



Canadian Cancer Society
Société canadienne du cancer

MANITOBA DIVISION



***The Financial Hardship of Cancer in Canada:
A Literature Review***

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Executive Summary

According to the Canadian Cancer Society, 39% of Canadian women and 45% of men will develop cancer at some point in their lives. Besides the physical and emotional hardship a cancer diagnosis brings to an individual and her family, financial burden is incurred.

In order to complete this literature review, 38 articles were reviewed; 30 of which were Canadian authored. The findings revealed that there are certain groups of people with cancer who are at-risk to incur a significant financial burden due to their cancer diagnosis.

The first group identified was individuals/families with high out-of-pocket expenses relative to their income. These out-of-pocket expenses are often incurred by rural residents who need to travel for their treatments; people not covered with private insurance and/or who work seasonal, part-time or are self-employed; people with high drug costs; and those with a significant loss of salary.

Secondly, individuals/families with low-income and/or no disability insurance incurred financial hardship as they have limited resources to pay for out-of-pocket expenses and may not be eligible for private or supplemental insurance.

The third group at-risk for financial hardship is parents with children who have cancer. In order to care for their child, many parents are unable to work, which decreases the family income at the same time as expenses increase if they need to travel for treatment, pay for accommodation or make childcare arrangements for siblings.

Compassionate caregivers to people in the palliative phase of cancer incur similar financial hardship as parents of children with cancer. They too may need to take a leave from work and take-on more of a financial burden as they care for a loved one in the final phase of cancer.

The fifth group recognized to be at-risk of incurring financial burden was adolescents and young adults with cancer. These individuals are at the early stages of financial independence and a cancer diagnosis may prevent them from maintaining it. Adolescents and young adults often require intensive treatments, which are expensive, especially if they do not have adequate private insurance.

Finally, persons with cancer receiving multiple modality treatments are at-risk because of high drug costs, long and intense treatments, and the loss of salary.

The literature provided many recommendations to address the problem of economic hardship incurred by people with cancer. There is both the potential and the responsibility to implement these solutions. Working together, the federal government, provincial healthcare systems, non-profit organizations, clinicians, communities, families and individuals can make a difference.

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Purpose

This review, initiated by Canadian Cancer Society Manitoba and Canadian Cancer Action Network in November, 2009, seeks to gather evidence on the financial burden incurred by persons with cancer and their family in the treatment, survivor and palliative phases of the cancer journey.

Objective

The objective of this systematic literature review is to determine which groups of people affected by cancer are most vulnerable to incurring a financial burden and solutions that can be developed to address their issues.

Review Method

Despite an exhaustive search, no other systematic review focusing on the financial burden incurred by persons living with cancer and their families could be found. This review considers any report, article, review, survey or study that discusses the financial impact of cancer on individuals and is written in English. Searches included articles from Canada, U.S.A., Britain, and Australia, but other international articles were not excluded. The majority of the content in this literature review is Canadian-based. The key words 'cancer', 'financial', 'burden', 'hardship', 'young adult', 'childhood', 'breast cancer', 'out-of-pocket costs', 'palliative', 'treatment', 'Canada', 'low-income', 'un-insured', 'caregiver', 'stages of cancer', 'phases of cancer', 'multiple modalities', 'cost of illness', 'neoplasm', 'finance', 'cancer cost' and 'oncology' were used in the initial searches on the databases www.cochrane.org, www.joannabriggs.edu.au, www.campbellcorportation.org, Medline, www.CMAJ.ca and PubMed. Finally, a search of the reference lists and bibliographies of all relevant studies was completed and a search of gray literature (i.e. Google) was done. This review is strictly literary. It is not a meta-analysis and does not have a statistical focus.

Search Results (article exclusions)

A total of 124 abstracts and full texts were reviewed and 38 met the criteria for this systematic literature review. Since Canada has a federally sponsored, publicly funded Medicare system where basic services are provided by private doctors and the entire fee for a doctor's visit and in-patient hospital care is paid for by the government, articles which dealt with the costs incurred by the government for cancer care were not used. Even though there are considerably more articles written in the US, the differences in the Canadian and American medical systems made many of the American articles unsuitable for this review.

Of the articles included in the review, 12 were quantitative, 16 were qualitative and 11 were either literature reviews or research reports.

The majority of the articles in the review were based on Canadian results: 4 from Newfoundland and Labrador, 1 from New Brunswick, 5 from Quebec, 6 from Ontario, 1 from Manitoba, 1 from Alberta and 2 from BC; 10 others discussed the issue from a national perspective and can be considered Canadian, 6 were from the US, 2 from the UK, 1 from Greece, 1 from Australia and 1 from New Zealand.

Synthesis

This review seeks to discover the scope of the financial burden that persons with cancer and their families incur through the cancer journey. Certain sub-groups of persons with cancer were identified as being more at-risk of financial hardship.

1. Individuals/families with high out-of-pocket expenses relative to their income
2. Individuals/families with low-incomes and/or no disability insurance
3. Parents of children with cancer
4. Compassionate caregivers to people in the palliative phase of cancer
5. Young adults with cancer
6. Persons with cancer receiving multiple treatment modalities

Individuals/families with high out-of-pocket expenses relative to their income

According to Mathews and Park (2009b), “although Canada’s universal public health insurance covers the costs of all medically necessary cancer care provided in hospitals and physician’s offices, patients may still incur substantial out-of-pocket expenses related to their care”. Depending on the province, costs for travel for treatment or appointments, accommodation, food, drugs not provided in a hospital setting, and some medical devices may not be covered by the provincial healthcare system. As well, the loss of a salary, need for childcare and housekeeping also lead to expenses for the person with cancer and their family.

