The Financial Hardship of Cancer in Canada

A Literature Review

Written by:
Colleen Nelson B. Ed. PBCE
December 2010

Contact:
Canadian Cancer Society, Manitoba Division
193 Sherbrook Street
Winnipeg, Manitoba R3C 2B7
Phone: (204) 774-7483
eMail: info@mb.cancer.ca
**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. In addition to the physical and emotional hardship a cancer diagnosis brings to an individual and the family, a financial burden can occur.

In order to complete this literature review, 72 articles were reviewed; 55 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. High 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 illness coverage or 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 or alternate income sources. Two provinces, New Brunswick and Prince Edward Island, do not provide public drug plans for their residents.

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.

A fourth group, compassionate caregivers to people during treatment or 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 and persons whose treatment duration exceeds their sick leave benefits 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.

Acknowledgements

I would like to acknowledge the assistance of Nadia Ezzahir, Information Specialist at the Cancer Society in Winnipeg for her nimble-fingered searching.
Purpose

This literature review, initiated by Canadian Cancer Society Manitoba and the Canadian Cancer Action Network in November 2009, revised in August 2010 and again in July of 2011, 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. This is not intended to be an academic exercise but a platform for action to ameliorate the financial impact of a diagnosis.

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’, ‘EI sickness benefits’, ‘economic burden’ and ‘oncology’ were used in the initial searches on the databases www.cochrane.org, www.joannabriggs.edu.au, www.campbellcorporation.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 158 abstracts and full texts were reviewed and 72 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, 23 were quantitative, 31 were qualitative and 18 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, 2 from New Brunswick, 5 from Quebec, 8 from Ontario, 1 from Manitoba, 1 from Alberta and 3 from BC; 34 others discussed the issue from a national perspective and can be considered Canadian, 8 were from the US, 2 from the UK, 1 from Greece, 2 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 and persons whose treatment duration exceeds their sick leave benefit**

**1. 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...
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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 [travel] 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” (Mathews, Buehler and West, 2009c), or decide not to get certain treatments due to the cost of travel, distance of treatment location or emotional stress of traveling to a big city (BC Cancer Agency, 2006). The most frequently cited example of altering treatment plan due to the cost of travel was women with breast cancer choosing mastectomy over breast-conserving
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surgery (Mathews, Buehler and West, 2009c and Longo et al., 2006) to eliminate the need for radiation treatment.

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 intravenous therapy to oral therapy resulting in the cost of treatment being shifted to the patient (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). While catastrophic drug
costs are a financial burden for any family, those in an already precarious economic position (i.e. low-income earners) are even more at risk. McLeod, et al. pointed out that ‘catastrophic drug costs were concentrated among less affluent households’ (2011) in their study of 14,430 respondents to the 2006 Survey of Household Spending. The study also suggests that ‘some policy intervention is needed to improve the welfare of households who face high drug costs without comprehensive coverage (McLeod et al., 2011).

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 and may have an annual maximum that is significantly below a normal course of cancer treatment. 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”. McLeod et al. concur that ‘some prescription drugs are simply unaffordable for some households and hence are not purchased’ (2011).

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 as a result incur lost salary. Hopkins, Goeree and Longo (2010) used six direct surveys identified in a literature search to estimate the national wage loss from cancer in Canada. One article cited in their review found that 91% of households suffered a loss of income or a rise in costs as a direct result of a cancer diagnosis. Using responses from six different studies, Hopkins et al (2010) calculated the average amount of wages lost due to a cancer diagnosis was $4,518 in 14.6 weeks. Hopkins, et al (2010) also found that variations occurred between estimates for wage loss depending on the age of the person with cancer and the type of cancer. Younger people with cancer had a higher wage-loss than retired people and men with prostate cancer had the largest decrease in household wage at $8,255.
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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).

2. 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) and it may put low-and moderate-income families at financial risk for bankruptcy or housing loss (Heymann, Gerecke and Chaussard, 2010). 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.

Low-income earners 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).

