of life (QoL). The most common perspective related to the economics of cancer is a burden of illness study presenting total societal cost of all

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cancer cases in one country. The most recent Canadian burden of illness study estimated the direct ($4.2b) and indirect ($11.9b) burden of cancer at $16.1 billion [1]. Although these figures are important to understand the total impact on our health care system and society, they typically provide very little detail on the financial impact of a cancer diagnosis on patients and their families directly. It is important to understand that although Canada has a publicly funded health care system, there are still a number of aspects of care that are not fully covered, and/or that vary by province in the comprehensiveness of the coverage. These financial costs include (but are not limited to) prescription drugs that are not provincially covered, and homecare beyond provincial funded limits. It is recognized that private health insurance can mitigate some of these gaps in coverage, and hence our interest in including an evaluation of private insurance behaviors. Private insurance comes in many forms and we inquired specifically about critical illness, long-term care, and supplementary care insurance schemes. Each of these cover items typically not covered by government and are either purchased separately or are part of employer benefits. Critical illness policies are lump sum payments based on physician confirmed diagnoses including cancers; long-term care policies provide a monthly payout when those insured require extended stays at health care facilities, and supplemental policies cover a variety of items including hospital room upgrades, non-funded drugs, and health care devices. Recent trends in terms of the number of person's uninsured or underinsured in Canada suggest that private insurance coverage is lacking or unaffordable for some individuals. This is supported by data showing increases in out-of-pocket costs and insurance premiums in Canada between 1997 and 2009, and low participation rates particularly in lowest income quartile of the population [2].

The indirect costs on patients can be substantial and there is some literature that has examined the impact of a cancer diagnosis on either patient out-of-pocket costs [3–6], lost income [7, 8] or both [3, 9]. Several articles have examined cancer related financial hardship [10], specific examinations of breast cancer patients costs [11], or those of palliative care patients including those with cancer [12]. This research on patient costs has consistently shown that lost time from work and lost productivity are the most significant of the financial issues, followed by travel costs, and then medical costs not covered through the Canada Health Act (government health coverage) nor by private insurers. Each of these is important, but little investigation into whether this represents all aspects of patients financial burden has been undertaken in a Canadian context. It was our intention to explore these under-examined aspects more completely. Although some exploration of health insurance behavior has been published [13–16], there appears to be a paucity of information reflecting on insurance behavior after a relevant health event has occurred.

One of our key objectives with this research was to examine the full scope of out-of-pocket costs and lost income, patients' private insurance behaviors, and their overall management of finances during their cancer treatment.

It was hoped that this research project would not only inform the qualitative research literature related to the financial burden of cancer but also inform future quantitative work in this field by ensuring new emerging themes from this work are appropriately measured in the quantitative research going forward.

Methods

A qualitative descriptive design was used for this study [17, 18], engaging participants in an in-depth interview. This method was selected to facilitate exploration of patient perspectives in an open manner so we could capture new insight regarding financial challenges beyond that of previous quantitative approaches. All patients signed an informed consent. The study and consent form were approved by McMaster University and Sunnybrook Health Sciences Research Ethics Committees.

It was felt that a qualitative approach was warranted to determine whether previous work in this area had accurately captured the scope and impact of the financial burden to patients and their immediate families from their perspective. We note that although the questions included in our research had many categories of cost and income effects like lost family income, we have focused this manuscript on areas where the existing literature provides little or no information. Participants for this study were selected on the basis of the following criteria: on active treatment for cancer for at least a month, could speak/understand English, between 18 and 80 years of age, and able to talk comfortably about financial concerns. This latter criteria was determined by a nurse or social worker who provided care to the individual, or the research assistant, asking them about their interest and comfort in participating in the study. Details on stage of disease, time since diagnosis and type of treatments were not captured as we believed these details are not reliably reported by patients.

Participants were initially alerted to the study by a member of their circle of care, a social worker or a nurse, or by posters concerning the study hung in the cancer centre. Patients who expressed an interest met with the study research assistant who explained the study fully and arranged and conducted the interview, following consent, at a mutually convenient time.