In an Ontario-based study, “a sizable minority of cancer patients find the burden of out-of-pocket costs to be significant (16.5%) or unmanageable (3.9%), even in a healthcare environment where much of the care falls within the public funding envelope” (Longo, Fitch, Deber and Williams, 2006). There are four groups of people identified by the literature as being most at-risk of suffering high out-of-pocket costs: (a) rural residents who must travel for treatments, (b) those not covered with private insurance (seasonal, part-time or self employed), (c) those with high drug costs, and (d) those with a significant loss of salary.

“Financial barriers that remain in Canada’s publicly insured health care system disproportionately affect rural residents, who make up almost 20% of the country’s population (Mathews, West and Buehler, 2009a). In the available articles, a common thread emerged: since ‘the treatment of complex diseases such as cancer requires highly specialized professionals, equipment and services’ which are often centralized in an urban area (Mathews et al., 2009a), rural residents must travel to receive treatment and incur costs for gas, accommodation, meals and childcare. Longo, Deber, Fitch, Williams and D’Souza (2007), sent a self-administered questionnaire to breast, colorectal, lung and prostate cancer patients in 2001-2003 and asked them to measure the categorical out-of-pocket costs. The questionnaire was sent to both urban and rural residents. The final results showed that travel does, indeed, have the potential to be a significant drain on the finances of a person with cancer as travel costs exceeded costs for all other categories combined.

In a study of 484 adults who presented for cancer care at clinics in Newfoundland and Labrador in 2002 and 2003, Mathews et al. (2009a) found that compared with urban residents, rural residents were 1.79 times more likely to report that travel costs were important considerations in their cancer care decisions” and that 19.5% of rural patients (9% of all cancer patients), had more than \$1000 in travel-related costs for a single trip to access cancer care. In a survey questionnaire given to 410 people with breast, lung, prostate, throat or colon cancer, all of whom lived in Northeastern Ontario and had to travel for cancer treatment, it was found that that travel had affected their ability to carry out their job. Almost a quarter (23.4%) reported that traveling totally prevented them from doing their job (Lightfoot et al., 2005). Rural residents face an added challenge because, many of them are likely to be in seasonally or self-employed industries (Mathews et al., 2009a), such as, agriculture or fishing. They may not have access to private insurance through their employers or, if a part-time employee, have worked enough hours to qualify for employer-sponsored programs.

In a national survey undertaken by the Canadian Breast Cancer Network (2004), 46% of the respondents lived in a rural community and 20% had to travel over 200 km to see the doctor. As one Manitoban respondent wrote “I experienced considerable financial burden related to travel expenses (\$7,200 in 2002) because [sic] the area I live in is not far enough away to qualify for assistance [from the government]”. An additional concern for healthcare professionals is that since high out-of-pocket costs are of particular concern to rural residents, people with cancer may choose a “radical form of treatment in an effort to reduce travel-related costs.” The most frequently cited example was women with breast cancer choosing mastectomy over breast-conserving surgery (Mathews, Buehler and West, 2009c and Longo et al., 2006).

Lack of private insurance greatly increases out-of-pocket expenses, as the uninsured will not be reimbursed for the cost of drugs or medical devices. In the study by Longo et al. (2007) of cancer patient’s out-of-pocket costs in Ontario, it was noted that “private insurance covered the majority of costs for prescription drugs (90%) and devices (67%), but not all patients have private insurance.” Mathews et al. (2009c) pointed out that “out-of-pocket costs are of particular concern to low-income and rural patients” since “a

greater percentage of their income will be consumed by these costs” and they are “less likely to have private health insurance that may offset out-of-pocket costs”. People with cancer may not have access to private insurance because of their current employment situation or age. As Longo et al. (2006) noted, ‘some cancers tend to have a younger population and, hence, are more likely to have uninsured or underinsured individuals”.

The Canadian Cancer Society (2009) published a paper titled ‘Cancer Drug Awareness for Canadians’ and reported that workers who lose their jobs are vulnerable because almost all private insurance is employer-sponsored. Lack of private insurance is also a problem for seasonally employed, part-time workers and the self-employed, all of whom do not qualify for employer-sponsored private insurance. Maria Mathews et al. (2009a), discussed the financial burden incurred by rural residents with cancer at length and found that “Although out-of-pocket travel and drug expenses may be cost-shared through private health insurance, it is usually offered as a benefit for full-time employees. Rural residents are more likely to be in seasonal or self-employed industries” and therefore, do not receive benefits. In a previous study, Mathews (2009c) reported that “patients who are self-employed, seasonally employed or employed in small business often do not have sick leave benefits and will therefore lose income for absences from work during treatment or recuperation”. The out-of-pocket expenses incurred by cancer on the uninsured is a financial burden to a group of people who may already feel the weight of economic hardship due to loss of income if they are part-time, seasonally or self-employed.