Low-income earners may be further penalized by a cancer diagnosis when they try to access Employment Insurance sickness benefits. The program allows for up to 15 weeks at 55% of salary to a maximum of $457 per week and the income is taxable (Canada, 2010). However, the limitations of the program make many low-income earners ineligible. An applicant must have worked 600 hours in the last 52 weeks, which means the long-term unemployed, part-time workers, seasonal workers will not have accumulated enough hours to receive benefits. The Human Resources Skill Development Canada EI Monitoring and Assessment Report for 2008 indicates that 18.1% of employed Canadians worked in part-time positions and 12% had temporary jobs (HRSDC, 2008). Individuals who leave employment to attend school, new immigrants, people who quit work for a reason considered invalid by EI rules are ineligible for EI sickness benefits (Prince, 2008). As well, if workers have reduced their hours before their claim due to illness, the reduced weekly earnings are used to determine their benefit amount (Heymann, 2010). Low-income earners are at risk for ‘tremendous financial and emotional stresses’ (Prince, 2008) due to gaps in the EI sickness benefit.

Other segments of the population who may incur a financial burden due to a cancer are the Metis and Aboriginal peoples of Canada. While there is relatively little research done about this issue, one research report commissioned by the Manitoba Centre for Health Policy and the Manitoba Metis Federation sought to investigate how healthcare is utilized by the Metis population of Manitoba. The report found that the mortality rate due to cancer is elevated among the Metis at 30.6% versus 27.8% for the general population (Martens et al, 2010). In terms of economic hardship, the mean income of the Metis population in 2005 was $5,000 less than the non-Aboriginal population (Statistics Canada, 2010). While no report has specifically targeted the financial burden to certain ethnic groups due to cancer, those in a perilous economic position are certainly more affected financially by cancer than others. An additional problem when dealing with Metis is that Metis and non-status Indians are more likely than the non-Aboriginal population to be underinsured or not insured at all. (Aboriginals who are Registered Indians or eligible Inuit have very some coverage because of the federal Non-insured Health Benefits program.) (Luffman, 2005).

Welfare recipients are another group at risk of financial hardship. Not only does the welfare benefit fall below the cost of basic living needs (Vozoris & Tarasuk, 2004), but welfare recipients must deplete all their liquid and fixed assets up to the exemption limit. In Manitoba, the liquid asset exemption limit ranges from $400 for a single employable person to $2,000 for a single parent with one child to $8,000 for a disabled, two parent family with two or more children (www.hrsdc.gc.ca, 2008). However, ‘households on income assistance should not be expected to deplete all of their financial assets to gain access to income support’ (Robson, 2008). Fixed assets, such as homes and vehicles,
provide greater stability and mobility, especially during illness. As Robson stated, ‘welfare policy is caught in a trap of its own making that strips applicants of the same productive assets they will need to leave and stay off welfare later on’ (Robson, 2008).

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. 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, Easley, Fortin, Hamilton and Mathews 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”.

A study examining poverty and health behaviours found that working Canadians with an income below the ‘low-income cut-off of $22,637 (Statistics Canada, 2010) are often caught without either employer insurance, due the nature of a low paying job, or government help. The working poor often do not seek proper medical care or fill prescriptions because they do not have funds to cover these out-of-pocket costs (Williamson & Fast, 1998). The study pointed out that families receiving social assistance do have access to medical coverage and supplementary benefits such as prescription medication, dental care and eyeglasses (Williamson & Fast, 1998; Battle, Mendelson and Torjman, 2010). A major issue with the Canadian welfare system is that once people leave income assistance for work, they lose supplementary benefits available to them on welfare and are at risk for financial hardship when they seek medical attention.
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 cannot afford it (Longo et al., 2007; Heymann et al., 2010).

3. 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.

The financial impact to a family with a child who has cancer is substantial. In the PhD thesis written by Argerie Tsimicalis (2010), 99 parents completed a cost diary of the resources consumed and costs incurred during one week for three consecutive months beginning with the fourth week after the child’s diagnosis. The average total cost incurred by families of a child with cancer was $28,475 for the first three months following a child’s diagnosis. (This amount includes out-of-pocket expenses, loss of salary and, for three respondents, the purchase of a car.) The median work loss for an employed father was $1260 per month and $2380 per month for employed mothers (Tsimicalis, 2010).

