



Canadian Breast Cancer Network
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ECONOMIC IMPACT OF BREAST CANCER

*An Update to the 2010 Economic Impact and
Labour Force Re-Entry Report*

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ACKNOWLEDGEMENTS

AS AN ADVOCATE FOR BREAST

cancer patients, The Canadian Breast Cancer Network (CBCN) believes that conversations regarding breast cancer should include the patient voice. CBCN has produced this report to shed light on the financial impact a breast cancer diagnosis can have on its patients and survivors. We would like to share our sincere appreciation to the women who took the time to complete CBCN's Lived Experience survey in 2017. Their willingness to so openly and honestly share their experience has allowed us to share the real-life impact breast cancer has on Canadians and put forward recommendations about improvements that can be made to better address these needs. Without them, this report would not be possible.

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EXECUTIVE SUMMARY

BREAST CANCER IS A DISEASE

that affects not only a person's health, but their finances as well. As an update to the *2010 Economic Impact and Labour Force Re-Entry* report published by CBCN, this report shows that breast cancer continues to have a negative impact on the finances of many Canadians diagnosed with breast cancer and their families. Based on a 2017 online-study, women diagnosed with early-stage and metastatic breast cancer answered open-ended and multiple-choice questions regarding the effects breast cancer had on their finances, among other topics. Our study

revealed that Canadian women are concerned with drug access, the cost of treatment, the psychosocial stress that can also burden family members as well as the economic impact of a breast cancer diagnosis. These findings echo many of the same themes found and discussed in the 2010 report. We show that the combination of various factors can expose some patients to significant financial burden. Using our results as a point of reference, we outline recommendations that will bring about needed change to help ease the financial burden that many breast cancer patients face.

INTRODUCTION

BREAST CANCER IS ONE OF THE

most frequently diagnosed cancers, reported to have affected 26,500 Canadians in 2017 and accounting for approximately 25% of all cancer cases detected in women.¹ Due to early screening, detection and advanced treatments, breast cancer has an 87%, 5-year net survival rate.¹ Paying for treatments and for travel, taking time off work, the long-term impacts of treatment and living longer means that breast cancer patients' and survivors' finances may be negatively impacted. Despite Canada having free public health care, those diagnosed with breast cancer may still incur costs as not everything is covered by the government. This fact is far from being widely known as many patients incorrectly believe that all treatment costs are covered by insurance.² Costs of breast cancer treatment have been shown to lead to stress and are used by patients to determine the type of treatments they are willing to undergo.² In cases where treatments and medications

are completely covered, patients still face other costs. These out-of-pocket costs can include parking, travel, wigs, and prostheses.

Financial distress induced from loss of income due to time off work has been shown to reduce quality of life and increase depression and anxiety.³ In the 2010 CBCN report, patients' household income reduced by an average of 10% because of taking time off work.⁴ While some breast cancer patients are able to return to work following chemotherapy without any problems, others may face cognitive impacts which can impact the quality of their work.⁵

This updated report highlights the fact that some breast cancer patients suffer a greater financial burden than others. The combination of a variety of factors, ranging from household income, to stage of breast cancer, to province of residence, all work to impact those who have been diagnosed with breast cancer.

METHODOLOGY

THIS REPORT WAS DEVELOPED

as a follow-up to the *2010 Economic Impact and Labour Force Re-Entry* report. The data from this report was compiled from CBCN's 2017 survey that informed "Breast Cancer: The Lived Experience" report. Only respondents who answered questions related to the financial impact of a breast cancer diagnoses were included in the data for this report. A total of 410 Canadian women (there were no male respondents) participated in an online survey that targeted breast cancer patients in Canada and covered a variety of topics. Most participants resided in Ontario (28%). No participants indicated they resided in Nunavut. 62% of respondents were early-stage patients with 38% having a diagnosis of metastatic breast cancer. 36% of the early-stage breast cancer patients were first

diagnosed between the ages of 40 to 49 and 31% of the metastatic survey respondents were first diagnosed as metastatic between the ages of 40 and 49. Women indicated that they had hormone therapy (51%), chemotherapy (56%) and radiation therapy (57%).

Participants responded to both multiple choice and open-ended questions which were analyzed using SPSS and NVivo respectively. Using NVivo, frequency counts were conducted on the quantitative data. For the open-ended questions, open coding was used. The codes that were generated were then fit into the following themes: access to insurance and coverage; cost of treatment; psychosocial impact including impact on family; and work, employment and income.