As the costs of drugs increase, so does the out-of-pocket expense for people with cancer. In recent years, there has been a shift from hospital-based to ambulatory care resulting in people with cancer incurring the costs of drugs provided outside of a hospital setting (Mathews et al., 2009a). While public drug insurance plans exist in almost all provinces, they are not universal. Residents of New Brunswick and Prince Edward Island (0.8% of the Canadian population) are not covered by a public drug program (Canadian Cancer Society, 2009).

According to the Canadian Cancer Society (2009), in 2006, 1 in 12 Canadian families paid drug costs amounting to more than 3% of their net household income, or ‘catastrophic drug costs’. BC, Alberta, Saskatchewan, Northwest Territory and Nunavut have introduced catastrophic drug programs which eliminate the cost of drugs to the person with cancer and all the other provinces have some sort of cost-sharing program for catastrophic drug costs, but even with those plans in place, 6% of Canadians pay over \$1,000 per year in drug costs (Canadian Cancer Society, 2009).

In the Canadian Cancer Society’s (2009) Cancer Drug Access for Canadians report, the price tag of the average cost per course of treatment with newer cancer drugs is \$65,000 and 3/4 of the new cancer drugs are taken at home, which means either the person with cancer or the insurance company must pay for it. If private insurance is available, 100% of the drug cost is not always covered. Private plans typically require a 20% co-payment for prescription drugs. Therefore, the person with cancer may be liable for up to \$13,000 for an average course of treatment for a newer drug (Canadian Cancer Society, 2009).

A number of studies reported on the financial burden incurred by high drug costs. An Ontario research report on women with advanced breast cancer found that prescription drugs were the most significant component of financial burden for the person with cancer. Those with extended health insurance paid \$5765 for their medication and those women with cancer who did not have extended coverage paid \$8292 over the course of the illness (Grunfeld et al., 2004). Longo et al. (2006), noted a 2001 study done in Quebec which found that a reduction in the use of 'essential' drugs occurred among the elderly and welfare recipients due to an increase in the amount of co-payments individuals had to make with their private drug plans. He goes on to target the highest risk group of people with cancer due to drug costs: females undergoing chemotherapy and under 65 years of age with a family income of less than \$50,000 a year (Longo et al., 2006). The Canadian Cancer Society's (2009) report correlates these findings by stating that "patients with low-income tend to forgo drug treatments as costs rise".

The final group of individuals with cancer who are affected by high out-of-pocket expenses are those unable to work at the same capacity due to their diagnosis and incur lost salary. In a study, Houts et al. (1984) asked cancer patients to track non-medical expenses spent during treatment and non-treatment weeks. (The dollar value has been corrected to 2009 Canadian currency.) The cost to patients and their families per treatment week was \$150.88 and for non-treatment weeks it was \$95.07. "Approximately 45% of these costs were out-of-pocket costs and 55% were wages lost". The majority of the studies had median ages of over 60 years, which means that many of the test subjects may already have retired, so loss of salary will not affect their income. However, "as more and more working-age individuals are screened for cancer, employed, as opposed to retired individuals, will be treated for cancer" thus producing a younger, employed demographic who will lose salary due to illness (Bradley, 2005). Bradley (2005) makes the point that annual prostate cancer screening in men 50 and over, or 40 and over for men with a family history of prostate cancer, will detect early-stage prostate cancer. Those diagnosed and treated for prostate cancer may find that there are complications which interfere with their daily living, including their ability to work (Bradley, 2005).

A study conducted in Ontario also found that "lost income may have had a larger financial impact than direct out-of-pocket costs" (Longo et al., 2006). In a focus group study in Quebec of both urban and semi-urban women undergoing breast cancer treatment in the last 18 months, it was found that "because of breast cancer, all patients stopped work completely once or twice for periods lasting from 2 days to more than a year" (Lauzier, et al., 2005). Lauzier et al. (2005) noted that "the individual's working conditions (for example insurance, sick leave) were seen as two factors contributing to the extent of wage losses." While some were partially or completely covered by their employers' income insurance benefits, others were not. "Due to absences that could last a whole year, they sometimes combined different types of compensation. During certain periods, however, they were without any compensating income and they had to draw on personal savings. This was particularly the case for self-employed workers without income insurance" (Lauzier et al., 2005).

Individuals with low-incomes and/or no insurance

The cost incurred by persons with cancer is most burdensome for the lower income groups because of limited financial resources (Houts et al., 1984). As discussed previously, the out-of-pocket expenses and loss of salary affect those earning less disproportionately since “expenditure, as a percentage of income, is greatest for those with low income” (Longo, et al. 2006). In Houts et al. (1984) study, 139 people with cancer kept two one-week diaries to track non-medical expenses in treatment and non-treatment weeks during their out-patient chemotherapy treatments. He found the highest percentage of subjects spending over 50% of their weekly income were in the lowest income groups.

While low-income earners face higher out-of-pocket expenses relative to their net income, they may also face disadvantages in regards to treatment. Patients with lower socioeconomic status are less likely to use specialist services. For example, a person with cancer who is a low-income earner may be less likely to use radiation as therapy in the palliative stage of cancer (Longo et al., 2006) and less likely to seek or receive certain health care services (Longo et al., 2007). As noted in the previous section, lower rates of breast conserving surgery are found among eligible women with breast cancer who have lower incomes (Mathews et al., 2009c).