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 (Limburg, Shaw & McBride, 2007).

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). The non-reimbursed work loss per family amounted to $4,178 for the first three months of a child’s illness according to Tsimicalis’ (2010) research.
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. Tsimicalis (2010) also pointed out that a ‘sudden change in parental employment status required two-parent households to rely on one income and single income or one-parent households to deal with the threat of no income.’ 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).

‘Parents whose financial situation was limited prior to their child’s diagnosis encountered the greatest challenge in finding ways to reduce their expenses.’ (Tsimicalis, 2010) and 74% of parents reported an increase in debt. For some families, making changes to their budget was enough to absorb the effects of the financial demands of their child’s illness, but for others seeking assistance from their support network or various charitable organizations and government agencies was necessary. 18% of the families involved in Tsimicalis’ (2010) research were considered low-income and vulnerable to having difficulty making their mortgage or rent payments on time due to the costs incurred by their child’s illness.

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. A child with cancer often relies on a parent to act as caregiver. The tasks associated with caregiving include attending to the emotional needs of the child, attending medical appointments, dispensing medication and comforting a child through painful procedures. According to Tsimicalis (2010), children with cancer received approximately 16 hours per day of caregiving time.

In a joint Australian/American study the financial concerns of families with a terminally ill child were discussed. Families whose child is experiencing palliative/end-of-life care face different demands than those whose child survives. Frequent hospitalization and increased caregiving demands resulted in 16% of American and 34% of Australian families falling below the poverty line (Dussel, et al., 2011).

Caregiving for a child 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 doctor’s prognostication, or a prediction based on indications of the individual’s health, that death will be imminent (e.g. 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 county 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). In the PhD thesis by Tsimicalis (2010), it was found that parents spent between $300-$47,470 on travel costs. Three families needed to buy a car due to their child’s cancer diagnosis. According to Tsimicalis’ (2010) research, the indirect costs increased by $18 for every extra kilometer a family had to travel. 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 accommodation (Miedema et al., 2008). Tsimicalis (2010) found that food costs ranged from $92 to $4,054 per month after a child’s diagnosis and that a family’s indirect costs increased by $244 for each inpatient tertiary hospitalization. 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 families of newly diagnosed children with cancer.

In a joint Australian/American study the financial concerns of families with a terminally ill child were discussed. Families whose child is experiencing palliative/end-of-life care face different demands than those whose child survives. Frequent hospitalization and
increased caregiving demands resulted in 16% of American and 34% of Australian families falling below the poverty line (Dussel, et al., 2011).

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). Five out of 99 parents in the study by Tsimicalis (2010) did not apply for financial assistance because they felt ineligible, didn’t have a chance to complete the forms, were not connected with a social worker or preferred to keep the funds available for ‘people who actually needed them’.

4. Compassionate Caregivers to People in the Palliative Phase of Cancer

The Canadian Institute for Health Information (2008) stated that the average cost of a neoplasm hospital stay in 2004-2005 was $11,000 and there were 150,000 stays that year. While no definitive amount could be found for the dollar amount saved by the Canadian health care system because of unpaid caregiving, the literature suggests that an increasing number of people are choosing home care over hospital care (Fast & Keating, 2000) and relying on caregivers for support.

According to the Canadian Caregiver Coalition (2008), in 1997 there were at least 2.85 million Canadians providing care for a family member with long-term health problems, but today that number might be as high as 4-5 million. As the Canadian population ages and cancer incidence rates increase, reliance on caregiving will become more common in Canadian society (Canadian Cancer Society, 2008).

With a trend towards the deinstitutionalization of palliative care increasing and more people in the palliative phase of cancer wishing to spend their last days at home, the number of informal caregivers providing 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’ and according to a 2005-06 estimate by Statistics Canada, a replacement cost can be assigned to the value of household work performed by the caregiver and represents a mean cost of $36 per day (Canadian Cancer Society, 2010). This calculation excludes the loss of
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income related to absence from work in order to provide care. 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). Similar findings were reported by the Lien Foundation which publishes a Quality of Death Index of 40 countries. Canada rated poorly on the cost of end-of-life care for families. The study found that 25% of the cost of end-of-life care falls to the family (Economist Intelligence Unit, 2010).