RESULTING THEMES AND DISCUSSION

ACCESS TO INSURANCE AND COVERAGE

GOVERNMENT COVERAGE OR INSURANCE

Coverage of cancer treatment and drugs differs from place to place meaning that some patients may not fare well financially, simply because of where they live while others may be more fortunate. Some breast cancer patients found their government coverage to be adequate.

"I'm extremely grateful for MSP [Medical Services Plan – British Columbia]."

This sentiment was not shared by all participants. The theme of not having proper access to drugs due to geographical location was especially noticeable within the metastatic patient population. Regarding provincial access, survey respondents living in rural areas or smaller cities expressed concern with whether they would receive better access and care if they were living in bigger cities. General concern about drug access surrounded the issue of why certain drugs or clinical trials were not accessible in Canada, followed by whether such drugs and trials would be covered by the government if they were made available.

"I'm concerned with how long it takes to get a treatment approved and on the public health care lists and with the high cost of new treatments that have become available but are not yet covered under the public health care lists."

"I am participating in a clinical trial, but have to travel to the U.S. I found it myself (but Canadian oncologist gave guidance) and have to pay for travel and other costs myself."

In British Columbia, Manitoba and New Brunswick, more women were prescribed support medications that were not covered than those whose support medications were covered. 51% of all women in our study were prescribed medications (cancer and/or support medications) that were not covered, 55% of whom had an annual household income of less than \$60,000.

While patients may have other government programs that they can apply for, many of these programs have income requirements. While those of lower socioeconomic status are at an obvious disadvantage to being financially distressed, those of middle socioeconomic status are also susceptible if they lack enough savings and depend on a steady flow of cash.⁶ Being a middle-income earner meant that some women did not qualify for such programs even though they did not have enough savings to pay for treatments and other costs. "

"Just because I am not in the lowest income bracket does not mean I don't need assistance. I am excluded from all programs I have tried to access."

Similarly, self-employed breast cancer patients can be at a financial disadvantage if they are not paying into any insurance program.

"I am a small business owner and had just finished college. I did not have disability insurance and we did not qualify for any kind of government assistance. Any financial help would have been appreciated for day to day expenses."

ACCESS TO INSURANCE AND COVERAGE cont'd

PRIVATE INSURANCE AND COVERAGE

Individuals who had private insurance prior to being diagnosed had another source of coverage if government coverage was inadequate which was a tremendous help to some.

"However, it made me realize I am lucky to have insurance, there are many who don't, I don't know what they do."

Unfortunately, among those who had private insurance, it was not always enough. Another issue faced by those with private insurance was that they had to get their claims approved. This meant either delayed or denied claims. Delayed claims meant delayed treatment.

70% of the women indicated that they had private insurance, 20% of whom had challenges accessing their claims and 13% of whom had their claims denied. 17% of women who were prescribed medication that was not covered had their claims denied and of those whose claims were denied, 42% reported a very large

negative impact on their finances. Denied claims meant alternatives; alternative methods of paying or alternative medications which would be covered instead. 42% of the women who had a claim denied covered costs by themselves and 42% accessed a manufacturer patient assistance program.

"I am having difficulty accessing drugs because my insurance plan is not approving my applications."

Not every patient had private insurance and they also had to make payments through other methods or use alternative medications. Of those who were prescribed medications not covered, 16% did not have private insurance. 82% of women who indicated that they had no private insurance also indicated that they covered the cost by themselves while 14% stated that they accessed a manufacturer patient assistance program.

COST OF TREATMENTS

EXPENSES OF CANCER

The cost of cancer being exorbitant is evident in the fact that even with government coverage and private insurance, some individuals still fall through the cracks and must pay the full cost of a drug. It is also important to note that despite how expensive cancer treatment might be, some individuals were protected from financial burden due to a variety of factors such as having enough savings or having few day-to-day living expenses.

"I didn't really require any additional financial support."

"We were able to handle expenses."

"I am retiring and on a private pension, so my financial concerns were minimal."