The interviews were completed between June 2011 and July 2012. Two interviewers, trained in qualitative interview techniques and supervised by the investigators (MF, CL), completed all the interviews. All interviews were conducted in person with one exception where the participant elected to have it completed on the telephone. In several instances, a caregiver also was present during the interview and offered input. In the instance where the caregiver had better knowledge and comprehension about the finances, because they actually managed the family finances, their comments were included in the analysis of the interview transcript. All interviews were audio recorded and later transcribed verbatim.

The interview guide was semi-structured and crafted for the purposes of this study. Participants were encouraged to share their experiences related to several categories: costs they incurred related to their cancer and its treatment for drugs, homecare, devices, travel/parking, other items; insurance purchasing behavior; financial concerns; and the impact of these financial concerns. Probes were only used to seek clarification or confirmation of details. We were seeking to understand more fully the financial challenges they experienced and how they managed the concerns both financially and emotionally.

Following the completion of three interviews, the research team (CJL, MF, AM, JR) reviewed the verbatim transcripts to determine if the interview guide was effective or there was a need to alter or add questions or probes. Each team member reviewed the transcripts independently, making marginal notes regarding significant categories or content areas. The team discussed their observations regarding the interview content together, documenting the range of perspectives and categories. The resulting list of categories became the preliminary content codes, and the full list served as the initial coding classification framework for the study.

Once it was determined that the interview guide was effective, the remainder of the interviews were conducted. Review of the interviews as they were completed allowed on-going identification of any new patient perspectives and insights that would warrant adding content codes to the initial coding classification framework. After interviews with 14 individuals had been conducted, it was evident no new content codes were emerging and the team felt that data saturation had been achieved.

Final analysis was conducted by three team members (CJL, MF, AM). All verbatim transcripts were reread independently by each team member. Discussion with the team members was held to determine if the initial coding classification framework needed any further content code additions. Subsequently, all interviews were coded using the agreed upon final coding classification framework. Interview transcript coding was completed by the lead author (CJL) and reviewed independently by the second (MF). Where discrepancies occurred, agreement was reached through discussion between the two investigators.

Once coding of the interview transcripts had been completed, the team members reviewed the content in each of the content codes and discussed together what significant idea or key perspectives had been shared by the participants. Subsequently, the team identified, through discussion and consensus, the cross-cutting themes woven through the content codes.

The coding classification framework revealed broad content categories. The cross-cutting themes emerged as two storylines or narratives: (1) there are personal financial costs associated with having cancer and challenges in managing those, and (2) financial burdens of cancer have a profound impact on quality of life.

In order to do complete justice to the rich data within the perspectives shared by our participants, we have elected to present the results of each of these storylines in two manuscripts. The description of the impact of the financial burden on quality of life is not included but will be the focus of a future manuscript.

Results

There were a total of 15 patients who consented to participation with 14 completing an interview between June 2011 and July 2012 (one consenting patients withdrew due to illness complications). Duration of interviews varied from 23 to 53 min, and were on average about 35 min. The ages ranged from 37 to 78 years and included seven breast, three colorectal, two lung, and two prostate cancer patients. Family income ranged from no income to >$80,000 with four patients declining to answer the income question. Seven were married or had common-law partners, four were widowed or divorced, two were single and living with family, and one was living alone (Table 1). We did not capture details on the one caregiver that participated with the patient. Initially, all participants described the shock of their diagnosis and the challenges related to treatment itself.

Table 1 Patient characteristics

Description	Sample distribution
Female	11 of 14
Average age	51.4 years
Income <$40K	3 of 14
Income >40K, but <$80K	4 of 14
Income >80K	4 of 14
Income unknown	3 of 14
Education—university	10 of 14
Education—high school	2 of 14
Education—unknown	2 of 14
Tumor—breast	7 of 14
Tumor—colorectal	3 of 14
Tumor—lung	2 of 14
Tumor—prostate	2 of 14
Status—married/common law	7 of 14
Status—single/divorced/widow	7 of 14

The participants were able to focus and describe their experiences related to their financial concerns, at times showing strong emotion when talking about the impact on themselves and their families. Costs that are well described in previous literature were not highlighted in this manuscript.