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). According to the Canadian Cancer Society (2008), 41% of caregivers relied on personal savings while providing care. Statistics from Health Canada show that in 2002, only 35% of households with caregivers had an income over $45,000, which is below the national average (Canadian Caregiver Coalition, 2008). In a poll conducted by the Canadian Cancer Society, 88% of Canadians agreed that giving care would have a negative impact on their financial situation and 57% said it would have a major negative impact (Canadian Cancer Society, 2011).

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. Lost salary due to caregiving amounts to an average reduction in annual household income of $4,978 (Hopkins, Goeree and Longo, 2010). 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. Due to extenuating circumstances (loss of work, high out-of-pocket costs), 41% of caregivers use their personal saving 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. The financial burden of caregiving becomes additionally challenging if the family is already identified as low-income and may be pushed below the poverty threshold (Canadian Cancer Society, 2010).

Compassionate caregiving is described as an ‘undue burden’ placed on families as they provide needed care and support to those with chronic illness or in the palliative stage of illness (Williams, et al., 2011). 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. In a 2010 study on the unmet needs of cancer survivors and support persons in Manitoba, 12.4% of the 550 survivors and support persons who completed the questionnaire felt that “finding what financial assistance is available and how to obtain it” was an unmet need (Propel Centre for Population Health Impact, 2010).

White and Keefe (2005) prepared a briefing paper on the issues and questions concerning payment of family caregivers. The report discusses two types of payment for caregivers: salary/wages and allowances, which are often used to purchase medical supplies or services. Keefe also examined payments available to caregivers in other countries. Australia offers a bi-weekly carer allowance that is intended for partial compensation and an additional carer payment for caregivers who are unable to participate in the workforce due to caregiving responsibilities. (Keefe, 2004). Norway provides a care wage flexible to care needs and Sweden’s carer’s allowance is equal to that of formal home help. In the United Kingdom, caregivers are assessed and provided with a bi-weekly carer’s allowance and can apply for additional compensation called the carer’s premium (Keefe, 2004).

Payment to family caregivers offers some ‘financial support to caregivers who may find themselves without immediate and long-term financial security’ (Keefe, 2004). As well, without financial support, the ‘sustainability of the caregiving relationship may be
threatened’ (Keefe, 2004). Currently, in Canada, the only program in place to support caregivers financially is the Compassionate Care Benefit.

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).

A 2011 study by Williams et al., found that the Compassionate Care Benefit is ‘not living up to its full potential in sustaining informal palliative/end-of-life caregivers’. After completing 57 telephone interviews in 5 provinces across Canada between October 2006 and October 2007, which included 22 successful CCB applicants, 5 unsuccessful applicants and 32 non-applicants, many issues related to financial burden were reported. Firstly, the household income of informal caregivers falls below the Canadian average. Since caregiving costs are often paid out-of-pocket, compassionate caregiving can represent a financial burden to a family in an already financially stressed situation. Secondly, only 22% of informal caregivers are full-time employees, which means that the overwhelming majority do not work enough hours to be eligible for CCB. Women are disproportionately excluded from eligibility for the CCB due to the higher percentage who work part-time, yet make up the majority of informal caregivers (Williams et al., 2011). Retirees who have not worked for more than a year are also ineligible for CCB (Williams, et al., 2011) and are often living on a fixed income.

The study also pointed out that the CCB compensation was not reflective of the costs associated with providing palliative care. Making 55% of a salary is not sufficient to cover the costs of maintaining a household, in addition to providing the needed medication and equipment not covered by the public health care system. According to participants, the unpredictability of palliative/end-of-life care made budgeting difficult, which added to the financial stress (Williams et al., 2011). While participants believed that CCB has the potential to ease financial strain for caregivers, it has many flaws (Williams et al., 2011).