For individuals not protected, when faced with expensive medications that they could not afford, patients were required to make decisions about how to proceed. Prior studies have linked financial stress to not taking medications, re-budgeting other costs in one's life, using in-patient care, and not keeping up with routine follow-ups in a timely fashion.^{3,7} A number of participants discussed buying a less costly option when the medications they had been prescribed were not covered. While this is not ideal, it at least meant patients still received

treatment. In other unfortunate cases, survey respondents (7% [72% of whom were metastatic]) described completely foregoing a medication due to its price tag.

"I had to leave the pharmacy empty handed because a one-month supply was over \$1,400 and I didn't have the money or amount available on credit."

Some studies have reported a variety of methods cancer patients have taken in order to afford treatments, from daily budgeting to refinancing their home, with extreme measures being rare in Canada.⁸ While we did find evidence of extreme measures (refinancing homes, going on welfare, holding fundraisers, setting up arrangements with their credit card companies and moving in with family) such cases did not represent the majority of women in our study.

"I got funding because my friends did a fundraiser - I wouldn't have otherwise. We need treatment funding while a drug waits for approval [...] At 11k per month [...] people WILL die due to lack of access. If my community did not raise the money for my [medication] I would likely not be here today. When I contacted every group or charity NO ONE offered financial assistance for treatment."

COST OF TREATMENTS cont'd

OUT-OF-POCKET COSTS

Due to the nature of breast cancer, a patient can have all their treatment and medication covered yet still have indirect medical costs. Such costs may be minimal for some or covered through various grants, or programs.

"The Ontario government travel grant covered my travel costs for radiation treatments."

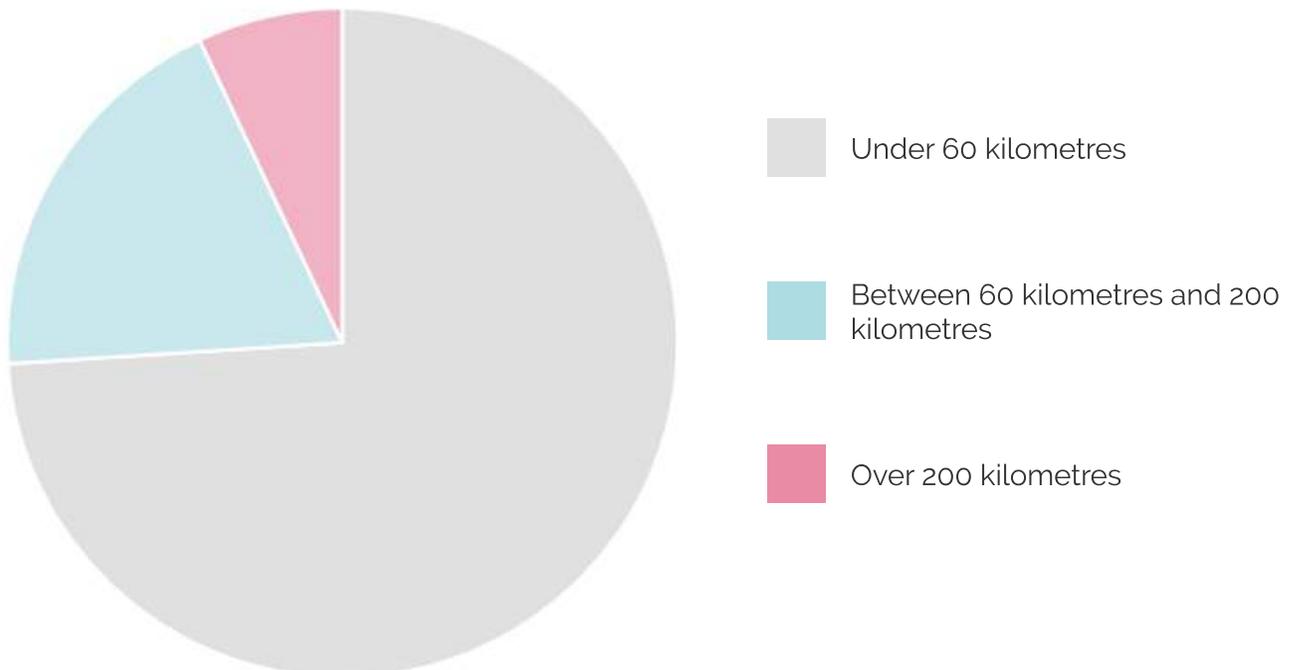
Though some patients might not have to worry about out-of-pocket costs, this is not the case for every patient. For example, a patients' stage of breast cancer can have different implications and lead to different outcomes.⁹ 57% of metastatic breast cancer patients reported that they experienced a very large negative

financial impact compared to 43% of the early breast cancer patients who reported the same.

