



Economic
Impact



CBCN · RCCS

Canadian Breast Cancer Network
Réseau canadien du cancer du sein

Breast Cancer

Economic
Impact and
Labour Force
Re-Entry

Re-Entry

Table of Contents

Foreword and Acknowledgements	2
Executive Summary	3
1.0 Introduction	5
2.0 Methodology	6
3.0 Who Provided Information: Profile of Survey Respondents and Interviewees	6
4.0 The Financial Impact of Breast Cancer	8
5.0 Labour Force Re-Entry	15
6.0 Health and Psychosocial Impact of Financial Burden	25
7.0 Treatment Type and Its Economic Impact	29
8.0 Survey Respondents' Views on the Roles and Responsibilities of Governments, Insurers, Employers and Patients Themselves	30
9.0 Public Awareness of These Issues	35
10.0 Discussion	37
11.0 Recommendations	40
12.0 Conclusion	44

Foreword and Acknowledgements

The Canadian Breast Cancer Network (CBCN) is the national network and voice of breast cancer survivors (www.cbcn.ca). As part of its mandate to inform Canadians and to advocate on issues related to the financial cost of having breast cancer, CBCN presents this report on the impact of a breast cancer diagnosis and treatment on labour force re-entry.

CBCN is issuing this report on the impact of a breast cancer diagnosis and treatment on labour force re-entry in the hope that it will inform Canadians, encourage dialogue and inspire them to take action on behalf of those living with, affected by, or at risk of being diagnosed with breast cancer.

This report was researched and written during a time of changes to the Employment Insurance laws, and the text should be read accordingly.

The Canadian Breast Cancer Network acknowledges with gratitude the generous support for this project provided by the Breast Cancer Society of Canada (<http://bcsc.ca>) and the assistance of Pollara public opinion and market research (www.pollara.ca), which conducted the research for the project.

Hundreds of women and two men took the time to participate in the survey and follow-up questions that provided the data for this report. The Canadian Breast Cancer Network extends sincere thanks to all those who provided information and told their stories. CBCN also thanks the more than 3000 Canadians who participated in the general population survey.

Janet Dunbrack developed and wrote the report.

CBCN thanks GlaxoSmithKline for generously providing in kind support for the translation, artistic design and printing of the report.

Mona Forrest and Jackie Manthorne edited the report.

CBCN's Board of Directors and the Project Advisory Committee generously provided time and feedback from the questionnaire stage to the final report.

The Canadian Breast Cancer Network is grateful to all those who made this research possible and to the women and men who shared their experiences. CBCN will work with its members and partners to help create a future where a diagnosis of breast cancer leads to treatment, survival and productive economic life rather than long-term financial hardship.



Cathy Ammendolea
President



Jackie Manthorne
Executive Director

Executive Summary

This report presents the results of research conducted for the Canadian Breast Cancer Network on the economic impact of breast cancer and the challenges of returning to work. Our research shows clearly that breast cancer is an economic, as well as a health, condition.

The research was conducted during the first six months of 2009 for the Canadian Breast Cancer Network (CBCN) by Pollara and consisted of an online survey, a qualitative follow-up survey and a general public opinion survey. CBCN undertook this research to update an economic impact study done in 2004 and to deepen its knowledge of work force re-entry. The research will be used to equip CBCN, its member groups and partners to engage in the current federal review of Employment Insurance and to advocate for positive change on economic issues with all levels of government, businesses, health care providers and researchers.

Of the 446 people who participated in the online survey, 98% were women and 97% were of usual working age (18-64) at the time of diagnosis.

The economic impact of breast cancer is huge and, in many cases, devastating for patients and their families. 80% of respondents experienced a financial impact from the disease. The average decline in household income was \$12,000, or 10% of family income. The average duration of treatment was 38 weeks and two-thirds of respondents took 16 weeks or more off from work. Because Employment Insurance (EI) benefits last for a maximum of 15 weeks, there was an average gap of 23 weeks during treatment without EI coverage. To cover medical expenses and make up for lost job income, 44% of respondents used their savings and 27% took on debt. Most respondents also relied on sick leave, Employment Insurance, long-term disability and financial help from their families.

73% of respondents had full or part-time jobs at the time of their diagnosis. There was a 16% decline in the number with full-time jobs after diagnosis and 16% had their jobs terminated. One-fifth had to quit their previous job due to the effects of treatment. The main reasons for leaving a job were work-related restrictions, side effects of treatment and fatigue/pain.

The number of self-employed respondents remained steady at 8%, but most suffered a loss of income and had to start their businesses again from scratch. They often had no income during treatment and recovery because they are not eligible for Employment Insurance benefits.

Respondents had mixed experiences of returning to work. One-fifth returned to work before they were ready because of financial pressure. Those who were able to make a gradual return to work were more likely to report a positive experience. Some (19%) had rehabilitation and ergonomic adjustments to their workplace to accommodate their new situation.

Those who did not have a gradual re-entry to work or adjustments in the workplace reported distress, pain, fatigue and, in some cases, having to leave their jobs. The attitudes of employers and co-workers were important factors in the ease of re-entry.

The health and psychosocial impact of financial burden was significant, with the most common experiences being stress and insomnia. One-third believe that the financial impact of the disease will have long-term negative effects on their health and many fear a recurrence of cancer because of stress associated with financial burden.

Families and close relationships were affected by the economic impact of breast cancer. Two-thirds of respondents reported a negative effect on family members. The most frequent effects on families were loss of income, taking on more work or taking time off from work to provide care, and having to economize on children's education and other needs. Some respondents indicated marital strain.

Chemotherapy has an economic impact. Those who received chemotherapy had the greatest drop in family income, took more time off work and were more likely to have to quit their jobs. "Chemo brain" was identified as a challenge in returning to work. Family members of those who received chemotherapy were more likely to have to take time off work to provide care.

Survey respondents were asked who they thought should be responsible for helping to alleviate the economic burden of breast cancer and ease workforce re-entry. Most thought that governments should cover costs, especially costs of all treatments (including travel and accommodation where required to receive treatment), drugs, supplies and prosthetics.

Respondents thought that the Federal government should improve Employment Insurance benefits and provide more generous tax breaks. Employment Insurance benefits were criticized for being too short and too little. EI coverage for 15 weeks (compared to an average of 38 weeks of treatment) at 55% of salary level was judged by many to be woefully inadequate. In addition, EI eligibility criteria exclude those without enough accumulated work hours, the self-employed and homemakers.

Respondents suggested that long-term disability and other extended health benefits could be made more generous and that the attitudes of EI and private insurance company staff need to be more understanding and compassionate.

The general population survey revealed that Canadians are aware that breast cancer can have a financial impact on patients and families and that close to 75% of Canadians support an increase in the duration of EI sickness benefits for persons living with breast and other cancers.

In light of the evidence that the financial impact of breast cancer is significant, that much can be done to ease the transition back into the workforce, and that public opinion will likely be in favour of lessening the financial burden of the disease, the Canadian Breast Cancer Network recommends a plan of action. Recommendations include:

- Dialogue federal officials and Members of Parliament in order to improve eligibility criteria and length of Employment Insurance sickness benefits
- Position breast cancer as an economic, as well as a health, issue in a population health policy framework

- Dialogue with Provincial/Territorial governments about full coverage of all drugs, medical supplies and treatments, including those associated with chemotherapy and lymphedema
- Develop partnerships with other cancer organizations, chronic disease organizations and women's organizations to work together to bring about positive change

Additional recommendations can be found on page 40.

1.0 Introduction

We may think of breast cancer as a health condition, but it is also an economic condition. A diagnosis of breast cancer can have an enormous cost for women and men living with the disease and for their families. Persons living with breast cancer usually have to take time off work for treatment and recovery. Their re-entry into the work force after treatment can be difficult.

This report provides information about the economic impact of breast cancer and the challenges involved in going back to work. It also provides recommendations for change that could soften the economic impact and make going back to work smoother. The information in the report was provided by women and men who have lived with breast cancer. This report gives a voice to those who often have to cope alone with the devastating economic and emotional impact of the disease.

This is the second report developed by the Canadian Breast Cancer Network on the economic impact of breast cancer and the first report to provide detailed information on the process of re-entry into the labour force after treatment. In 2004, the Canadian Breast Cancer Network conducted a survey on the economic impact of breast cancer which showed that Canadian women paid a financial, as well as a health, cost following a diagnosis of breast cancer.¹ Out-of-pocket expenses paid by women and their families included travel costs for treatment, child care, drug costs and loss of earnings and jobs. Women reported that they went without treatment or drugs because they could not afford them. Many went into debt to cover their treatment costs and make up for lost job income.

By 2009, the Canadian Breast Cancer Network (CBCN) wished to update this information and take a closer look at labour force re-entry, which had emerged as an important concern in the 2004 study. CBCN's intent is to equip its member groups with current information to enable them to participate in ongoing debates on economic issues and advocate for changes to assist persons living with breast cancer. This report is being shared with CBCN members and partners and with the media to raise awareness of the issues and ways of bringing about positive change.

The facts and figures from our research are the framework for this report. The quotations from those who have lived through breast cancer appear in indented italics throughout the report. Their experiences tell the human story behind the figures.

¹ Canadian Breast Cancer Network. 2004. Results of the National Survey on the Financial Cost of Having Breast Cancer.