The Canadian government is aware of these flaws. In the Federal Poverty Reduction Plan, chaired by Candice Hoeppner and released in 2010. The report states the eligibility criteria to qualify for compassionate care benefits should be reviewed and the program
improved to extend benefits to people who occasionally have to care for people with episodic illnesses or other serious illnesses but who are not in need of end-of-life care’ (Canada, 2010). Due to 60% of CCB recipients exhausting the six-week entitlement and a third going on to claim another type of benefit (EI regular or sickness), it is recommended that the length of the CCB be extended to 12 weeks and that the eligibility criteria be expanded (Canada, 2010).

Keefe and Fancey (2005) compared compassionate care programs in Australia, France, Germany, Israel, Norway, Sweden, The Netherlands, United States, United Kingdom and Canada. The comparisons illustrated the variety of programs available to support caregivers. For example, Australia offers direct compensation, in the form of a universal allowance, and a payment for low-income caregivers. However, there is no labor policy to protect the employed if they leave work to provide care. In France, caregivers, who may be non-relatives, receive direct allowances, tax relief and a pension benefit, but there is no labor policy to protect employed caregivers and spouses are ineligible for benefits.

German caregivers are able to register themselves as employees and receive an allowance via the care receiver, respite coverage and pension benefit. As well, payments are made according to a gradient scale based on the functional need of the care receiver. In Norway and Sweden, caregivers are given an allowance and wage, paid leave from employment and a pension credit. Sweden’s Care Leave Act allows for up to 60 days at 80% salary for care of a terminally ill relative. In the United Kingdom, caregivers receive pension protection and an allowance that continues up to 12 weeks even if the care receiver is hospitalized and 8 weeks after the care receiver’s death (Keefe & Fancey, 2005).

Another study compared Canadian leave policies against other countries’ and found that 90 countries provide benefits for 26 weeks or until recovery. And while Canada replaces 55% of an employee’s salary, 127 countries provide a higher wage replacement rate, some even offering 100% for part of the leave (Heymann et al., 2010).

Keefe and Fancey concluded by stating that financial compensation should include tax relief and a labour policy. As well, ‘an approach that considers immediate short and longer term compensation is important…and makes a value statement on time spent caregiving’ (Keefe and Fancey, 2005).
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5. Adolescents and Young Adults with Cancer

The Canadian Cancer Society defines adolescents and young adults as individuals between the ages of 15-29 (Canadian Cancer Society, 2009). Between 2002 and 2006, an average of 2252 new cases of cancer were diagnosed every year among adolescents and young adults (Prithwish et al., 2011). It is also notable that in the period of 1973-1995, cancer among adolescents rose 30% (the most noticeable increase among any age group (Pentheroudakis & Pavlidis, 2004)) 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 set-backs 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 involve combined modalities and incorporate multi-agent chemotherapy, high-dose radiotherapy and aggressive surgery. As well, the chemotherapy treatments are dose-intensive, 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 implications faced by an adolescent or young adult with cancer are long-term and disproportionally greater than in older adults (Fernandez, et al., 2011). 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 set-backs 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
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Adolescent and young adult cancer survivors may face discrimination in the workplace. 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. An American study asked oncology health professionals and young adults with cancer and survivors to rank the importance of health and supportive care needs. The young adults ranked the need for financial assistance and benefits counseling during post-treatment survivorship as a higher priority than the health professional groups (Zebrack, et al., 2006). The authors point out that ‘this divergence suggests that young adults may be more cognizant of the stresses of ongoing financial liabilities following cancer treatment.’ (Zebrack, et al., 2006).

Prithwish et al. (2011), pointed out that ‘several challenges must be overcome to improve the coordination and quality of care for this age group’ and suggested providing care and counseling in same-age peer settings so that AYA’s with cancer can discuss issues, such as career plans, with others sharing the same concerns (Prithwish et al., 2011).

In 2008, the Canadian Task Force on Adolescents and Young Adults with Cancer was formed. Stakeholders were asked to examine priorities in care for AYA’s with cancer. As mentioned in other reports and studies, developmental tasks of becoming a young adult, such as financial independence, are often delayed as the individual undergoes treatment for cancer (Fernandez et al., 2011). Surviving cancer as a young adult brings unique challenges since 1/3 of survivors experience serious late or long-term effects from their treatment. Fernandez et al., recommended the ‘implementation of life-long monitoring and follow-up of survivors of cancer in childhood, adolescence, and young adulthood will provide economic and other societal benefits and help mitigate late-or long-term treatment effects’ (Fernandez et al., 2011).