When discussing the costs that financial aid would have been useful for at their time of treatment, many participants mentioned out-of-pocket costs. Costs related to travel, parking, and accommodation were raised 33 times. 33% of those who indicated travelling over 200 kilometres from their home to the cancer centre also claimed a household income of less than \$60,000.

"How to deal with extra costs after being diagnosed. Transportation, parking. Loosing weight, gaining weight and needing new clothes, shoes, wigs, makeup."

HOW FAR DID YOU TRAVEL FROM YOUR HOME TO THE CANCER CENTRE?



PSYCHOSOCIAL IMPACT INCLUDING IMPACT ON FAMILY

UNFORTUNATELY, THE FINANCIAL strain of cancer and its consequences are not only felt by those who have been diagnosed.

"I had to get help from my parents to pay my bills during EI, and they had to postpone their retirement because of it."

Of the women who felt that their cancer diagnosis had a very large negative impact on their lives, 77% were in a relationship. The result of a cancer diagnosis on a spouse's job can lead to either an added worker effect or a caregiver effect. In the added worker effect, the healthy spouse increases how much they work while in the caregiver effect, they reduce how much they work as a means to care for or spend more time with their diagnosed partner.¹⁰

"My husband felt that he had to work overtime to make up some of the income."

"My spouse had to take every other week off without pay to look after me."

Aside from spouses and parents, children were also affected, which prompted participants to express a need for subsidies and grants related to children such as daycare costs. Using savings to treat a breast cancer diagnosis can

impact a child if the money was being saved for their future. Of the women with children, 24% experienced a very large negative impact on their finances and 42% reported some negative impact. Even more vulnerable were single mothers, 72% of whom reported a very large or some negative financial impact. Only 21% of respondents claimed that cancer had no effect on their finances. However, even when the costs of cancer did not negatively impact them, many women were worrisome of the future, along with the fear of how different their experience would have been, had they not been covered, insured or had savings. All in all, participants voiced that having to deal with the expenses of cancer added more stress to an already dire situation.

"For me, the experience and effects of breast cancer treatment have significantly negatively impacted my life. I will give serious thought to receiving any further treatment in the event of recurrence. To me, the decreased quality of life is not worth the minimal extended life expectancy that it claims to provide. Why live a longer life when its quality has been greatly diminished? And I certainly don't expect to be able to recover from the financial loss that it has caused me as well. My life as I knew it is GONE. Guess I'll just need to see what the future holds."

"The living part is hard when you're broke."

WORK, EMPLOYMENT AND INCOME

EMPLOYMENT IMPACT AND RETURN TO WORK ELEMENTS

While returning to work has been reported to be in large a decision made by the individual without outside input, there are factors which have been shown to influence this decision.^[1] Within our study, some of these factors included cancer stage, side effects and income level. For women with advanced breast cancer, getting back to work was more delayed than for women with localised breast cancer.¹¹ Having localised breast cancer may also contribute to breast cancer patients being able to continue working while undergoing treatment.

"I didn't take time off other than a week for the surgery. Sometimes I would take a day or two after chemo but would schedule chemo for a Thursday or Friday to minimize time off."

"Thankfully I didn't need chemo. I only had to do 16 treatments of radiation, which went well overall. I could even do it around my work schedule."

Ironically, individuals diagnosed with cancer may need to return to work to recuperate from financial loss incurred while undergoing treatment, yet the financial distress experienced may delay when they can go back to work.⁷ Regardless of the course of action, there were individuals whose choices felt forced upon them, either due to needing money or because of side effects which hindered the quality of their work.

"Personally, I could not afford to go off work permanently at the time of my treatment. I took weeks off at a time that was required and worked through other weeks."