Financial challenges and financial management

One of the foundational issues for individuals was the actual unexpected shock of the financial issues. Much of this shock was a product of how they had been managing their overall finances before their cancer diagnosis. We noted that participants were not particularly ready for the additional expenditures and found there were challenges in dealing with them for a variety of reasons. There were numerous examples where participants were in a difficult financial situation due to lack of financial planning generally in the period before their cancer diagnosis. For example:

> "I never look at money as my master…like, if I have 10 dollars, I spend 15". (pt #1)

> "Well, over, say the last 12 years, 15 years, since we got a mortgage, we kind of just have been spending as if we didn't have one. So there's money that's accumulated. [It's} not that we can't cover these cost and aren't covering these costs" (pt #11)

Many of these participants were also caught unaware or unprepared for the financial expenditures that accompanied their cancer diagnosis and its subsequent treatments. Many expressed surprise that there were expenses they would have to cover themselves.

> "Well, I mean, certainly we got into unexpected… financial…expenses that was not in, within our resource" (pt #12)

In some cases, the cancer diagnosis and treatment resulted in a loss of job-security and economic self-reliance. In other words, the cancer patients spoke of how they could feel they are more reliant on others following the cancer diagnosis.

> "So, at that point, you become dependent on other people. You know, like, I have worked hard my whole life. I've paid into this system my whole life. And now, because I'm critically ill, um, I'm told that basically, you know, I'm given an income that is not enough for me to live on, to pay rent, ah, to eat properly. And so you become entirely dependent. It's a very bleak outlook. And that's been a real kick in the teeth to me". (Pt #7)

Insurance value and accessibility

Several participants suggested that although supplemental health insurance made good sense, there were some financial barriers making it difficult or impossible for them to consider taking it up. In one particular case, the participant's spouse only tried to purchase insurance after her diagnosis and was struck by the cost.

> "I checked [with] the people from some private insurance. It's very expensive. I dunno if… the normal guy like me who works can afford it for the family. It cost a lot. I, I consider it, but it cost too much." (pt #9 spouse)

In other cases, participants stated they made decisions not to purchase supplemental insurance as they did not think they would need it. This was the case even in situations where their employer would provide it as an option on their flexible benefit plan.

> "Also, it's my choice when I picked it out on my benefits statement. I could have had more, but I didn't expect to be sick. I never expected to be on long term disability." (pt #13)

> "If someone had tried to sell me disability insurance, I don't think, I wouldn't have taken it … because there is not history of cancer in my family." (pt #7)

In other cases, as illustrated below, participants clearly saw the value of supplemental health insurance and made it a priority purchase in order to mitigate risk.

> "Well, I'm a believer in insurance. I think you can quite tell that. …I think it's important for everybody" (pt #6)

It should be noted, however, this particular individual was in a financially secure position and could afford the insurance. This was not the case with all participants.

One patient highlighted that supplemental insurance can be helpful and take many forms, not just extended hospital care but coverage for critical illness or long-term care as well. In this particular case, although she was dealing with her own cancer, she had just helped her mother through cancer in the recent past, so had gained some valuable insights from the caregiving of her mother.

> "Critical care [insurance] was [purchased] with my mom. [when i] was diagnosed, I thought of it. And then the long term care [insurance] is because, since I'm not working, I'm going to be paying...for medication, so I thought maybe this would help." (pt #1)

In this particular situation above, the participant had insurance and recognized its value, its limitations, and that not all scenarios or costs will be covered. In the example below, the participant found that it was not clear what would be covered and what would not be covered by her insurance.

> "Because, you know, in the insurance, [the] thing is criteria in breast cancer and all, there are so many stages. It's not just breast cancer, there are so many things, right? So they… it's kind of approved and not, kind of not approved. Is it enough? It's never enough". (pt #1)

Additionally, some patients often realize upon reflection that additional insurance would have helped, whether they were able to purchase the insurance or not.

> "..you never expect it to, you know, have little expenses, add up. And I think extra insurance should, would have been really nice. Like, I was turned down for critical illness one year before my diagnosis and would have been paid $100,000 just for having a cancer diagnosis." (pt. 13)

What these patients often articulated was that they recognized if they had chosen to, or were able to, purchase insurance it would have minimized the financial challenges they were currently experiencing.