6. Persons with Cancer Receiving Multiple Treatment Modalities and Persons whose Treatment Duration exceeds their Sick Leave Benefit

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. Those who are too ill to return to work, or whose treatment exceeds the 15 weeks available to them under the Employment Insurance Sickness Benefit, may face financial hardship.

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 the time the person with cancer and her family needs to take from work (Lauzier et al., 2005).

In an update of a 2004 study on the economic impact of a breast cancer completed by the Canadian Breast Cancer Network (2010), 80% of the 446 people who completed the survey experienced a financial impact from the disease. The average decline in household income was $12,000 or 10% of family income. The same study found that there was a gap of 23 weeks between the 15-week EI sickness benefit and the duration of treatment. People with breast cancer resorted to using savings (44%) or incurring debt (27%) as they dealt with disrupted earnings and no income protection (CBCN, 2010).

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).

In an update of a 2004 study on the economic impact of a breast cancer completed by the Canadian Breast Cancer Network (2010), 80% of the 446 people who completed the survey experienced a financial impact from the disease. The average decline in household income was $12,000 or 10% of family income. Similar to Lauzier (2005), it was found that women who received chemotherapy had the greatest drop in family income. They took more time off work and, due to the treatments, were more likely to have to quit their jobs. According to the survey, those who received chemotherapy saw their household income decline by $13,219 while those who did not saw a decline of $8,682. The women who received radiation had a smaller drop in income, but they had a greater burden in travel costs, especially for rural residents, because they had to travel further to receive radiation treatments (Canadian Breast Cancer Network, 2010).

Additionally, chemotherapy treatments affect women with breast cancer and their ability to work. Of the women who received chemotherapy, 81% had to take more than 16 weeks off work compared with 32% of women who did not receive chemotherapy. More women receiving chemotherapy chose to quit their jobs (21%) versus 14% of women who did not receive chemotherapy. The Canadian Breast Cancer Network (2010) study found that 39% of women undergoing chemotherapy treatment believe the financial burden of breast cancer will have a long-term effect on their health compared with 23% of women who did not receive chemotherapy.

The Canadian Breast Cancer Network (2010) study reports that many of its 446 participants were forced for financial reasons to choose sub-optimal treatments due to the financial burden incurred from the diagnosis of breast cancer.
Another group who often receive multiple treatment modalities are adolescent and young adults with cancer 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).

Employment Insurance Canada’s sickness benefit is in place to help people unable to work due to illness. It covers 15 weeks absence from work at 55% of salary (to a maximum of $457/week) to eligible employees (Canada, 2010). The Canadian government’s Federal Poverty Reduction Plan (2010) recommended that the 15-week sickness benefit be extended to 50 weeks for those who suffer from a prolonged and serious illness (Canada, 2010) since 1/3 of claimants exhaust their benefits before they are able to return to work. The current statistics on EI sickness benefits are as follows: In 2007-08 there were 319,120 claims at a cost of $954.9 million. The average duration of benefit was 9.5 weeks (Canada, 2010). While the Canadian Pension Program provides payment for those individuals considered ‘disabled’ and unable to work, only 10% of EI sickness beneficiaries receive this benefit (Prince, 2008). The Canadian Breast Cancer Network found that 20% of respondents returned to work before they were ready due to financial pressure (2010). Heymann et al., (2010) found pointed out that only Saskatchewan, Quebec and federally regulated industries offer job protection for leaves extending over 12 days, since job protection due to sickness is provincially legislated.

Another recommendation outlined in the Poverty Reduction Plan was to provide more flexibility in the sickness benefit to allow recipients to work part-time and receive partial benefits (Canada, 2010). As it stands now, ‘when an individual works while in receipt of the EI sickness benefit, any earnings are deducted at a marginal tax rate of 100 percent—or dollar for dollar from their benefits-representing a strong discouragement to beneficiaries to improve their own situation and contribute to the productivity of the labor force’ (Prince, 2008).