2.0 Methodology

Initial information was collected by means of an online survey conducted by Pollara from January 13, 2009 to February 27, 2009. The survey consisted of 50 questions aimed at women aged 18 and over who had received a breast cancer diagnosis within the past five years. The survey included quantitative questions (multiple choice) and qualitative questions (written comments). A small number of respondents (eight people) opted to complete the survey in a shortened hard copy version. A brief online follow-up questionnaire was offered by Pollara to a selection of survey participants chosen at random from those who had indicated their willingness to provide more information about their return to work.

Finally, a general population survey of 3125 people was conducted by Pollara in June 2009 to measure public awareness of the economic impact of breast cancer. Copies of the full Pollara breast cancer patient survey results and the general population survey results can be found on the Canadian Breast Cancer Network website at www.cbcn.ca.

3.0 Who Provided Information: Profile of Survey Respondents and Interviewees

The initial online survey was aimed at Canadian women aged 18 and older with a breast cancer diagnosis within the past five years.

A total of 446 people responded to the survey, of whom 98% were women.² Of these, 97% were of usual working age (between the ages of 18 and 64) at the time of their diagnosis. Close to half of the respondents were aged between 45 and 54. The next largest group (28%) was aged between 35 and 44. Only 3% were older than 65.

Ontario (40% of respondents) was the province most heavily represented, followed by Quebec (15%), British Columbia (14%) and Nova Scotia (8%). All other jurisdictions were represented except the Northwest Territories and Nunavut. Most respondents lived in urban areas (68%) rather than rural areas (32%).

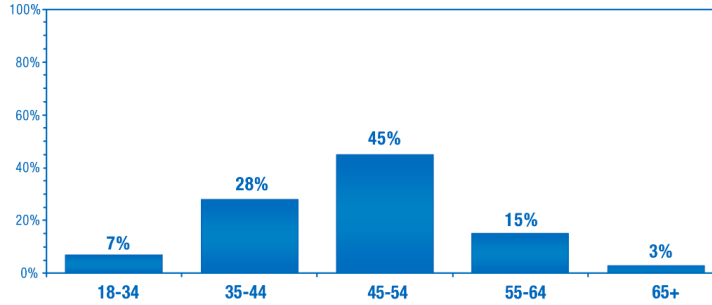
English was the first language of 84% of respondents and French of 16%. Many respondents (68%) had college diplomas or university degrees.

More than 90% of respondents had surgery and almost 75% had radiation, chemotherapy and medication. On average, treatment lasted a total of 38 weeks.

The type of treatment, especially chemotherapy, appears to have an important effect on financial burden and return to work. This disproportionate effect is discussed in more detail in section 7.0.

² Most persons with a diagnosis of breast cancer are women, but men can also have breast cancer. In Canada, fewer than 1% of breast cancer cases occur in men. Source: Canadian Cancer Society. www.cancer.ca

Almost half of respondents received their breast cancer diagnosis while they were between the ages of 45 and 54

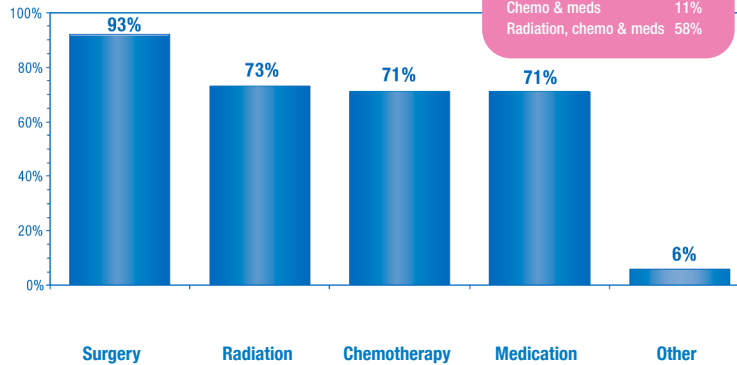


Over 9-in-10 respondents had surgery and almost three quarters received radiation, chemo and/or medication

- On average, respondents' treatment lasted a total of 38 weeks.

Treatment Regimens:

Radiation only	2%
Chemo only	2%
Medication only	1%
Radiation & chemo	13%
Radiation & meds	13%
Chemo & meds	11%
Radiation, chemo & meds	58%



4.0 The Financial Impact of Breast Cancer

Breast cancer affects many Canadians. Every year, an estimated 22,700 women and 180 men will be diagnosed with breast cancer. Breast cancer is the most common cancer for women: one in nine women is expected to develop breast cancer during her lifetime and two-thirds of women diagnosed with breast cancer will live through it. The estimated number of close to 150,000 persons living with breast cancer in Canada in 2009 represents nearly 40% of all persons living with cancer. The breast cancer death rate is currently the lowest it has been since 1950 because of improvements in screening and treatment.³

If we estimate the circle of family and close friends affected by each case of breast cancer to be five people, then in 2009 at least three-quarters of a million people are directly affected by breast cancer. As the findings in this report show, the economic impact of breast cancer on these Canadians can be devastating.

The experiences of survey respondents paint a picture of the situation of Canadians facing breast cancer. The unexpected high cost of treatment and the need to take time off work caused women and their families to lose income. In order to make up for lost income, many relied on Employment Insurance or long-term disability, and many depleted their personal savings. Some lost pension benefits. Respondents thought that the long-term health effects of their income loss could be serious.

Cost of Treatment

Direct costs of treatment that must be paid for by the patient include some drugs, medical supplies and prosthetics. This can impose an enormous burden on those without private insurance who do not qualify for government assistance. Contrary to a commonly held belief, public health services in Canada do not pay for all costs associated with a disease. Services of physicians and most in-hospital costs are covered by public health plans, but drugs and supplies needed outside the hospital must often be paid for by the patient.

Most provinces and territories have a list of approved drugs (the formulary) that are available for reduced or no payment, but the list varies from one jurisdiction to another. This means that a woman in one province may have her out-of-hospital drugs covered while a woman in another province will have to pay for the drugs herself or through insurance, if she has private coverage.

I had no money. As a single parent, I had to pay for medication that cost \$750 a month. This might have kept the cancer at bay. My work insurance refused to provide samples until I had gathered the money. I decided to go for radiation instead. Ironically, my cancer recurred in 2007, with marked involvement at the radiation site, with multiple radiation-induced nodules.

³ Source of information in this paragraph: *Canadian Cancer Statistics 2009*. Canadian Cancer Society, Statistics Canada, Provincial/Territorial Cancer Registries and Public Health Agency of Canada. Available online at www.cancer.ca/Ontario/About%20cancer/Cancer%20statistics/~/_/media/CCS/Canada%20wide/Files%20List/English%20files%20heading/pdf%20not%20n%20publications%20section/Stats%202009E%20Cdn%20Cancer.ashx

There is a program with the Ontario government to provide women being treated with medications for \$2 a prescription for most routine medications. However, it does not cover some expensive medications including the one which supports white blood count during chemotherapy. This medication costs close to \$3000 for each round of chemotherapy. My interest would be for the provincial government to cover this drug for all women. There is an equity issue here. Women who have good health insurance and are able to have this medication covered may be able to receive their chemo according to the required schedule and therefore may receive more benefit from it. Those who are delayed due to infection may not benefit as much from the chemo.

Women with private insurance reported having more of their treatment costs covered than those without insurance.

I had good extended health coverage, so about 75% of additional medical costs were covered (travel, hospital stay, wig etc, prescription medicine).

I had insurance, so for the year and a bit that I was off I received full salary for six months, and then two-thirds for the remaining time. We also spent \$40,000 out of pocket for some of the drugs, and were lucky that our insurance plan agreed to pick that up.

My drug plan had no coverage for massage therapy. I have continued chronic upper back and arm pain, which would be helped by massage therapy. As I have no coverage I do not receive it.

Where you live affects treatment costs. Significantly more respondents living in rural areas (31% of respondents) had to travel more than 50 kilometres and spend at least an hour travelling to receive radiation or chemotherapy compared to their urban counterparts (7% of respondents). Travel costs include transportation, accommodation, meals and parking, which had to be paid for in most cases by the patient.

Many respondents, whether urban or rural, noted the high cost of parking for medical appointments. Others cited the cost of child care while they were unable to provide care themselves because of appointments or feeling sick.

Loss of Income

Respondents to the 2009 survey told us that 80% of them experienced a financial impact because of their breast cancer diagnosis. On average, they reported a \$12,000 drop in annual household income following their diagnosis, amounting to about 10% of mean annual household income.