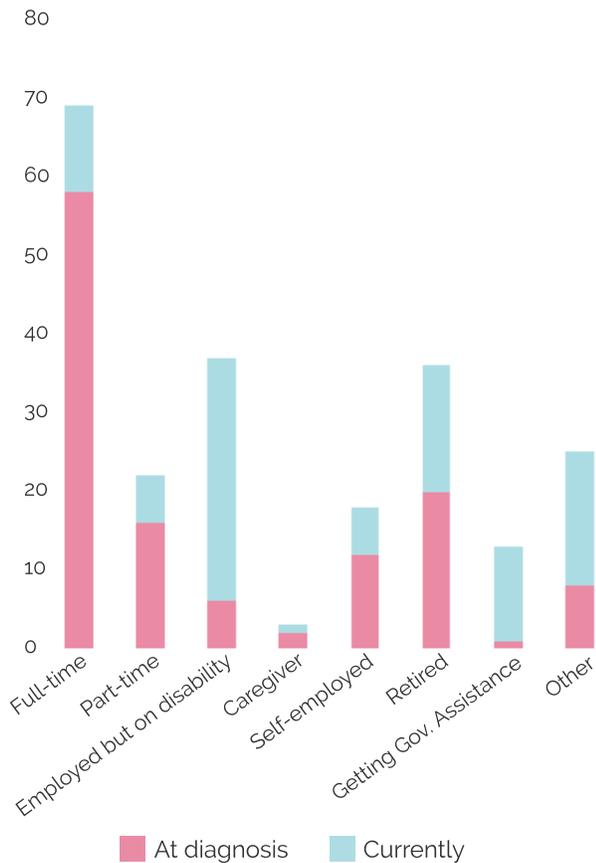
"For myself, as someone who has not yet been able to return to work due to fatigue, low energy, cognitive deficits related to chemo, I find that the isolation has increased significantly - most have done treatment, had a recovery period and are able to return to work. It is possible that I will not be able to return to work due to the cognitive deficits. It would be good to have someone to speak to. Not everyone recovers enough to return to their previous employment."

"There was lots of support for dealing with cancer, but lymphedema ended my career when I was just hitting my peak earning years and ended several other recreational activities for me. I even had to learn to write with my other hand. It took about 5 years to get this very painful condition under control. It's better now, but it will always have a huge impact on my life."

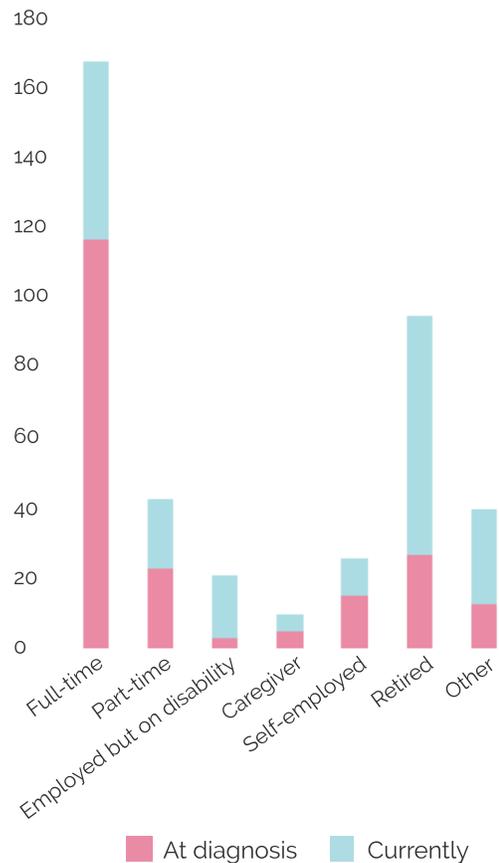
"I was self-employed to bolster my pension. I was unable to work and have closed my business."

WORK, EMPLOYMENT AND INCOME cont'd

EMPLOYMENT IMPACT AND RETURN TO WORK ELEMENTS cont'd



This illustration includes only metastatic breast cancer patients. Current employment status only represents those who reported being employed at the time of diagnosis.



This illustration does not include metastatic breast cancer patients. Current employment status represents all participants regardless of status at time of diagnosis.

The accommodations an employer was willing to make had an impact on those who wanted to return to work. 37% of the metastatic patients who wished to work had employers unwilling to make accommodations for them.

"LTD & CPP disability; my job isn't available any longer. Employer refused to create a job share option for the future even though I said that was my goal ultimately. If I could work part time I'd have to move to be able to. Also, I can't always work at the same time - my SE/illness varies greatly. Easier to stay on LTD. Sadly can't even drive so not possible now."