The Mowat Centre for Policy Innovation sent out a survey to stakeholders in Ontario in order to develop an Ontario proposal for modernizing the EI system. The EI Task Force Report Back points out the problems associated with the current design of the EI sickness and compassionate care benefits. The length of both programs and strict parameters were two common issues (Mowat Centre, 2011).

An exhaustive search provided no estimates on the cost of extending sickness benefits from 15 weeks to 52 weeks. However, it should be noted that among other industrialized countries, Canada has one of the shortest sickness benefit programs. Greece, Italy and the United Kingdom offer 26 weeks, while Austria, Belgium and Norway offer a year’s leave and Denmark, France, Finland and Germany provide between one and one and a half years of benefit over a multi-year period. The Netherlands, Portugal and Switzerland allow an even longer duration of sickness benefits (Prince, 2008).
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).

In a recent study on the unmet needs of cancer survivors, a survey completed by 550 survivors ranked their unmet needs in five areas. Finding out about financial assistance and how to obtain it ranked third, after fear of cancer spreading and fatigue (CancerCare Manitoba & Canadian Cancer Society, 2007). The financial hardship accrued during other phases of the cancer journey often does not end as a survivor, in fact, it can leave a lasting impact as survivors struggle to regain the level of financial security they had before their cancer diagnosis.

What solutions are suggested by the research community to ease the financial burden?  

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<tr>
<th>What needs to be done?</th>
<th>Source</th>
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<tr>
<td>Provide medical travel subsidies for patients who must travel outside their region to access health services.</td>
<td>Mathews et al., 2009a</td>
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<tr>
<td>Provide care closer to home through regional</td>
<td>Mathews et al., 2009a</td>
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Note that since this work was done to provide support and direction to an action plan, the potential source of action has been added by the CCS/CCAN Advisory Committee
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<th>Recommendation</th>
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<td>Provide re-imbursement for meals and accommodation and gas.</td>
<td>Lightfoot et al., 2005; Housser &amp; Mathews, n.d.</td>
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<td>Universal catastrophic drug coverage needs to be provided for all residents.</td>
<td>Canadian Cancer Society, 2009</td>
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<td>Open communication between patients and their cancer care team is critical.</td>
<td>Mathews et al., 2009c; Mathews &amp; Park, 2009b</td>
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<td>Cancer care providers should inquire about financial concerns at various phases of the cancer journey</td>
<td>Mathews et al., 2009c; Mathews &amp; Park, 2009b</td>
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<td>Establish standard in-take assessment to ensure that all patients with financial concerns have been identified.</td>
<td>Mathews et al., 2009c; Mathews &amp; Park, 2009b</td>
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<tr>
<td>Note non-verbal cues that cost may be a concern in conversation.</td>
<td>Mathews et al., 2009c; Mathews &amp; Park, 2009b</td>
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<td>Provide standardized tools (worksheets, organizers) to help people with cancer plan for the expenses they may incur.</td>
<td>Bradley, 2005</td>
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<td>Initiate discussion about cost with healthcare providers before beginning treatment.</td>
<td>Mathews &amp; Park, 2009b</td>
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<td>Use the internet as a forum for providing patient-centered worksheets and exchange of information regarding the cost of care.</td>
<td>Bradley, 2005</td>
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<td>Persons with cancer need to be asked about their ability to pay for out-of-pocket costs over time.</td>
<td>Mathew and Park, 2009b</td>
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<td>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.</td>
<td>Mathew and Park, 2009b</td>
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<th>Individuals/ families with low-incomes and/or no disability insurance</th>
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<tr>
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<tr>
<td>Establish catastrophic drug coverage for all Canadians and make drug pricing equitable across private and public programs.</td>
</tr>
<tr>
<td>Institute a pan-Canadian standard for drug coverage.</td>
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<tr>
<td>Change policies concerning illness insurance in order to help workers face severe illness.</td>
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<tr>
<td>Increase duration of EI sick coverage from 15-weeks.</td>
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### The Financial Hardship of Cancer in Canada: A Literature Review