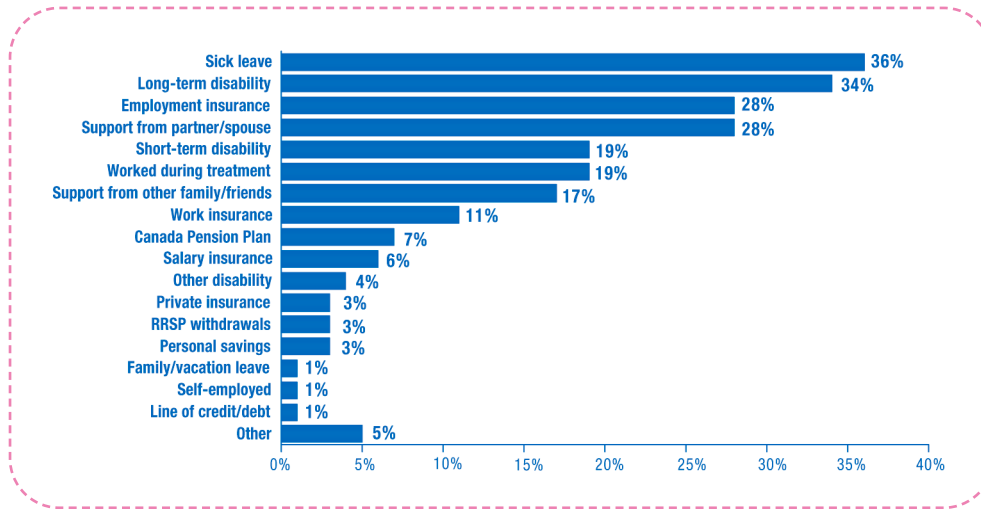
On average, respondents' annual household income dropped by almost \$12,000 following their breast cancer diagnosis

	Pre-Diagnosis	Post-Diagnosis	Mean Change
Mean Annual Household Income	\$122,290	\$110,357	\$11,933

- The mean difference in income pre- and post-diagnosis is greater for respondents who did not receive radiation (\$23,932) compared with those who did receive radiation (\$7,265).
- In contrast, those who received chemo (\$13,219) saw a greater decline in their household income following their breast cancer diagnosis, compared with those who did not receive chemotherapy (\$8,682).

How did women support themselves and their families during their treatment? The most common approach involved using savings and investments (44%) and taking on debt (27%). Most respondents used sick leave (36%), long-term disability (34%), Employment Insurance benefits (28%) or assistance from their partner/spouse or other family and friends (36%), in addition to using savings or loans. Some reported that they worked during treatment (19%), in many cases while feeling sick. Treatment required many women to take time off work. Those with jobs fared better than the self-employed who stop earning when they stop working and are not eligible for Employment Insurance support.

Most respondents used sick leave, long-term disability, employment insurance or assistance from their partner/spouse to financially support themselves through their treatment



Income Replacement

Employment Insurance

Many women spoke of the difficulty of surviving on Employment Insurance (EI) payments or of not being eligible for benefits. Current EI provisions allow 15 weeks of payment at 55% of salary to a maximum of \$447/week during illness after a two week waiting period. Applicants for sickness benefits must have worked for 600 hours during the past 52 weeks, or since their last claim. ⁴

Some women had a good experience of dealing with EI staff.

After the initial application process was completed, I found the staff at Employment Insurance and Canada Pension Plan Disability understanding, compassionate and patient to deal with. I was thankful for that.

⁴ www.servicecanada.gc.ca/eng/sc/ei/benefits/sickness.shtml

Others reported a frustrating experience.

They told me I should go back to work when I felt that I couldn't. They gave me some suggestions that were very unreasonable with long wait lists for these jobs. Maybe they should make a house call or interview the patients and see for themselves what you are able to do and not do. Then they could make better observations and decisions for individual cases.

I found the experience of dealing with EI frustrating. It's enough to deal with cancer without having to struggle with the EI staff as well.

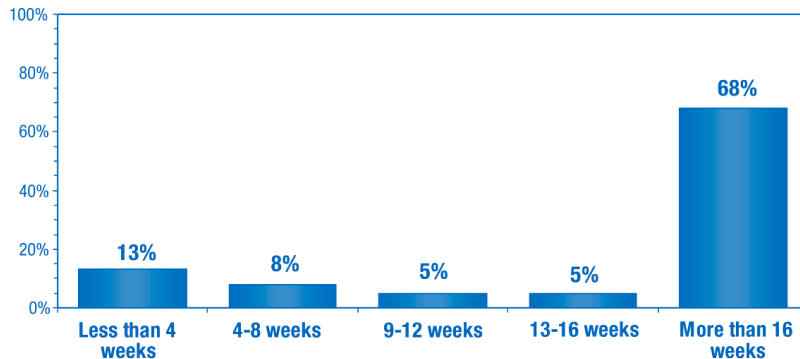
Many suffered because of the EI eligibility criteria and payment levels. Two-thirds of respondents took off 16 weeks or more from work. The average length of treatment for respondents was 38 weeks, whereas EI benefits lasted only a maximum of 15 weeks.

I faced financial hardship after I was laid off, even though I had worked all my life. I didn't have enough hours the last two years, when I was ill, so I was not eligible for EI benefits.

The EI system however is woefully inadequate if you have to depend on it for support. 15 weeks of benefits barely gets you through your surgeries and maybe one or two chemo treatments.

Time Off Work for Treatment: *Two-Thirds Off 16 Weeks or More*

- Two-thirds (68%) of respondents took off at least 16 weeks for their treatments.
- Chemotherapy patients were more likely to take off at least 16 weeks (81%) than those who had not received chemotherapy (32%).



I found that only 15 weeks of EI medical benefits is appalling. Individuals who quit their jobs are entitled to 50 weeks of benefits and breast cancer patients receive only 15 weeks – certainly not fair!

The problem isn't the return to work; it's the inadequate number of weeks of EI payments.

A few respondents were homemakers and not eligible for Employment Insurance benefits.

Some of us were homemakers at the time and weren't employed and so not qualified to receive unemployment benefits. But I was 'unemployed' in a way – I couldn't do my regular things as a mom, but there wasn't a government program to help take up the slack.

Long-Term Disability and Salary Insurance

Some women had income insurance during treatment, while others did not.

I'm grateful to be alive still, and glad to have long-term disability insurance unlike many of my peers who have been evicted from their homes due to lack of insurance.

I had no salary insurance at my job because I work on annual contracts. I didn't have long-term sick leave or disability insurance either. After I used up all my sick leave and vacation time I had to go on Employment Insurance. That's why I had to go back to work early.

Those with long-term disability or other income insurance told us that their experience was often frustrating.

I had five months of no salary before long-term disability caught up, and I was one of the people with the safety net. I would have liked to be able to have reimbursable sick leave or income during that time. If I'd been single or in a single income household, I would not have been able to pay any bills for shelter, food or utilities, let alone cover any costs for getting to treatment or drugs during that time.

Long-term disability entirely ate away my savings (after all, I only received 70% of my regular pay) and I've been playing catch-up since.

I was fortunate to have disability insurance which covered 70% of my salary during my period of leave and during my "gradual return to work" period but the insurer did not take income tax off the amounts I received at source. I ended up owing \$3500 in back taxes. This was a challenge for me to pay on time.

The long-term disability company has access to a lot of personal information that they do not necessarily understand, and retelling the trauma to new people each time for the check-in phone calls tends to create more trauma. (I have had at least three or four different people in my time off.)

Personal Savings and Other Sources of Income

The impact on savings, pensions and RRSPs was particularly hard on some.

I have savings of course...I will use them all...What happens when I do not have savings anymore? I doubt the government would assist me. This is sad and scary for me and I feel very alone.

It took 10 months during the meltdown of my RRSPs. I've been set back many years from retirement and no longer have the stamina to work full-time.

I have no choice but to work after cashing in my RRSPs at a time in my life when I wanted to retire. Cancer robbed me in so many ways.

It takes many years to regain the finances lost during that time. I was also not able to repay the company pension (which is matched by the company) which I did not contribute to during my illness – that equates to several thousand in my pension fund.

I am now 64 and have been laid off from my job. I am still trying to repay the debts I acquired while going through treatments. My retirement savings are all but gone. The stress of knowing I will have to work at least part time for the rest of my life, regardless of how I feel, is overwhelming.

I had to go on welfare.

Impact on Self-Employment

Self-employed people told us of the financial hardship of losing earnings when they could not work during treatment.

I had to sell the business to relieve stress and also to have some income to live on for the next 6 months of treatment.

I was clinically depressed for many months; basically closed my consultancy and suffered major mood problems for many, many months. I went from +\$150,000 in billings to zero.

The difficulty for me was that I wasn't able to drum up other business, so my income was very much a part-time income – and the drugs were expensive. Financially, things were difficult.

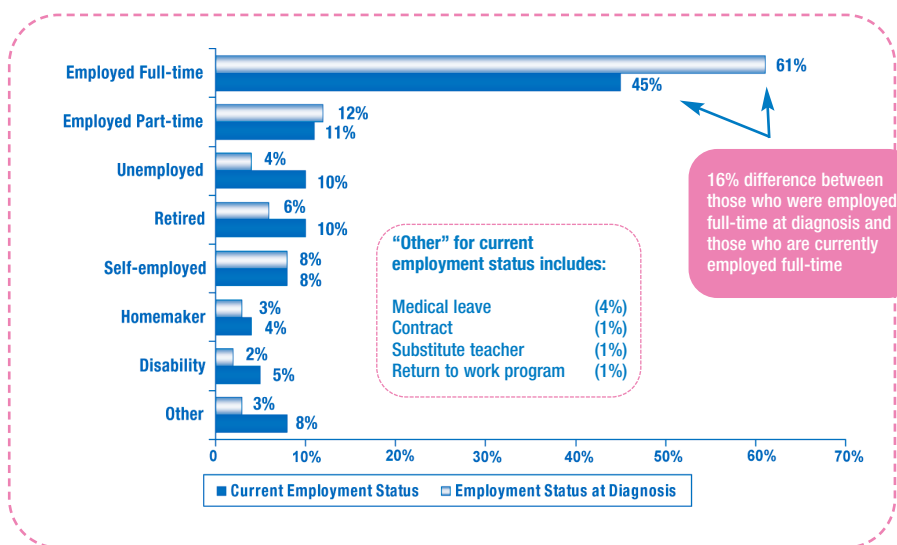
5.0 Labour Force Re-Entry

A breast cancer diagnosis causes significant disruption to the workforce participation of patients. All survey respondents had received their diagnosis not more than five years ago. At the time of their diagnosis, 81% of respondents were employed full time, part time or were self-employed. Of those who were employed, two-thirds had to take more than 16 weeks off work for treatment.