WORK, EMPLOYMENT AND INCOME cont'd

LOSS OF INCOME

Prior studies have demonstrated that income loss is a large part of costs cancer patients face.⁵ The majority of respondents were diagnosed when they were between the ages of 40 to 49 which is well below the retirement age (65). This group also boasted the highest household incomes out of all other age groups. Of those with a household income of \$80, 000 and higher, just under half (44%) were between the ages of 40 to 49. This means that the majority of breast cancer patients are well into their careers, making the diagnosis of breast cancer possibly more devastating and career-altering.

"I was in financial hardship and had to contact my credit card companies and speak to them about payment arrangements because we went from two incomes to one."

It was even more financially strenuous then, for single women who started off with only one income. No participant who stated they were single had a household income higher than \$100, 000.

"Last thing you need to worry about is finances when you are fighting for your life. I'm a single person and found it challenging on a reduced income."

Self-employed individuals diagnosed with breast cancer are also more susceptible to a large amount of income loss due to losing contracts and/or professional networks.¹²

INCOME REPLACEMENT

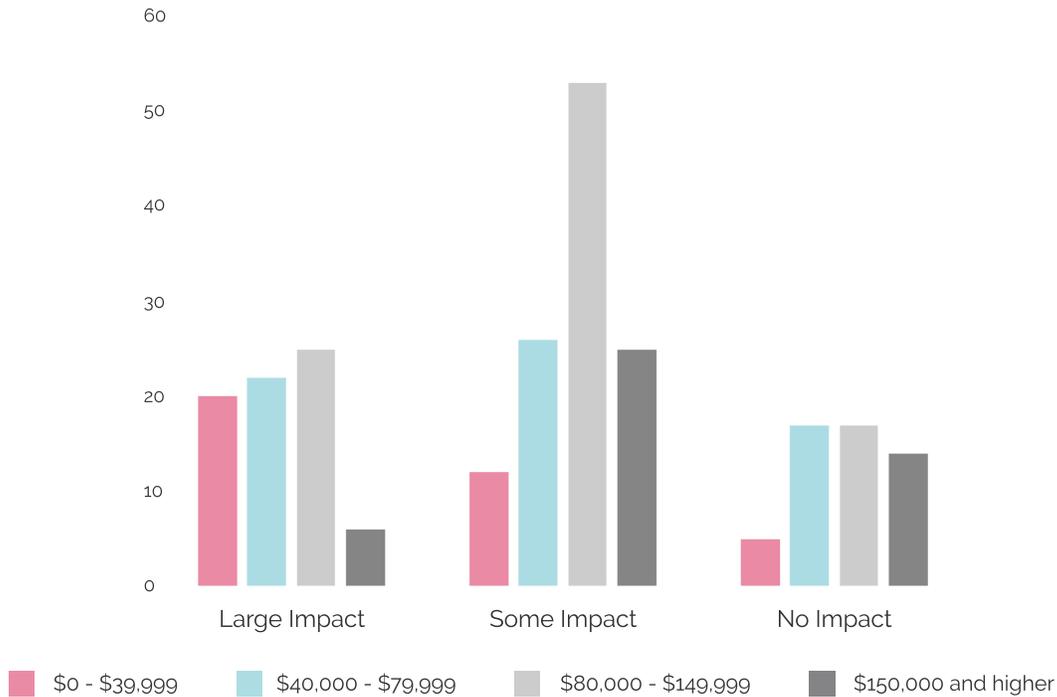
Of the participants who used Employment Insurance (E.I.), 71% indicated that 15 weeks was not long enough. Respondents also felt that it did not provide enough of an income replacement. Respondents in the 2010 report took an average of 38 weeks off work, resulting in an average of 23 weeks of treatment without E.I. coverage.⁴

"I could not believe that you could be laid off or fired and access 52 weeks E.I. but could be dying or fighting a life-threatening illness and only access 15 weeks."

"15 weeks only covered time off up to my first chemo treatment. I had 6 then followed by 5 weeks radiation. Being single made it that much harder with only 15 weeks of E.I. sick benefits and the cost of travel etc. I had to be off work for nearly a year total."

WORK, EMPLOYMENT AND INCOME cont'd

INCOME REPLACEMENT cont'd



Similarly, the percentage of wages being covered directly through an employer was not always enough to cover day-to-day living expenses.