As already mentioned, many Canadians are not eligible for private insurance: part-time, seasonally or self-employed people, which results in a more substantial financial hardship incurred at all stages of the cancer journey. Many employers offer supplemental insurance as a benefit to employees, or it may be purchased by the individual, which is often more expensive (Miedema, Easley, Fortin, Hamilton and Mathews, 2008). According to Statistics Canada, 20% of Canadians lack private supplemental health insurance and the percentage is higher in Newfoundland and Labrador and New Brunswick where 30% and 32% of the population do not have private supplemental health insurance (Miedema et al., 2008). While most provinces provide some degree of coverage for their residents, New Brunswick and Prince Edward Island have no system of universal protection and do not provide catastrophic drug coverage for families (Canadian Cancer Society, 2009). Another group that has a history of being underinsured is adolescents and young adults, who have the lowest rate of insurance coverage (Bleyer, 2007). Soliman and Agresta’s (2008) review of issues facing adolescent and young adult cancer survivors points out that young adults are less likely than adult patients to be insured or they may be in a transition period between their parents’ insurance and their own. Often the insurance they receive as a student or early in their professional careers may not be adequate for a diagnosis like cancer. The authors also acknowledge that survivors face challenges to find health insurance as they are considered high-risk candidates because there is a potential for a recurrence of the cancer (Soliman and Agresta, 2008). The authors found that 29% of survivors (N=227) had difficulty obtaining coverage, compared with only 3% of the survivors’ siblings.

In the Stewart et al (2001) study, 7.7% of women with breast cancer reported insurance refusals or premium increases for extended health. Based on the lack of response to

insurance questions (up to 65% compared to under 5% for other questions in the survey), Stewart et al. (2001) concluded that “women are poorly informed about insurance issues and are often unaware of what health insurance is available or provided through their or their spouses work”.

Similar to those with low-income, lack of insurance may impact a person with cancer’s choice of treatment. As Mathews et al. (2009a) found in the study of people with breast, lung, colorectal and prostate cancer, those without private health insurance are more likely to consider costs for drugs or travel in their decisions about care. A self-administered questionnaire given to people with breast, colorectal, lung and prostate cancer in Ontario to measure out-of-pocket expenses found that, although the sample was small, those without private insurance spent less compared to those with insurance. The findings suggest that individuals without private insurance may be foregoing the use of some drugs and devices in their cancer treatment because they can not afford it (Longo et al., 2007).

Parents of Children with Cancer

The parent of a child with cancer faces unique challenges. At a time when a family is already consumed with other challenges, the parents must deal with a financial burden that is necessary in order to heal their child. The financial hardship incurred by parents of a child with cancer can be divided into three areas: (a) loss of work, (b) travel expenses for treatment and follow-up care, and (c) out-of-pocket expenses.

As Miedema et al. (2008) noted in a qualitative study using semi-structured interviews of 28 French and English families whose child had been diagnosed with cancer in the last 10 years in New Brunswick, Newfoundland and Labrador, parents are completely involved in the illness, which makes it different from adult cancer. The child depends on the parents for transportation, accommodation, meals and support and is unable to go to the hospital or appointments with physicians unless accompanied by a parent. Of the 106 families in British Columbia who responded to a self-administered questionnaire, 64% of mothers and 16% of fathers reported leaving their job due to their child’s diagnosis. Parents of children under 10 had the highest percent of lost work and mothers whose children were diagnosed with leukemia had the highest percent of lost work at 92%. An increase in lost work was also noticed during palliative versus curative treatment of the disease (Limburg, Shaw and McBride, 2007).

In an Australian study by Cohn, Goodenough, Foreman and Suneson (2003), 39% of parents took a leave with no pay, 28% reduced paid hours and 21% closed or suspended business. A comparison was also made by geographic group which found that 27% of urban parents left work without pay and 44% of rural residents did so. Barr and Sala (2003) observed that an increase in out-patient care means caring for a child with cancer at home is now the responsibility of a parent. Since that care is ongoing, even during working hours, it is a challenge to hold a full-time job. Self-employed parents who take time off work to help a child through treatment experience an immediate loss of income:

“There were times..when we weren’t able to work the hours that we normally work, so there was much less money coming in[...] If you do not go to work, you don’t get paid” (Miedema et al., 2008).

The role of caregiver to a child with cancer is different than that of a caregiver to a person in the palliative phase of the disease, which is discussed later. This issue was given attention at the December 9th Standing Senate Committee on National Finance chaired by Senator Irving Gerstein. While the Compassionate Care Benefit provides job security and 55% of a successful applicant’s wage (up to a maximum of \$435 per week) for a six week period, there are additional problems when the Benefit is used for a parent to care for a child with cancer. One of the restrictions of the Benefit is that the care receiver needs to have a prognosis (a prediction based on the individual’s diagnosis and current state of health) from a physician that death will occur within six months. However, in children with cancer, palliative care is not necessarily end-of-life care, but rather comfort-focused care or quality of life focused care since palliative care is often a parallel process to aggressive care (M. Harlos, Standing Senate Committee on National Finance, December 9, 2009). Since the Compassionate Care Benefit focuses on end of life care, it may be difficult for parents of children with cancer to be successful applicants. Doctors are often optimistic about a child’s chance of survival and, as mentioned, in order to receive the 6 weeks of paid leave, the child’s death must be ‘imminent’ according to doctors (Senate Committee on National Finance minutes, December 9th, 2009). The result is that few parents are able to make use of the Compassionate Care Benefit.