By the time they answered the survey, the proportion of those employed in salaried jobs had declined to 64%, with a 16% decline in the number of those employed full time. Many women had to retire from their jobs or go on disability or medical leave. In some cases (16%), their jobs were terminated. The rate of self employment stayed the same at 8%.

Those who remained employed after treatment, either on salary or in their own business, often saw their earnings decline. Total household income declined by about 10%. Many self-employed women saw their earnings decline to near zero and had to rebuild their businesses from scratch.

Fewer respondents are currently employed full or part-time and more are unemployed, retired or on disability compared with at the time of their diagnosis

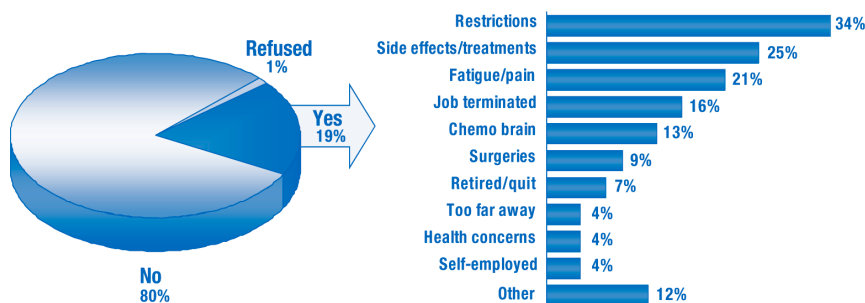


A Job to Go Back to – or Not?

Even if women wanted to return to work, did they have jobs to go back to? 19% of respondents were forced to quit their previous job because of their diagnosis. This was most often due to work-related restrictions, side effects from treatment, fatigue and pain, job termination or “chemo brain”. Among those who kept a job, 12% were unable to return to their prior job with the same title and salary because of medical issues, reorganization, reassignment, termination, seniority issues, long hours, restructuring or fatigue.

Almost one-fifth of respondents were forced to quit their previous job due to their breast cancer diagnosis

- Top reasons for quitting include work related restrictions, side effects/treatments, weakness/fatigue/pain, termination of job and “chemo brain”.



- More respondents who received chemotherapy (21%) were forced to quit their jobs compared with those who did not receive chemotherapy (14%).

Many women faced the need to find a new job when the old job was not there or was no longer suitable.

I worry to the point of no sleep about the lack of income. I try to hide the fact I was treated for cancer because when it is found out, I don't get jobs I apply for (company physical exams I dread because the scar is seen). I've considered lying but that is fraud. I feel like some sort of criminal.

My nest egg is gone. I'm now five years older and have been out of the work force for all that time. Where do you get a job – at McDonalds or Tim Hortons?

During my treatment I was told my job was being eliminated. After my treatment I was terminated by mistake on several occasions. Finally, when I was ready to go back to work they terminated my employment.

They laid me off after 18 years of employment, when there were others with much less seniority than myself who could have been laid off.

I was “let go” (fired) because my boss was concerned I wouldn’t have the strength to perform duties and that I might become ill on the job. He “was concerned for my health”.

I had to change careers and take care of my own retraining expenses.

Making the decision to retire because of all my issues was sad and disappointing as I no longer enjoyed the career I had loved to work in for so long.

Some women wanted to go back to work because of the psychological benefits of working.

It was my choice to return to work. I wanted a “normal” life back – not focusing on breast cancer.

Work helped me maintain a focus other than my illness.

Many women (21%) reported that they had been forced to return to work before they felt ready because of financial pressure.

I rushed back as they were paying me while I was off, so I felt guilty staying at home. I knew that I couldn’t have paid my mortgage/bills on long-term disability wages. I had no choice but to go back. I would have liked to take more time after treatment to rest and recover, but that wasn’t an option.

They started to pressure me to return when I wasn’t yet finished treatment. At a time when I should have been recuperating, I was dealing with the stress of losing my job.

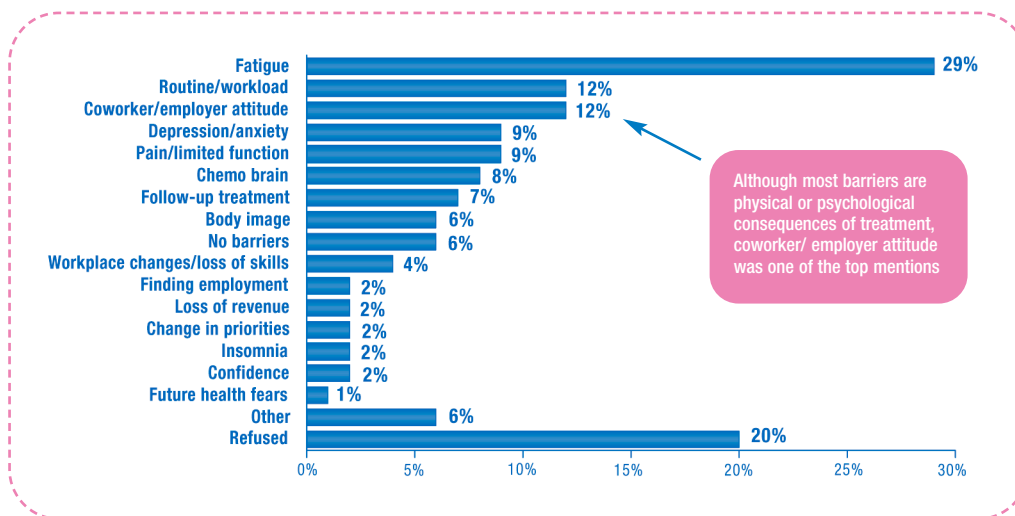
I had run out of sick leave at the end of treatment and I feel my recovery was longer and more draining by having to work full time before I had regained my energy.

I was not mentally ready to go back to work, but I had to as my Employment Insurance ran out after 15 weeks, and I needed the money to take care of my family.

The Challenges of Returning to Work

Women who returned to work told us of the challenges they faced. Fatigue was experienced as the greatest barrier to labour force re-entry (29% of respondents) and reduced physical ability to work (45%). Other physical challenges included weakness, lymphedema, pain and nausea.

Fatigue is the greatest barrier to returning to work, mentioned by almost one-third of respondents



My work is very physical work and my level of endurance due to fatigue and joint pain is not back to normal. I can only work about 25% of my normal day so far. My business has suffered as well from my being off work. It has been hard to get business back. But I am also not able to work a full day.

Treatments take their toll on the body and mind and it is difficult to come up with the energy and mental alertness to give a new job what it requires. I couldn't negotiate my way into a better paying job. I knew I didn't have the stamina that it would demand.

When I was still trying to work in my trade, I was unable to carry the heavy things I needed to carry. When you have a new body and you're not used to it, other people pick up on the lack of trust you feel in your physical abilities and it isn't comfortable at all.

My job was a very physically demanding one done mostly by men. When I returned to work I was not put on a lighter duty job to recoup but directly on my previous job which was very much a drain on my strength.

I was chemically induced into early menopause. The hot flashes were very hard when trying to think quickly on the spot.

The greatest psychological barrier to job re-entry was identified by 19% as “chemo brain”: poor memory and inability to focus or concentrate. Other psychological barriers included anxiety, lack of self-confidence, depression, feelings of being overwhelmed and fear.

Chemo brain is one of those side effects that no one really talks about and so you keep it to yourself and don't discuss it.

After two sets of chemotherapy, I could not retain the information as I had in the job over the past ten years and I was feeling very incompetent in a career I had loved and worked in for over a decade.

It's hard for me to concentrate for long periods – it's very tiring. I also find it hard to multitask or navigate the work environment – finding things, understanding and putting things together mentally. Everything happens so fast.

I lost confidence despite my best efforts. Being bald isn't a fashion statement in the consulting world and the chemo was debilitating.

The drugs had affected my critical thinking and multi-tasking skills, slowed down my thinking and gave me poor recall of facts. All this contributed to stress.

I was emotionally vulnerable and really afraid to go back to work feeling so afraid that I would cry. I look different now and hate the thought of wearing prosthetics, so I was sensitive to how others would view me.

I was depressed, frazzled, would go and cry desperately in private, and felt frustrated and alone. I was a wreck.

I worried extremely about my mental capacity to function at my former level and started doing puzzles and Sudoku as a way to sharpen my analytical skills.

After being off for two years, I had to be re-trained and found it hard to remember things and felt really unsure of what I was doing.

I couldn't go back to my former physical work, couldn't make a go of it at self employment (too distracted and physically incapable), so I ended up at a temporary agency.

Administrative changes made by the employer often made return to work difficult.