Expenditures by type

Several types of expenditures were identified during these interviews. Much of what was uncovered is consistent with existing literature as it relates to items such as drugs, devices, homecare, and homemaking expenses. New emerging ideas not highlighted in the existing literature included financial impacts/consequences related to residence changes, diet and exercise choices, and clothing needs. These items are highlighted in the following paragraphs.

Residence changes

In the case of several participants, either due to financial limitations or because the living conditions were not suitable, it became necessary to change their place of residence. In the particular example below, where shared accommodation had been the arrangement, it was clear that a new independent residence was needed to reduce exposure to second-hand smoke.

> "I thinking of the new accommodation because my sister, they smoke... And I am the second hand smoker. So I want to find a place to move because, during the winter time, they would smoke in the house; but for summer, it's okay, they smoke outside". (pt #2)

Experiencing decreased mobility and wanting to be safe led some participants to make alterations in their existing home facilities. In this particular situation below, the participant was speaking about her mother's cancer diagnosis and treatment that had occurred less than a year before she herself was diagnosed with cancer.

> "So, bathroom expenses, and those are not covered by anything. You know, things like, I had to get the bathroom all set up for her, with the hand thing…the one that you put …on the tub for you to walk in and another hand one… I changed it. Now, what I've done for me, is that I've changed it to a hand shower. So I had to pay for that." (pt #1)

> In this second example below, the loss of income and the additional expenses have resulted in the participant contemplating selling their primary home in order to cover living expenses.
> "All I have is my condominium and I've thought about selling it, which I don't want to. It's the only thing I have." (pt #3)

Diet and exercise choices

In several cases, either based on their own independent research or on advice of a health professional, participants felt compelled to improve their eating habits. In this first example, the participant had decided to improve their nutrition in order to improve their response to chemotherapy.

> "So basically, when I was first diagnosed, I started spending more on anti-oxidant kind of, you know, the food and stuff and researching on stuff I should be having before I start my chemo, and changing my diet even more during my chemo." (pt #13)

In this second example, a participant made a personal decision to improve the chances of a successful outcome despite knowing that there would be a financial cost.

> "Well, I believe because I am going to be following a cancer free diet the best way I can, it's gonna be quite expensive, because a lot of fresh food and salads and things that are not going to be in season is going cost a little bit of money. Yep, it's gonna cost more to take care of myself now that, I've been diagnosed with cancer. I'm gonna follow the right way of eating according to the cancer society." (pt #1)

This third participant identified diet as a modifiable risk factor, but recognized it added to the treatment expense.

> "Okay, the easiest thing to change is eating. So you go on to these websites and they all saying the same kind of food. So, you know, so it's usually fresh this and fresh that. And to get that, it's expensive. Your gonna have to change your diet. Not unless you ate like that already. I mean, some people do eat like that. I never did. So you think, okay, maybe it was that but you don't know. So you try to do everything you can yourself to avoid getting cancer again. So drink lots of filter water, change your diet to a lot of fresh vegetables and fruits. And it's basically what your diet is. It's a lot of fruits and vegetables And to get that, it's quite expensive." (pt #5)

Some participants believed a healthy physical regime is important. For example, this participant felt yoga could help manage chemotherapy.

> "… that's why I enrolled in yoga stuff. I don't want to be, like, I want to be strong enough to be able to take chemo. But I see some people, when they come, they are like so tired before they go inside for the chemo. I don't want to [be like that.] But, I know it's gonna be expensive for the next few months". (pt #1)

Clothing needs

Several patients highlighted that due to the frequent visits to the clinic special clothing was needed.

> "…because I am wearing to come [to treatment]…I bought special clothes to come… when I come for chemo because they said to wear loose clothes,…"(Pt. #1)

In other cases, existing clothing was damaged and would require replacement.

> "… going back to my radiation treatments the one that probably annoyed me the most was ruining two bras as a result of being marked up for … the radiation treatment." (Pt. #8)

In all cases, patients felt that investment in new or replacement clothes was needed or required to accommodate their ongoing care.