As previously discussed, rural residents with cancer are at a distinct disadvantage as they often need to travel to receive cancer treatment which can become a financial burden. Since children are unable to travel alone, the cost is increased if one or more parents accompany their child (Limburg et al., 2008). In a geographically vast country like Canada, where pediatric treatment facilities are centralized, 34% of children with cancer traveled 100 km or more for treatment. Parents of patients located a significant distance from the cancer treatment center remain especially vulnerable to incurring extra expenses (Cohn et al., 2003). As one parent was quoted: “Financially, it set us back 10 years because of the loss of salary and the wretched trips” (Miedema et al., 2008).

In the Miedema et al. (2008) study, many of the interviewees found they were spending many thousands of dollars on equipment related to treatment for their child, such as feeding tubes, needles and medication. The out-of-pocket expenses parents of a child with cancer incur are often related to the extra costs of parental accompaniment (Miedema et al., 2008). The out-of-pocket costs with the highest expense in the Cohn et al. (2003) Australian study of 100 parents of pediatric cancer patients were travel, accommodation and communication. The out-of-pocket costs incurred by families of children with cancer are considerable and amount to approximately 1/3 of after-tax income in a 1996 study cited in Barr and Sala (2003). The Australian study placed an exact dollar figure on the amount of out-of-pocket money spent by parents of a child with cancer as \$9,723, which translated into a 26% decrease in the family’s income when loss of income was included (Cohn et al., 2003). In the Bodkin, Pigott and Mann (1982)

study from the UK, out-of-pocket costs also accounted for 26.2% of the family's weekly income based on his interviews with newly diagnosed children with cancer.

A family's financial distress may also increase with time since diagnosis as on-going travel and drug treatment can be draining on the family income. Cohn et al. (2003) found that use of credit and accessing charity were higher for families where the child had spent relatively longer on treatment programs, such as for leukemia. Bodkin et al. (1982) found that the first week of in-patient treatment was twice as costly as outpatient care due to the travel and accommodation costs accrued by the child's parents. Younger parents were also found to have a slightly higher rate of being 'unable to pay the bill' (Cohn et al., 2003).

Compassionate Caregivers to People in the Palliative Phase of Cancer

Following more recent health care reforms in Canada, a trend towards the deinstitutionalization of palliative care is increasing. And since a large number of people in the palliative phase of cancer wish to spend their last days at home, the role of informal caregivers in providing ongoing care to end-of-life patients is on the rise (Dumont et al., 2009; Grunfeld et al., 2004). Caregivers, "the invisible backbone of the healthcare system", provide a needed service in Canada; providing \$6-9 billion in unpaid care every year (Canadian Cancer Society, 2008). Although, the contributions of caregivers vary considerably, they can contribute one half of the overall care costs of home care (Chappell et al., 2004). In a situation where a compassionate caregiver is responsible for caring for a person in the palliative phase of cancer, not only is the person with cancer at-risk of incurring a significant financial burden, but so is their caregiver.

Hayman et al (2001) noted that 'family caregiving is not an insignificant cost'. Due to the familial relationship between the caregiver and care receiver, financial compensation is usually not expected. However, as the population ages and policies emphasizing community care and acute care substitution are implemented, there is an increasing reliance on family caregivers (Keefe & Rajnovich, 2007). Serge Dumont et al (2009) embarked on a study to determine the costs to the family, public health care system (PHCS) and not-for-profit organizations (NFPO) for people in the palliative phase of cancer in five urban sites: Halifax, Montreal, Winnipeg, Edmonton and Victoria. The results were based on interviews of 248 people in the palliative phase and their informal caregivers. Overall, it was established that costs for people in the palliative phase of cancer were shared as follows: 71.3% by PHCS; 26.6% by the family; 1.6% by NFPO; and 0.5% by other payers (Dumont et al., 2009). Included in the mean total cost to the family were out-of-pocket expenses and caregiving time costs, which amounted to 17% and 66.4% respectively (Dumont et al., 2009).

Caregiving costs tend to be underestimated, especially when compared with the costs of institutional care (Stommel, Given and Given et al., 1993). However, once family labor costs are taken into account, the actual cost of the caregiving becomes substantial (Stommel et al., 1993).

Chappell et al (2004) examined the cost effectiveness of home care for seniors as a substitute for long-term institutional services by asking community clients to keep track of the amount of informal caregiving they received in a two-week period. Nurses in the long-term care facility were also asked to record time spent giving care to their clients. In the study, a replacement wage was given to informal caregivers in Victoria and Winnipeg in order to assign a dollar value on their services. A 'somewhat dependent' community client in Winnipeg cost the caregiver \$3,372.22 in out-of-pocket expenses and \$13,374.30 for replacement wages; for a total of \$16,746.52 as the cost per year to clients and families. In Victoria, a caregiver to a person receiving intermediate care 3 (out of 4 levels) spent a total of \$41,749 if the replacement wage is used (Chappell et al., 2004). The clients in this study were either in long-term care facilities or community clients. Neither of the groups of individuals had been admitted to an acute-care hospital more than once in the past month and, if admitted, the stay had to be 3 days or shorter (Chappell et al., 2004).