There was reorganization at work and all the jobs were re-evaluated according to a new salary scale. Most of the jobs like mine kept the same status, but mine was downgraded. I don't think it's because I had cancer, but because I was away during the reorganization and wasn't able to take part in the process and stand up for myself when I needed to.

There had been 100% turn-over of the supervising part of the organisation and they were unfamiliar with me when I returned to work. They stated that I needed to "prove myself" to them as though I were a new employee.

My position was changed prior to my return. I was not given any notice (my responsibilities were given to someone else) and I am now expected to work extra hours in order to assume these new responsibilities.

Gradual Return to Work

Those with a responsive employer were fortunate: survey participants reported that 43% of employers made arrangements to accommodate their needs. One of the greatest facilitators of return to work was a gradually increasing workload. 20% of respondents reported that a gradual return eased their transition back into the workforce.

Some women had a positive experience of returning to work.

My employer is the Federal government, which has a gradual return to work program. The level of support I received from the disability/return to work insurance provider and from my employer was outstanding. I feel truly fortunate.

I actually had a very flexible arrangement with my supervisor. When I felt able to work, I was able to. When I felt fatigued, I was free to return home. I was allowed to let some aspects of the job slide temporarily. As my energy levels improved, I was able to increase the number of hours and days I was able to work.

My employer was amazing and allowed me to return to work part time, set my own hours and do only what I was able to do until I was ready to work full time. He has been a tremendous support throughout the past year.

When I found a full week too much, I was able to go to a four day week with no problem from my employer. I was made to feel very much a part of my return back to work program.

Other women were less fortunate.

I was to have had a graduated return to work. However, my boss felt that since my cancer was 'gone', I should be expected to increase my hours more rapidly. No understanding of the fatigue, physical, mental and emotional healing was given.

When I returned to work they gave me a high exposure new job that required lots of learning and overtime. I totally ran out of steam. It was a horrific experience.

Some women reported that their employer worked with them to reduce the physical adjustment to work.

My work station was changed to one that was more ergonomically correct: a raise/lower keyboard tray and a raise/ lower monitor stand. I also received a cordless headset.

My employer completed an ergonomic evaluation of my computer work station and purchased a new office chair and new computer keyboard.

My employer hired extra help to do the heavy work, allowing me to do only the less demanding physical work.

I was able to lie down if I needed to rest.

It turned out that some things did flare up my lymphedema – I was then placed in an area where I didn't use the affected arm as much.

Attitudes of Employers and Co-Workers

The positive or negative attitudes of the employer and co-workers had an important effect on the ease of re-entry to work. 12% of respondents reported that negative attitudes by others were a barrier that resulted in lack of support and understanding.

Some women told us of positive experiences.

I was given a standing ovation by all of the staff the day I returned.

I was welcomed back with hugs, flowers, cheers and compliments on how well I looked. This was a great morale booster since my hair was still sparse and short and my eyelashes were nearly non-existent.

My colleagues, from the highest level to those I worked with day to day, were very supportive. A wellness officer was assigned to me and she saw her role to make sure I did not get caught up in day-to-day stress and work too many hours. In addition, my colleagues and supervisor did not demand more than I could give. Their attitude was that it was great to have me back – that I was valued. In particular the most senior person in my immediate work group was friendly and casual about my return, which set the tone for everyone else.

They were always there for me. Great moral support, wonderful assistance with meals for our family, a beautiful orchid which has been flowering every year since my surgery, transportation where necessary, cards, e-mail messages, celebrations, and fun wherever possible.

I was worried I would not be able to keep up at first, but with wonderful support from my colleagues and employer, I soon realized I was still the same person, with the same skills and strengths as before my illness. If anything, I feel I am a better employee and colleague now because my experience with cancer has increased my empathy for others.

I took all the ladies aside and pulled out my prosthesis. Q&A and then that was done – back to work, ladies!

My co-workers made sure that I was treated well by others outside of our department – especially when my hair was not coming back in. Most importantly, we got a new supervisor, and my co-workers insulated me from him. They covered for me.

Other women found the lack of support from colleagues to be difficult.

What is most difficult is the lack of understanding of others – giving you lectures on how much better you should feel and how much more you should be doing. People who knew you could put in a hard 10-hour day will not accept that six hours may be your maximum.

There are so many odd reactions to cancer. One woman told me to cut out sugar. Another told me I should eat more blueberries and mushrooms. I wanted them to just shut up. I wish they would have kept their opinions to themselves and just listen and take their cue from what I was saying about how I was dealing with it. I also remember a co-worker actually running away from me the first time I had cancer. I guess in a nutshell people need to be educated as to what it feels like to have this disease and to be more sensitive to what the person going through it wants or feels.

One puts on a brave face and just pushes on to recoup the income loss and try not to take attitudes of people to heart as some people almost behave as if breast cancer is catching.

My colleague had the “run of the place” while I was off and made my return to work extremely unpleasant when I stepped back into my position.

There was unspoken pressure exerted by supervisors and colleagues who acted sympathetic but told me it would be wise to slow down and rest. I had to realize that I didn't have the same energy level and couldn't compete with younger people at work who haven't had to deal with sickness and the punches that life throws at you. Their unkind remarks made me feel guilty about not being up to speed and giving 100% of the level I had before my diagnosis. Competition in the workplace is hard and is a huge obstacle to a satisfying return to work.

I wish there had been fewer comments about my 'new work hours' from co-workers. I came in later in the morning post-surgery and worked later into the night after everyone had gone home. This elicited negative comments from co-workers.

I was looked upon as if I somehow caused the disease and I might rapidly develop more and die. Employers are afraid you are a drain on health care and benefits.

Rehabilitation

Some respondents reported that the counselling and rehabilitation offered by their employers eased the transition back to work, although only 19% received rehabilitation (physical, psychological, or training).

I'm one of the lucky ones because we have a rehabilitation officer at work who spoke to management on my behalf. I was able to have a gradual return to work. I also received massage, physiotherapy and aqua fitness. This was all covered by my benefits plan.

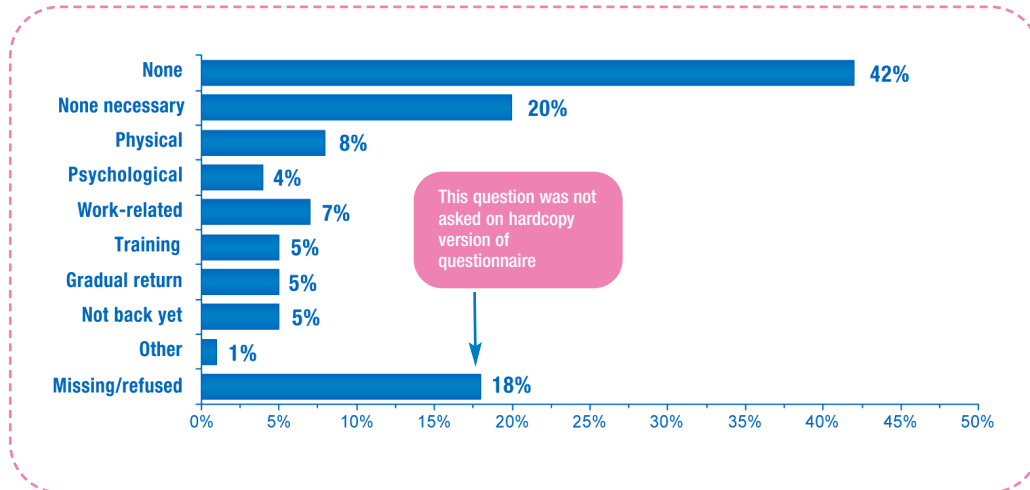
While I got good medical care for the diagnosis, the after care for the emotional hit is really almost nonexistent.

Some women wished that their employer had involved them more in planning for their return to work.

Involving me in decisions about how the job should be done would have made the return psychologically easier – and that's something that's just a good management principle at any time.

More communication would have been nice. No one asks how I am doing or how they can assist in my job.

Only 19% of respondents received any rehabilitation to ease their return to work



Challenges of Return to Self-Employment

The situation of self-employed persons deserves special mention. The 8% of respondents who were self-employed reported no change in their self-employed status after treatment, but they did report the serious impact of treatment on their work and income.

I'm a self-employed solo consultant and was managing 35 contracts when I was diagnosed. It has been a nightmare trying to meet contractual obligations by hiring subcontractors or just giving work away to competitors; after having been out of circulation for a year and having given my competitors some of my best clients, I'm afraid I will have to rebuild my practice from scratch. I expect no income for at least six months after treatment is complete. Most people (and this survey) assume that women can just shut their door and then come back to it a year later, having had salary insurance all the while: not true for the self-employed or those who run their own businesses.

Being self-employed provides me with no job security. My clients were really good and held most of my contracts open for me. However, they had to get other contractors to do my job and then when I returned, I had to share my duties with them as well. Over the last couple of years, I have recouped almost all of those duties, but one contract is gone permanently. Not exactly poor treatment, but it shows that job security does not exist for self-employed women who are diagnosed with breast cancer.

Some of my clients might have been more supportive if I had asked for more support (in terms of more flexible contracts, relaxed deadlines etc) but it is not to my competitive advantage to ask for this type of support – so I have only done this with clients I'm very comfortable with and I know they won't mind.

I got lots of emotional support from clients (or, put another way, the clients that were not supportive have elected to get these services elsewhere).