"I did not claim E.I. sickness benefits. I received STD and LTD through my employer. I received 70% of my wage through my employer. However, a loophole in their policy obligated them to only provide that based on my permanent position with them, one that I hadn't worked in for over a year. So, in addition to the reduced 70% wage, it was based on a wage substantially lower than what I was making, which cost me to lose over \$20,000 in annual wage. I subsequently moved in with family as couldn't afford my current housing costs.

Populations particularly at-risk when it came to E.I. and income replacement were the self-employed, teachers, contract workers, stay

at home mothers and those who were retired. Due to not being part of the traditional workforce, these patients may have had no work coverage or coverage that came with stipulations.

"As a teacher I didn't qualify for sick benefits during the summer months ... benefits get cut off on [the] last day of school but can resume in September when school reopens."

Very few patients were in a situation where they received enough of a wage replacement.

"I have a full-time position, but I am currently on a gradual return to work schedule, so my employer pays my salary for the hours worked & disability insurance pays the remainder."

RECOMMENDATIONS

The financial burden of cancer can be significantly reduced through targeted change. CBCN recommends the following to ease the financial burden of current and future breast cancer patients, outlined by the various levels such changes should occur at.

GOVERNMENT

FEDERAL

- Lengthen E.I. coverage to reflect the average time needed off work for breast cancer treatment.
- Increase wage percentage replaced by EI.
- Amend the health care system to have the same coverage in all provinces and to cover all breast cancer treatment, cancer medications and support medications.
- Implement a group coverage program for all self-employed individuals.
- Provide paid time-off work allowances for spouses and primary caregivers of breast cancer patients.

PROVINCIAL/TERRITORIAL

- Provide coverage for typical out-of-pocket costs such as parking, transportation, wigs etc.
- Reassess income-level qualifications of support programs to ensure middle-income patients who lack savings are not being left out.
- Increase locally available support groups and treatment centres to reduce travel distance.
- Invest in earlier screening and detection to reduce costs of treatment as earlier-stage cancers are often less costly.
- Implement a standardized assessment tool to identify financial need and provide patients with comprehensive treatment plans and options that outline direct and indirect costs.
- Increase healthcare professionals' awareness of locally available financial resources.

RECOMMENDATIONS

COMMUNITY

- Create an official database of locally available financial support resources so patients have a tool they can access at any time.

INDUSTRY

INSURANCE

- Shorten the time between when patients submit claims and when they get a response to eliminate delayed treatment.
- Provide coverage for generic and other therapeutic alternatives in cases when claims are denied.
- Broaden items patients can submit claims for such as parking, accommodation, prostheses etc.

EMPLOYERS

- Combat workplace discrimination to ensure a more accommodating work environment so patients return to work when they are ready and can contribute effectively when they do.
- Implement work flexibility options to support a successful re-integration process.

CONCLUSION

WHILE SOME PATIENTS MAY BE slightly less vulnerable financially due to their assets, income or income of a partner, they may not be protected from the high cost of medication if they are prescribed a drug that is not covered by the government or their private insurance. While some patients may have lower treatment costs, they may experience a large and negative financial impact if they are retired or are the sole earner in their household. What these show is that various factors can lead to different financial implications. As per our results, attention should be paid to the following groups that have been identified as the most vulnerable: single mothers,

self-employed individuals, those without private insurance, low to middle income earners, those in rural areas, women with children, single women, contract workers, stay-at-home moms, and retirees. Similarly, how they are impacted will be different. While these groups have been identified as at-risk, it is important to understand that financial distress is neither guaranteed for everyone belonging to these groups nor limited to only individuals belonging to these groups. Work must be done that utilizes a standardized approach to minimize the possibility of a negative financial impact due to a breast cancer diagnosis.

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ABOUT CBCN

PATIENT EDUCATION. PATIENT ADVOCACY.

The Canadian Breast Cancer Network (CBCN) is Canada's only patient-directed national breast cancer health charity. CBCN strives to voice the views and concerns of breast cancer patients through education, advocacy activities, and the promotion of information sharing.

EDUCATION AND INFORMATION – CBCN provides credible breast cancer related information and education to those affected by breast cancer.

ADVOCACY – CBCN promotes equitable access to support and care throughout the breast cancer experience to ensure best quality of life. CBCN also ensures that the issues affecting breast cancer patients, survivors, and their families inform health care policy and guide research.

NATIONAL NETWORK – CBCN connects groups and individuals to promote information exchange and collaboration.



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