There are also wage losses due to caregiving, which can lead to financial hardship for the caregiver. While many of the people with cancer requiring caregiving are no longer working due their age, often their caregivers (children, spouses, in-laws) are younger and still employed. According to the Canadian Cancer Society (2008) statistics, 22% of caregivers miss one or more months of work. In another study, caregivers missed 7 days out of 22 working days in a month to assist family member or friend with their care (Longo et al., 2006). Grunfeld et al. (2004) reported that of employed caregivers, 69% reported some form of adverse impact on their work. The same study compared the work missed by caregivers between stages of cancer and found that during the palliative period 53% of the caregivers missed work compared with 77% during the terminal phase. In fact, due to extenuating circumstances (loss of work, high out-of-pocket costs), 41% of caregivers use their personal savings to survive (Canadian Cancer Society, 2008). Chappell et al (2004) noted that government policy should take into account the impact the loss of gainful employment has on the caregiver when they become an informal caregiver to a person needing care.

In Canada, there are "currently no national direct financial support policies for caregivers, as we rely on indirect and delayed financial support through taxation" (Keefe & Rajnovich, 2007). While there are tax relief measures at the federal level, they are minimal and are not accessible to most caregivers. The Compassionate Care Benefit, 'which recognizes that caring for a gravely ill person has implication for both economic and job security', provides 55% of a successful applicant's average insured earnings over a six week period to provide care for a family member who is determined to be at risk of death within a six month (26 week) period (Williams et al., 2005). The six weeks can be taken at once, broken down into one week periods and spread out over six months and/or shared between two or more family members. There is also a two week unpaid waiting period before starting the Benefit and the first payment is made within 28 days of beginning the claim (Williams et al., 2005). Williams et al (2006) investigated the experiences of 27 family caregivers caring for people with advanced chronic illness (12 out of 27 responders cared for a person with cancer). The responses from the caregivers make it clear that the length of the funding period needs to be increased and, given the

challenges of predicting end-of-life, the requirement that the care recipient be within 6 months of death be more flexible (Williams et al., 2006). An additional pilot evaluation funded by the Canadian Institute of Health Research reported similar findings (Williams et al., 2005).

Adolescents and Young Adults with Cancer

The SEER (Surveillance, Epidemiology and End Results) program of the National Cancer Institute in the USA defines adolescence as the years between 15-19 (Barr, 2001) and 20-30 as the age range for young adults (Pentheroudakis & Pavlidis, 2004). The incidence of cancer in adolescents and young adults has risen to 220-250 cases per million youths (Pentheroudakis & Pavlidis, 2004), which is the most noticeable increase in any age group. It is also notable that in the period of 1973-1995, cancer among adolescents rose 30% versus 10% for childhood cancer (Barr, 2001). Many of the articles reviewed use the abbreviation AYA (adolescents, young adults) (Soliman & Agresta, 2008; Pentheroudakis & Pavlidis, 2005). “AYA’s represent a particularly vulnerable segment of the population [because of the] financial ramifications of a cancer diagnosis” (Soliman & Agresta, 2008). The financial burden that adolescents incur due to cancer is different than adults or children for three reasons: (a) they often require intensive treatments, which are expensive, (b) they are often uninsured, and (c) the financial setbacks incurred at a young age have a lasting economic impact on the survivors.

The types of tumors common in the 15-30 year old age group necessitate an intensive form of treatment in order to maximize the chances for a cure. The treatments often involved combined modalities and incorporate multi-agent chemotherapy, high-dose radiotherapy and aggressive surgery. As well, the chemotherapy treatments are dose-intense, dose-dense or use autologous marrow/stem cell rescue (Pentheroudakis & Pavlidis, 2004). The intensive treatments and use of ‘state of the art’ therapies add expense for the person with cancer. The types of cancers prevalent in young person (including leukemias, lymphomas and brain cancer) are treated with some of the high-cost drugs noted in the Canadian Cancer Society’s 2009 study of Cancer Drug Access for Canadians. The study also points out that ‘cancer is a disease which affects all age groups, including adolescents and young adults who bear a higher burden of years lost due to their disease’ (Canadian Cancer Society, 2009). Loss of salary and the potential for high out-of-pocket costs due to travel to specialized centers where more effective multidisciplinary treatments are given (Pentheroudakis & Pavlidis, 2004), mean that adolescents and young adults with cancer are at-risk for serious financial hardship.

As previously discussed in the section on the uninsured, AYA’s with cancer are often in a period of transition from a state of dependency on their parents to the independent life of an adult. Their student health or work insurance may not be adequate or in place at the time of a cancer diagnosis (Soliman & Agresta, 2008). As well, if a young adult with cancer is the primary wage earner in a family without adequate insurance, they risk bankruptcy due to medical costs and lost income (Soliman & Agresta, 2008).

The financial implication that an adolescent or young adult with cancer faces are long-term. They may lose time from school, work or their community at a time when economic independence from family is an objective (Bleyer, 2007). The financial setbacks due to expensive treatments and lost work may mean that the person with cancer is forced to rely on his family's help at a time when financial independence is a goal (Pentheroudakis & Pavlidis, 2005). Adolescent and young adult cancer survivors may face discrimination in the work place. In an interview with 227 childhood cancer survivors, 11% cited some form of employment-related discrimination (Soliman & Agresta, 2008). Unfortunately, no further explanation was given about whether the discrimination affected their salary or promotions. As previously discussed, it may also be difficult for AYA survivors to get private health insurance as they are considered high-risk individuals due to their prior diagnosis.