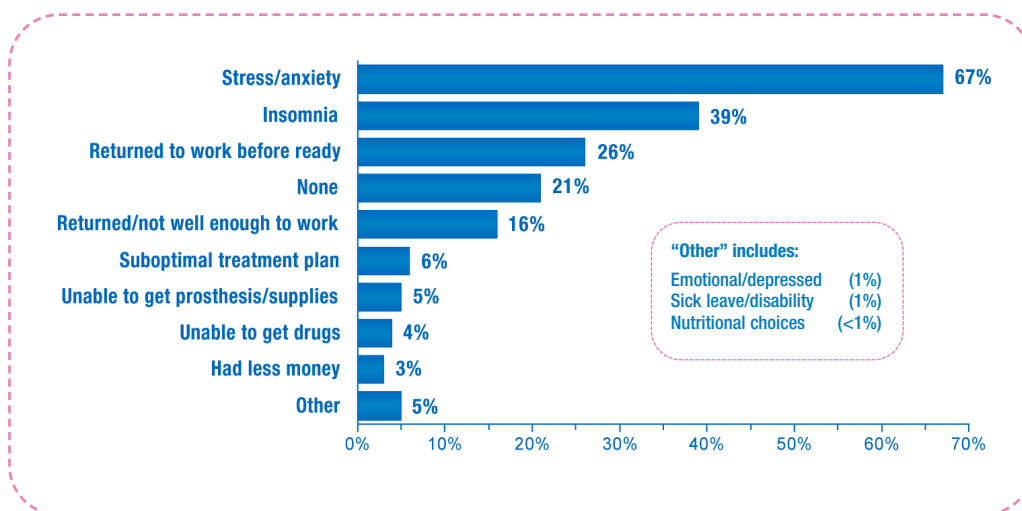
Dealing with breast cancer while being self-employed (working only from contracts) has been a very difficult situation for me. I had only a very small amount of insurance payments and so I have been under constant stress about finances since the beginning. This continues to be the case even though I am now working again, as it will take a few months before I can: (a) obtain some contracts; (b) do the work; then (c) get paid. (I get paid on deliverables, usually only at the very end of a several-month project.)

6.0 Health and Psychosocial Impact of Financial Burden

The financial costs of a breast cancer diagnosis are not the only costs incurred by women and their families. The diagnosis, treatments and financial costs contribute to psychological and social costs that can be detrimental to long-term health and well-being.

The whole question of psychosocial effects may have touched on deep feelings because 78% of respondents refused to talk about the psychological impact of the diagnosis and its impact on working. Those who did talk about the effects of quitting their job reported feeling a range of emotions from positive and “thankful to be alive” to depressed, angry, anxious, rejected and devastated. The most frequently experienced psychological effects of financial stress were anxiety (67%) and insomnia (39%).

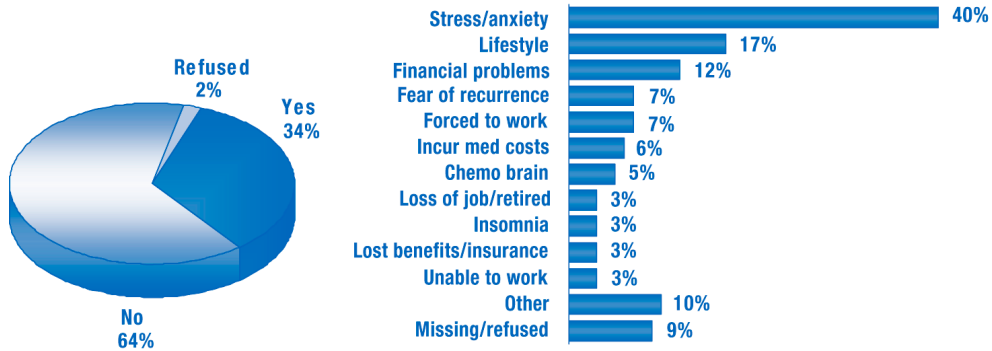
The financial burden of breast cancer led to stress/anxiety and/or insomnia for most respondents



One-third of respondents believe that the financial burden of their treatment has had or will have negative long-term effects on their health. Stress/anxiety is the main cause (40%) given for long-term effects. Less frequently mentioned reasons included change of lifestyle (17%), general financial problems (12%), fear of recurrence (7%) and being forced to work in order to survive financially (7%).

More than one-third of respondents feel the financial consequences of their breast cancer diagnosis have had or will have a long-term effect on their health

- Stress/anxiety due to the financial burden of breast cancer is the top reason for respondents feeling there are/will be long-term consequences for their health.



- More respondents who received chemotherapy (39%) and radiation (35%) believe the financial burden of the disease will have a long-term affect on their health than those who did not receive chemo (23%) or radiation (30%).

I felt I was going to have a nervous breakdown and that the stress from my job would cause a recurrence. Based on these factors I chose to quit my job and focus on stress reduction and my health.

I was told to live a 'stress-free life' but how could I do that with all the debts hanging over my head? I'm facing bankruptcy if I don't get back to work soon.

I can never make up the money we had to use to cover off the time that I did have off. We are in debt so far that I do not sleep at night and am paralyzed by fear that recurrence or metastases will make us bankrupt.

Due to the loss of income during short-term disability and having to borrow money, plus quitting my job due to not being able to handle the same stress load post-surgeries, I feel greater financial stress than before. This stress makes me worry that a recurrence will occur, adding to my anxiety.

After my first diagnosis, the biggest obstacle when I returned to work was constant fatigue. I had a hard time keeping up and always took work home at night and on weekends. What an unbalanced life. I think this contributed to my recurrence of breast cancer two and a half years later.

I did not eat well, because I could not afford to buy the best types of food, so that lead to increased fatigue, lower blood counts, more infections (colds, etc.).

A few respondents told us about the social isolation that was caused by their decline in income, leading to feelings of loneliness and depression.

The financial burden became more stressful than the cancer itself. I am still not working. I have completely lost my social life and contact with friends as I have no money to get together with them. I spend a lot of time by myself now.

Impact on Close Relationships

The financial burden of breast cancer has psychological, as well as financial, effects on close relationships and families.

Two-thirds of respondents reported that the financial impact of their diagnosis negatively affected other family members. Total household income dropped by almost 10% as a result of the diagnosis. More than half of survey respondents had at least one dependent living at home while they were undergoing treatment. The most frequently mentioned effects on families were financial burden, worry, having to reduce spending, borrowing money, taking on more work to make up the financial gap and having less money for the children's education or other needs.

There was a huge financial burden on my husband, so I felt very guilty they he had to take on extra work because I couldn't work.

I have borrowed from my family and am paying them back now. My children had to do without lots: activities, classes, Christmas, birthdays and basics.

I'm working instead of fully recovering because I don't want my illness to affect my family any further.

It will affect my teen's desire to pursue post-secondary education. We have been unable to have a family vacation for over two years. It also affected my children's ability to participate in extracurricular activities.

My son keeps asking me when I'm returning to work due to our tight budget.

Survey respondents reported little change in their marital status because of their diagnosis in answer to the multiple choice questions, but many spoke of strain or broken relationships in their written comments.

When my spouse and I separated due to the stress of the cancer I did not qualify for income assistance as I owned my own home and received child support.

Having breast cancer put an additional strain on our already strained marriage and we now are separated. Having money problems didn't help.

I separated from my husband and we were not able to re-establish our relationship afterwards – after treatment – although we did try.

My relationship with my husband was already somewhat strained before my diagnosis, although workable. He is not aware of the amount of debt I incurred during my treatment, but I feel that if he did it would have devastating effects on our marriage.

Others spoke of the financial and emotional strain on their spouses.

My husband had to work longer hours and we ended up claiming bankruptcy.

My husband had to take two extra jobs in order to pay our regular monthly household expenses as I was unable to work while going through surgery and treatments. Now he is exhausted and I worry about his health being compromised. So he's had to take many days off work for his own health.

My husband has faced so much more financial pressure being our sole income and he knows he will have to carry the burden into the future as I will not be able to contribute the way I used to.

Some women said they could have used more help at home, while others reported a beneficial effect on the family division of labour.

Getting help with preparing meals and housekeeping would have made the return to work easier.

My family help out more since I returned to work. Women usually do most of the house work and that had to change. My husband and two kids stepped up to the plate.

Almost half of respondents had a family member or friend who had to take time off work to take care of them. In most cases (76%), this was their spouse. Although most family members or friends took off less than four weeks to provide care, between 21% and 36% of close relations took off several days a week for a period of several weeks or months.

We couldn't afford to have my husband take any time off to be with me.

My husband used some of his vacation time.

My husband, who owns his own business, had to pay staff to cover for him while he was away from work. This was an extra expense for the business.

My mom, who was 81 years old, drove four hours each way to stay with me after each chemo treatment as I was so sick. That enabled my husband to go back to work and not take so much time off.

People living alone mentioned practical and emotional difficulties when they had no one to help out with finances or practical things while they were sick.

I live alone, no family support. I am frustrated as to how and who can help me and bring a peace of mind and heart to me.

Making a living is always a struggle when you are alone and trying to keep up, so I have always worked harder and longer than most people. Now I feel that work has contributed to my illness but financial worries have caused more stress. If things were easier on that front I would have had a better recovery process but I kept worrying. It's easier when you're sick if you have money to take care of things.