Discussion

Our qualitative investigation uncovered a rich and diverse set of financial issues related to patients' cancer treatment. Many of these we expected to see and are consistent with existing published literature [3–7], especially those expenses related to drugs, devices, homecare, travel and parking. New insights about financial burden, not before reported in the Canadian literature, related to changes in living arrangements to accommodate cancer treatments, investment in a healthy diet and exercise program, and investment in appropriate or new clothing. Although these can be significant expenditures they are not costs governments or private insurers would normally bear, but they still impact the disposable income patients have including those funds needed for medical care. Discussions regarding insurance behavior suggest that a number of those interviewed were unprepared for the financial shock associated with a cancer diagnosis and treatment, and in hindsight, felt some or more supplemental health insurance would have mitigated many of these concerns. In some cases, although they recognized the value of the insurance, it was unaffordable for them. Others felt that they never thought there was a need for insurance as they were not in the "at risk" population. Although this is a small sample, it might suggest that much of the public is ill-informed about how much of health care is covered by government or that the magnitude of patient costs does not warrant the purchase of supplemental health insurance. Previous literature for Ontario, Canada cancer patients suggests that in fact non-government financed healthcare costs was a "significant or unmanageable burden" for about 20 % of the population studied [3]. One possible solution to mitigate these financial burdens would be to include public education on both financial literacy and an understanding of the options cancer patients have with private insurance. Conversely, it also highlights that government programs for some aspects of care are inadequate for the needs of cancer patients.

An interesting finding in this research was around the lack of financial literacy in many patients, and the implications this had once they developed cancer. We use the term financial literacy to describe patient's ability to effectively manage their household finances. This includes exploratory retrospective questions on their financial decisions before their cancer diagnosis. We define financial literacy as the ability to comprehend and manage the impact of household expenses and revenues on overall net financial status [19]. It highlights that one area that cancer centre support staff should consider is directing patients and their families toward education in financial literacy where it is clear that help is needed. It is less clear if this type of assistance exists currently in some cancer centres, what the best approaches are, when they should occur, or whether further research on this is warranted. It also begs the question, who is responsible for this service? Should government policy ensure financial literacy programs are available to patients? In any case a greater emphasis on improving financial literacy may prove beneficial to many patients and their families regardless of how or who delivers it.

The intent when undertaking this research was twofold: (1) to better understand personal financial costs associated with having cancer and the decisions and challenges of managing them and (2) to capture the financial burdens of cancer and its personal impact on patients and families. The research allowed us to obtain a deeper understanding of how costs affected patients' lives, their decisions about insurance purchases, and the overall impact on the patient and family's lives.

This research allowed us to revisit questions on categories of cost, and current behaviors for financial management. The benefit of these findings will be realized when we undertake subsequent quantitative examinations of patients financial burdens by reframing some questions and incorporating new questions that address these previously unexplored expense categories.

This research uncovered some new cost categories, not previously explored, that could have potential implications for developing and offering of support programs to patients and families at risk for financial challenges.

Limitations

As with all interviews and surveys we are relying on the accuracy of a patient's memory, and earlier research suggests that patients tend to under-report or omit smaller expenses so some minor financial categories may have been missed [20, 21] so in this regard we expect these results to be a conservative estimate of patient costs. This is a relatively small sample, and drawn from a single institution in an urban setting, with no information on stage of disease so it would be inappropriate to assume we could generalize this to all cancer patients at all stages of disease. However, several of these findings occurred multiple times, and it is plausible that these issues would be likely to occur in other institutions and in both urban and rural settings.

Future research

Applying these findings to current prospective quantitative survey tools to more comprehensively capture patient costs will allow researchers to determine how significant these additional cost categories are, and provide a more complete picture of financial impacts on patients and families.

Conclusions

Our work confirms and supplements the results of earlier research. Although literature exists providing analyses of the magnitude of the costs associated with cancer treatment, this research uncovers a number of issues not otherwise well described. The research suggests that attention to issues of changes in residence, food related expenditures, fitness and special clothing needs may prove to be important aspects of financial burden. Future quantitative work would be well served by examining these types of qualitative studies to ensure all aspects of financial shocks to patients are captured. This work also highlights the need to ensure cancer patients are informed of the financial demands that accompany cancer treatment and the ability of private health insurance to mitigate these costs, even in an environment where public funding of cancer care exists.

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