#### What needs to be done?

<table>
<thead>
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<tbody>
<tr>
<td>Provide additional assistance to those who cannot access employment insurance benefits.</td>
<td>Lauzier et al., 2008; Mathews et al., 2009a.. Prince, 2008, Canada, 2010</td>
</tr>
<tr>
<td>Identify the resource requirements to address the particular health needs of Metis who live in rural, remote and/or socio-economically challenged communities.</td>
<td>Health Council of Canada, 2005</td>
</tr>
<tr>
<td>Provide supplementary health benefits to the working poor.</td>
<td>Battle et al., 2010</td>
</tr>
<tr>
<td>Increase liquid asset limit so individuals accessing welfare are not so impoverished.</td>
<td>Battle et al., 2010</td>
</tr>
</tbody>
</table>

#### Parents of children with cancer

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<tbody>
<tr>
<td>Develop programs for parents who care for children with catastrophic illness.</td>
<td>Miedema et al., 2008</td>
</tr>
<tr>
<td>Extend the Compassionate Care Benefit needs to include all phases of catastrophic pediatric illness beginning with the diagnostic phase.</td>
<td>Tsimicalis, 2010</td>
</tr>
<tr>
<td>Increase awareness of the stress that parents of a pediatric cancer patient faces.</td>
<td>Miedema et al., 2008</td>
</tr>
<tr>
<td>Provide early financial counseling and prompt connections with potential sources of funding support.</td>
<td>Barr &amp; Sala, 2003</td>
</tr>
<tr>
<td>Develop pre-emptive strategies with families when cancer is diagnosed.</td>
<td>Barr &amp; Sala, 2003</td>
</tr>
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</table>

#### Compassionate caregivers to people in the palliative phase of cancer

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<tr>
<td>Increase Compassionate Care Benefit period to 52 weeks, accessible during a 52-week period.</td>
<td>Canadian Cancer Society, 2009; Williams, Crooks, Stajduhar, Allan and Cohen, 2006</td>
</tr>
<tr>
<td>Build more flexibility into the Benefit program.</td>
<td>Canadian Cancer Society, 2009; Williams, Crooks, Stajduhar, Allan and Cohen, 2006</td>
</tr>
</tbody>
</table>
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.

Model similar programs in Sweden, Norway and the Netherlands which provide longer leave periods over a longer period of time.

Provide direct financial support in the form of wages, allowances or vouchers and are paid directly to the caregiver or to the care receiver to pay the caregiver.

Canadian Cancer Society, 2009; Williams, Crooks, Stajduhar, Allan and Cohen, 2006

Canadian Cancer Society, 2009; Williams, Crooks, Stajduhar, Allan and Cohen, 2006

Williams, et al., 2006

Keefe & Rajnovich, 2007, White & Keefe, 2004

**Young adults with cancer**

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<tr>
<td>Integrate financial assistance can be into a survivorship plan.</td>
<td>Soliman &amp; Agresta, 2008, Fernandez et al., 2011</td>
</tr>
<tr>
<td>Secure sources for healthcare funding, insurance, debt relief and disability income for the AYA population.</td>
<td>Soliman &amp; Agresta, 2008</td>
</tr>
<tr>
<td>Co-ordinate social workers to help navigate paperwork and regulations.</td>
<td>Soliman &amp; Agresta, 2008</td>
</tr>
</tbody>
</table>

*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)

**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 expensive to conduct and present many challenges. Financial burden is difficult to assess as it is based, in part, on 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 influencing the financial burden incurred by people with cancer are income, employment benefits, 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.

- Role of communities, NGO’s, service clubs, churches, etc. in addressing individual and family financial challenges.

- Cost/Benefit analyses related to the extension of EI sickness benefit to 52 weeks and other potential government initiatives to address this problem.

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 and persons whose treatment duration exceeds their sick leave benefit.

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.

References


Canadian Cancer Society’s Steering Committee: Canadian Cancer Statistics (2010)


Canadian Caregiver Coalition. www.ccc-ccan.ca


CancerCare Manitoba and the Canadian Cancer Society, Manitoba Division (2007). The Unmet Needs of Cancer Survivors and Support Persons in Manitoba.


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Economist Intelligence Unit. The quality of death: Ranking end-of-life care across the world. 2010


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