7.0 Treatment Type and Its Economic Impact

An important pattern was clear from the research. The type of treatment received, especially chemotherapy, had an economic impact.

Those who received chemotherapy saw a greater decline in their household income (decline of \$13,219) than those who did not receive chemotherapy (decline of \$8682). Those who received radiation had a smaller drop in income (decline of \$7265) than those who did not receive radiation (decline of \$23,932). Only 17% of those who received chemotherapy said there were no financial consequences from their diagnosis, compared to 26% who did not receive chemotherapy. There was a greater burden of travel costs for radiation, especially for rural residents, because patients had to travel farther to receive radiation.

Chemotherapy also emerged as having a bearing on time off work required and ability to return to work. Those who received chemotherapy (81%) had to take more than 16 weeks off compared to those who did not receive chemotherapy (32%). The effects of chemotherapy may play a role in whether a woman chooses to leave her job. More respondents who received chemotherapy (21%) were forced to quit their jobs compared to those who did not receive chemotherapy (14%).

“Chemo brain” was identified by 19% as resulting in difficulty in doing a job. On the positive side, the employers of those who received chemotherapy (35% of respondents) were more likely to make arrangements to accommodate their needs than the employers of those who did not receive chemotherapy (23%).

Chemotherapy affected the amount of time off taken by family members to provide care: those who received chemotherapy (52%) were more likely to have a family member take time off work to care for them than those who did not receive chemotherapy (34%).

The type of treatment influenced the belief that the financial burden of breast cancer will have a long-term effect on health: more persons who received chemotherapy (39%) and radiation (35%) believe that the financial burden of breast cancer will have a long-term effect on their health than those who did not receive chemotherapy (23%) or radiation (30%).

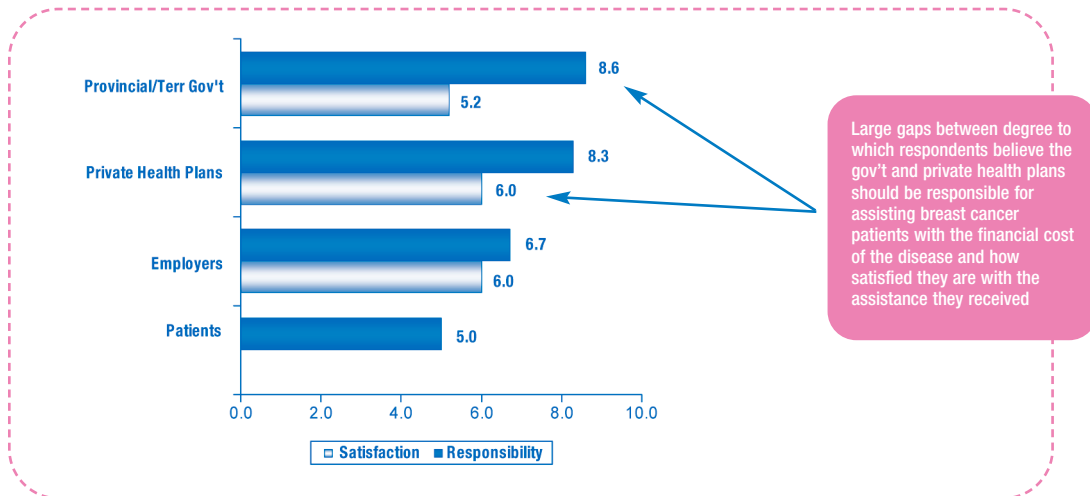
This evidence makes it clear that not all breast cancer treatments are equal in their economic impact. The greater impact of chemotherapy compared to surgery and radiation opens up the question of whether the economic and workforce re-entry needs of those undergoing chemotherapy must be met through special support programs. Certainly this question deserves further research.

8.0 Survey Respondents' Views on the Roles and Responsibilities of Governments, Insurers, Employers and Patients Themselves

Survey respondents were asked for their views on who was responsible for taking on the burden of the financial impact of breast cancer and for helping people to re-enter the work force.

Most respondents believe that governments (Federal and Provincial/Territorial) and private health plans should have the greatest responsibility for helping with the financial burden of breast cancer, followed by employers and responsibility for one's self. Their satisfaction with the assistance they received from governments and private health plans, however, was rated significantly lower.

Respondents believe that the government and private health plans should have the greatest responsibility for assisting patients with the financial burden of breast cancer



Governments

Respondents thought that provincial/territorial governments should cover the cost of all drugs and procedures (44%), offer financial compensation (27%) and reimburse patients for travel and accommodation costs. 12% thought that the Federal government should modify and extend Employment Insurance eligibility and benefits and 6% thought that greater tax benefits would help.

Considering that lots of people don't have employers, private health plans or even savings, the only common support is government. It is critical that governments support patients with a breast cancer diagnosis because there may be no one else who can do it. Breast cancer affects too many women for the government not to step up.

Federal Programs and Taxes

Respondents suggested changes in federal programs.

The Employment Insurance payments for illness are too low. Everyone should have disability insurance. This insurance could be obligatory – the same as Medicare coverage. I also think that a person's salary should be covered to a level of 75%.

Make it easier to get on EI and allow a worker to still get EI during a modified return to work program.

I think the sickness benefits on the national EI program should be extended to a year. Possibly the provincial government could assist in this area.

The process of obtaining EI sick benefits could be made a lot simpler. Worrying about waiting periods is very stressful.

EI disability should be longer than 15 weeks. That covered my recovery from surgery but only got me half way through chemo and through none of radiation.

The EI rate should be changed for those living through a critical illness diagnosis and the time frame should be extended to at least one year. 15 weeks of EI for cancer care is a joke. It takes much longer than that. I ran out of EI before I ever got to radiation treatment.

Perhaps we need a plan to cover the first three years after a cancer diagnosis for those who are in the workforce. A shortage of workers is predicted for the next few decades, so we need help instead of being left all alone, without help, thinking that we haven't the mental capacity to function in today's hyperactive society.

We need grants and support to update/increase our credentials to make them more appealing to new employers. Employers don't like taking on potentially sick people as new employees, so we (breast cancer survivors) have to be made very competitive.

Provide a financial assistance program similar to employment insurance but open to ALL patients, not only those employed “traditionally” (salaried) but also to contract workers and self-employed individuals.

If a family member is helping you financially it should not be considered “unearned income” and every penny be paid back to the government. They should allow you to receive financial help until you are able to go back to work. We are not trying to be fraudulent here. We are just trying to survive while we take care of our health.

More is needed for the working poor.

Federal/Provincial/Territorial Programs

Respondents suggested a variety of ways in which governments could help patients and their families.

For women who do not have a disability plan at work, the province needs to allow a higher level of earnings to be retained once return to work has started, instead of clawing back dollar for dollar. This just extends the negative psychological effects of being poor.

The government will have to more strongly legislate against employee termination and also assist employers with paying for employees like me while they are undergoing cancer treatments.

There should be assistance for family caregivers that have to leave work, not just job security.

[The government could] assist the employer with the costs of the employee being away. Then patients would not feel guilty to their employers.

The government should be working with smaller businesses that employ patients, to provide some funding to give patients time off.

Provide more transportation to travellers for treatment. Eliminate the taxes on short-term and long-term disability benefits, and cover medication costs. Give a cancer tax credit on the income tax, similar to the disability tax credit, for the time that the patient was unable to work.

Perhaps excuse my house taxes, reduce my income tax and reduce my utility bills – anything that will not directly cost the government in additional funds, but can assist me trying to be a single parent, pay my mortgage and bills and cope with cancer.

The overinflated price of prosthetics really annoys me. The government pays for part of it, but to purchase prosthetics that don't feel like Styrofoam coffee cups floating in my blouse, I would have to buy prosthetics valued at \$400 apiece. The gouging of retailers for medical devices is ridiculous. There should be some sort of legislation controlling these costs.

Insurance Providers

The insurance industry and private health insurance were seen as having responsibility for covering all breast cancer costs (25% of respondents), all medications (18%) and materials such as prostheses, wigs, bras and lymphedema sleeves. Respondents also noted the need for coverage of lost wages, less paperwork, more compassion on the part of insurance company staff, shorter waiting times, longer coverage and more information. Only 1% of respondents expressed satisfaction with things as they are.

My Employment Insurance cheque ended. My long-term disability cheque won't come for one month. Perhaps they could work together somehow to bridge that gap.

It took me over five months from when I started a back to work program (as I was on long-term disability) to get back to full-time hours. The biggest barrier was trying to get the long-term disability person to realize that I really was too exhausted to keep increasing my hours each week.

I still worry that the long-term disability carrier will cut me off, even though I have an oncologist wanting me to be off [work]. The LTD carrier has assigned a company that specializes in cancer return to work and they call every week or two. If I do not participate I am sure they will call this 'not participating in rehab' and will cut me off.

They should provide coverage for those with a pre-existing condition (I could not get coverage).

Incorporate the costs of cancer into the coverage they provide other than just simply covering lost wages.

Cancer treatments change constantly. Companies should update their policies on a regular basis to reflect changes in treatments. Paying into a plan that does not provide coverage when most needed is useless.

The need for emotional healing needs to be included in costs, supporting people to work and possibly collect supplement insurance throughout the illness. It shouldn't be so cut and dried.