Persons with Cancer Receiving Multiple Treatment Modalities

People with cancer who receive multiple treatment modalities are at-risk for incurring a significant financial burden due to the cost of medication, the length and intensity of the treatments and the loss of salary.

Breast cancer is now managed using multiple treatment modalities like surgery, radiotherapy, chemotherapy and hormone therapy in combination. Along with a shift from hospital-based treatments to ambulatory-based care, the responsibility for cost has shifted from the healthcare system and to the person with cancer (Lauzier et al., 2005). A more protracted treatment course results in more frequent clinic visits, more side effects and an increase in time the person with cancer and her family needs to take from work (Lauzier et al., 2005). The financial burden increases with multiple treatment modalities because the out-of-pocket costs are increased due to travel and lost salary. In phone interviews conducted by Lauzier et al. (2008) of 800 women with breast cancer in Quebec, it was found women who got less burdensome treatments were less likely to suffer from substantial salary losses. In another article by the same author, it was reported that "receipt of chemotherapy was strongly associated with a higher proportion of annual salary lost because of its associations with both longer absence from work... that extends over several months. It is often followed by radiotherapy" (Lauzier et al., 2005).

As explained in the previous section on adolescent and young adult cancer, this age group often receives multiple treatment modalities due to the curative nature of the disease. The intensive treatments used with adolescents and young adults with cancer are often given at specialized centers and require the person with cancer to travel. The treatments incorporate multi-agent chemotherapy, high-dose radiotherapy and aggressive surgery (Pentheroudakis & Pavlidis, 2004).

Phases of the Cancer Journey

Initially, this review sought to also discuss the financial burden as it related to each phase of the cancer journey. However, almost none of the literature referenced the costs in this way. It seems clear from the studies that, for the most part, the treatment and palliative care phases of the cancer journey are where the financial burden is likely to be the greatest. For example, based on two years of data collected in Alberta on dying patients, it was found that costs rapidly escalate for cancer patients in the last six months of life (Fassbender, Fainsinger, Carson and Finegan, 2009), however, none of the data were specific to costs incurred by the person with cancer. It should be noted that as palliative care is increasingly delivered away from public institutions and into community settings, many of the costs incurred by the public health care system are shifted to people with cancer and their families (Dumont et al., 2009).

The costs associated with lung, colorectal, breast, prostate and bladder cancer patients tend to be highest in the first six months after diagnosis and in the last 12 months before death with the time in between these two periods begin significantly less expensive (Longo et al., 2006). But, since for many cancers, acute care and palliative care tend to be fairly limited in duration, the expenses do not accrue the same way they do when the cancer becomes a chronic condition (Longo et al., 2006).

What solutions are suggested to ease the financial burden?

Problem	Solution	Source
Programs and policies need to address barriers to cancer care for rural residents	<ul style="list-style-type: none"> • Provide medical travel subsidies for patients who must travel outside their region to access health services 	Mathews et al., 2009a
	<ul style="list-style-type: none"> • Provide care closer to home through regional clinics or tele-oncology. 	Mathews et al., 2009a
Revise the Northern Highway Travel Grant Program (Ontario) and Medical Travel Assistance Program (Newfoundland)	<ul style="list-style-type: none"> • Provide re-imburement for meals and accommodation and gas. 	Lightfoot et al., 2005; Housser & Mathews, n.d.
High drug costs	<ul style="list-style-type: none"> • Provincial governments need to provide universal catastrophic drug coverage for all residents. 	Canadian Cancer Society, 2009

Problem	Solution	Source
Healthcare providers unaware that financial hardship is a source of stress	<ul style="list-style-type: none"> • Open communication between patients and their cancer care team is critical. • Cancer care providers should inquire about financial concerns <i>at various phases of the cancer journey</i>. • Establish standard intake assessment to ensure that all patients with financial concerns have been identified. • Note non-verbal cues that cost may be a concern in conversation. 	Mathews et al., 2009c; Mathews & Park, 2009b
Newly diagnosed persons with cancer feel overwhelmed about cost issues	<ul style="list-style-type: none"> • Provide standardized tools (worksheets, organizers) to help people with cancer plan for the expenses they may incur. • Initiate discussion about cost with healthcare providers before beginning treatment. • Use the internet as a forum for providing patient-centered worksheets and exchange of information regarding the cost of care. 	Bradley, 2005; Mathews & Park, 2009b

Problem	Solution	Source
People with cancer and their families unaware of out-of-pocket costs	<ul style="list-style-type: none"> • Healthcare professionals need to ask persons with cancer and their families about their ability to pay for out-of-pocket costs over time. • Healthcare professionals need to explain that the government won't pay for everything and that the person with cancer will incur expenses for travel, meals, etc. 	Mathews and Park, 2009b
Disparities between people with cancer who have public or private insurance	<ul style="list-style-type: none"> • Catastrophic drug coverage be established for all Canadians and drug pricing be equitable across private and public programs. 	Canadian Cancer Society, 2009
Disparities of people on public insurance plans based on where they live, age and income	<ul style="list-style-type: none"> • Institute a pan-Canadian standard for coverage. 	Canadian Cancer Society, 2009
Salary lost from illness	<ul style="list-style-type: none"> • Policy makers should change policies concerning illness insurance in order to help workers face severe illness. • Duration of coverage should be increased from 15-weeks. 	Lauzier et al., 2008
Self-employed, seasonal and part-time workers have lowest levels of financial compensation due to wage loss	<ul style="list-style-type: none"> • Provide additional assistance to those who can not access employment insurance benefits. 	Lauzier et al., 2008; Mathews et al., 2009a
Women with cancer poorly informed about insurance issues	<ul style="list-style-type: none"> • Coalition/advocate groups need to make women aware of public and private insurance application and adjudication processes. 	Ontario Breast Cancer Community Research Initiative, n.d.; Stewart et al., 2001

Problem	Solution	Source
Parents of children with cancer struggle financially to properly care for the child with cancer and the child's siblings	<ul style="list-style-type: none"> • Develop programs for parents who care for children with catastrophic illness. • Clinicians in the healthcare system need to be aware of the stress that parents of a pediatric cancer patient faces. 	Miedema et al., 2008
No agency addresses the issue of income loss due to a child's illness	<ul style="list-style-type: none"> • Early financial counseling and prompt connections with potential sources of funding support. • Develop pre-emptive strategies with families when cancer is diagnosed 	Barr & Sala, 2003
Compassionate Care Benefit does not provide adequate support for those caring for a person with cancer in the terminal phase	<ul style="list-style-type: none"> • Increase benefit period to 26 weeks, accessible during a 52-week period. • Build more flexibility into the program. • Create a complementary program, not based on employment status for those who are not eligible for the current Compassionate Care Benefit.* • Amend 2-week unpaid waiting period before CCB compensation starts. 	Canadian Cancer Society, 2009; Williams, Crooks, Stajduhar, Allan and Cohen, 2006

* *As of January 1, 2010, self-employed people can sign up for the federally sponsored Fairness for the Self-Employed Act, which extends medical and compassionate care benefits to self-employed workers (www.cbc.ca, 2009)

Problem	Solution	Source
Canada's current Compassionate Care Benefit stipulation that death be imminent (within 6 months) is a difficult prognostication	<ul style="list-style-type: none"> • Model similar programs in Sweden, Norway and the Netherlands which provide longer leave periods over a longer period of time. 	Williams et al., 2006
As palliative caregiving moves outside of hospital setting, more financial responsibility shifts to caregivers	<ul style="list-style-type: none"> • Direct financial support policies provide monies in the form of wages, allowances or vouchers and are paid directly to the caregiver or to the care receiver to pay the caregiver. • Indirect financial support policies offer delayed monetary support and take the form of tax relief or pension security. 	Keefe & Rajnovich, 2007
Need for financial assistance for adolescent and young adult cancer survivors	<ul style="list-style-type: none"> • Financial assistance can be integrated into a survivorship plan. • Secure sources for healthcare funding, insurance, debt relief and disability income for AYA population. • Co-ordinate social workers to help navigate paperwork and regulations. 	Soliman & Agresta, 2008

Limitations

In general, studies of out-of-pocket costs, lost wages and the overall financial burden placed on persons with cancer and their families are very expensive to conduct and present many challenges. Financial burden is difficult to assess as it is influenced by an individual's perception of what they consider a burden. Some of the studies noted that families who did not feel they incurred financial hardship due to cancer may have chosen not to take part in the research. Other families may have had lower out-of-pocket costs, but, to them, the perceived impact may have been more substantial than a family with higher out-of-pocket costs. Other factors which influence the financial burden incurred by people with cancer are income, employment benefits, and the extent of the social

safety net for those on income assistance and other vulnerable people, and the awareness of, access to and availability of programs to prevent financial hardship for persons with cancer and their families.

Further research is required in the following areas:

- Out-of-pocket costs associated with each phase of the cancer journey and more robust studies with larger numbers of people involved who are more representative of the broad spectrum of financial burden across Canada.
- A comparison of the costs incurred from different types of cancer.
- The financial hardship incurred by
 - Canadian adolescents and young adults with cancer
 - Parents of children with cancer.
- Research explaining the financial impact on the person with cancer undergoing multiple treatment modalities.

Conclusion

This systematic literature review intended to determine the financial hardship incurred by people with cancer during all phases of the cancer journey. While information on specific phases and the personal costs incurred during the phases was limited, enough published articles existed to establish six sub-groups of individuals who are at-risk of encountering financial hardship: individuals/families with high out-of-pocket costs; individuals/families with low-incomes and/or no disability insurance; parents of children with cancer; compassionate caregivers to people in the palliative phase of cancer; adolescents and young adults with cancer; and persons with cancer receiving multiple treatment modalities.

Based on the research available, there is a potential for these groups of individuals to incur a financial burden from which it may take years to recuperate. The Canadian government has made changes to its Compassionate Care Benefit Plan and more recently introduced the Fairness for the Self-Employed Act, but the costs incurred due to medication, travel, accommodation and lack of insurance fall in the laps of people already tackling a stressful and difficult time in their lives. The salary lost due to caring for a child with cancer or a loved one in the palliative phase of cancer can be a debilitating sacrifice for a family, who often choose to ignore the long-term financial implications. The out-of-pocket costs accrued from diagnosis and on may jeopardize an individual's future economic stability and put a family in a precarious financial position.

There are a variety of solutions and 'next steps' that offer some foundation for providing a more solid financial future for people with cancer and their families.

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