Employers

Respondents had a variety of suggestions for employers. One-fifth thought that employers could provide a gradual return to work and lighter workloads to ease their transition back to the workplace. Other suggestions for improving return to work included guaranteed job security, better sick benefits, paid leave, more disability and extended health insurance coverage, more support and compassion and topping up Employment Insurance benefits.

Employers could add a top-up to Employment Insurance sickness benefits because they are too low.

Employers in the U.K. give you your full salary for the first year and 50% the following year(s) for any long term illness. We need to adopt a similar policy in this country.

If the patient fully intends to return to work, I think they should pay us a portion of our salary rather than having to go through all these disability insurances. We aren't disabled, we just need recovery time.

Employers should support patients and their families by providing leave to care for family members. My partner was forced to quit her job because her employer was unwilling to give her unpaid leave of more than ONE day.

I think employers should attend training and sensitivity workshops to fully understand how to communicate clearly with someone diagnosed with breast cancer.

Employers pay money to assist charities. Why don't they first assist employees of their own who are burdened with finances if they are dealing with cancer or a life-threatening disease?

A number of respondents saw a more limited role for employers.

I don't think any of the burden should be with the employer. This burden just gives MORE incentive to discriminate. Increased insurance premiums alone are an incentive to get rid of the employee. There are lots of ways to quietly get rid of an employee and get around human rights law.

I cannot say that an employer is responsible for dealing with the consequences. As a society we need to be more responsible for ourselves. We shouldn't punish a person for wanting to start a business and give people jobs.

Other than holding the job open for the employee's return, the employer shouldn't be expected to provide financial assistance.

It's not the employer's fault that the person got the diagnosis, so I don't see the employer as having to do a whole lot.

Self-Reliance

One-fifth of respondents thought that patients themselves should take responsibility by saving and being financially prepared for a crisis. Ideas included saving, being self-reliant, having health coverage and reducing expenditures.

Everyone is responsible for purchasing insurance and disability if they would be in a financial bind if a crisis hit. Insurance is extremely expensive if one cannot be part of a group plan. This is where some advocacy work needs to be done. Everyone must do some responsible financial planning in good times. It cannot be expected that government agencies take ALL our financial pain away. It's a reality of life – it will not always be good.

We are all ultimately responsible for ourselves but I do regret my pre-diagnosis attitude that I did not need health insurance or disability insurance because I was healthy and fit. Now I will never be eligible.

Self Employment

A total of 8% of respondents reported being self-employed and challenged the assumption that everyone has an employer and a job to go back to. Many of them suggested that Employment Insurance be extended to cover those who are self-employed and that the insurance industry work with them to provide suitable benefits.

For self-employed women who risk losing their businesses because of being unable to work, it would be helpful if there could be additional support. I really think that most people in government only think about women in salaried (and unionized) jobs like themselves, who have all kinds of protections, insurances and recourses and haven't a clue of what it's like to be running a business and then get sick (even though small business is the motor of the economy).

9.0 Public Awareness of These Issues

Canadians living with breast cancer have told us about the significant financial impact of breast cancer, but how aware are Canadians of this reality? A general population survey conducted by Pollara in June 2009 sheds light on this question. The online survey of Canadians aged 18 and over was completed by 3125 people. The large number of respondents allows us to generalize the results to the Canadian population.

A high proportion of Canadians believe that a breast cancer diagnosis carries a heavy financial burden. 81% believe that a diagnosis results in a moderate or major financial impact for the patient, and 75% believe it carries the same degree of impact for the patient's family. The perception of Canadians matches actual patient experience: 80% of breast cancer patients told us that they experienced a financial impact from their diagnosis.

A wider gap appears between patients' experiences of return to work and the perceptions of Canadians. Canadians underestimate the number of patients who return to their jobs: they think that 63% of patients return to their jobs, while patients report an 80% return rate. Canadians also underestimate the challenges of returning to work: 89% of patients reported barriers to labour force re-entry, but only 69% of Canadians believe that patients face barriers and only 14% believe that patients experience major difficulties.

Contrary to the experience of many patients who found they were unable to maintain their previous workload after treatment, Canadians believe that 62% of survivors are able to work the same number of hours.

Public perception matches patient experience with respect to how many employers make special arrangements to accommodate the needs of patients returning to work: Canadians believe that 43% of employers make special arrangements, which is exactly the percentage reported by patients.

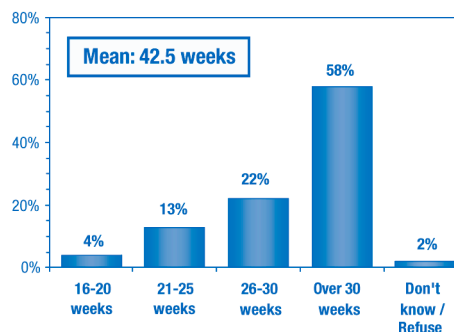
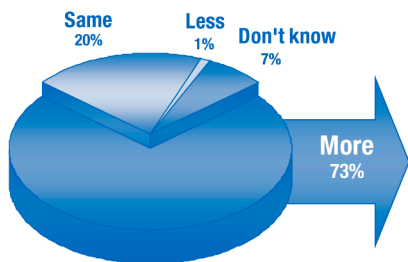
The expectations of Canadians about who should be responsible for assuming the financial burden of breast cancer are close to those of breast cancer patients. Most see primary responsibility falling on provincial/territorial governments and private health plans, followed by employers and patients themselves.

There is strong support by Canadians for increasing the duration of Employment Insurance payments to breast cancer patients. Close to 75% of Canadians support a longer period of sickness benefits for breast cancer and other cancer patients. This is higher than the degree of support for longer benefits for all persons on EI sickness benefits (42%). More than half of those who support longer payments for breast cancer patients are in favour of granting more than 30 weeks (instead of the current 15 weeks), with an average suggested time of 42.5 weeks.

Gender plays a role in the perception of economic impact: women are more likely than men to believe that a breast cancer diagnosis results in a major financial impact on patients (61% of women versus 50% of men) and their family (47% of women versus 36% of men). Men are more likely to think that former patients can work the same number of hours when they return to work after treatment (65% of men versus 60% of women), while women are more supportive than men of increased length of EI sickness benefits (78% of women versus 67% of men).

Increased EI Benefits for Breast Cancer Patients: Most Support Over 30 Weeks of Benefits

- Among the three-in-four (73%) Canadians who believe breast cancer patients should receive longer EI sickness benefits, over half (58%) support more than doubling the current 15 week period.
- Among *all* Canadians, 42% support increasing the maximum number of weeks of EI sickness benefits to over 30 weeks.
- On average, those who want to see benefit time increased suggest providing up to 42.5 weeks of EI sickness benefits.



10.0 Discussion

It is clear from our research that breast cancer is an economic, as well as a health, condition. Survey respondents told us that they often found the financial burden to be as stressful as the disease and that the financial impact was sometimes longer lasting than the disease itself.

The 446 people who participated in our patient survey speak for thousands of Canadians affected by breast cancer. Because breast cancer is the most commonly occurring form of cancer in women, the economic burden of the disease affects thousands of women, families and employers. The experiences of our survey respondents are probably shared by those affected by other commonly occurring cancers, such as colorectal and prostate cancer. We would argue that many of the experiences described in this report are likely be shared by the more than 700,000 Canadians living with all types of cancer.⁵ This makes the findings of our research important to the public, health care providers, governments, the insurance industry, employers and families.

Breast cancer death rates are now at their lowest level since 1950. Breast cancer also affects many women during the years when they are in the workforce (ages 18 – 64). This means that women experiencing breast cancer are important contributors to our economy and that many can, and want to, return to work after treatment. From an economic standpoint, it makes sense to help them re-enter the workforce and contribute to Canada's economic well-being.

People can survive breast cancer, but they may live with the economic impact for the rest of their lives. Loss of work or return to work at a lower salary can have long-term effects. Pension benefits may be lost or reduced. Debts may take years to repay. Standard of living for the patient and their family may be permanently reduced, leading to a loss of university education for their children and poverty in old age.

A number of population health studies have shown the link between income and health. Those with higher incomes enjoy better health. The stressful experiences of those who participated in our survey and the link that respondents made between financial burden and anticipated negative health outcomes show that the economic burden is experienced as a negative determinant of health. Employment and working conditions are also determinants of health.⁶ The experiences many of the respondents to our survey show that many women and their families living with breast cancer are working against at least two negative determinants of health. This has implications for public health policy.

⁵ *Canadian Cancer Statistics 2009*. Canadian Cancer Society, Statistics Canada, Provincial/Territorial Cancer Registries and Public Health Agency of Canada. Figure for prevalence of cancer is the number of Canadians living with a cancer diagnosed within the previous 10 years. The latest figure available is for 2005.

⁶ The determinants of health are income and social status, social support networks, education and literacy, employment/working conditions, social and physical environments, personal health, healthy child development, biology and genetic endowment, health services, gender and culture. Public Health Agency of Canada. <http://www.phac-aspc.gc.ca/ph-sp/determinants/index-eng.php#determinants>

Many respondents were unaware of the high cost of the disease until they began treatment. Like many Canadians, they had assumed that public health care would cover most of their costs. The economic reality came as a shock.

The big question of who is responsible for health costs is one that requires dialogue among patients, governments and the public at large. Even those respondents who stated that people should be responsible for their own costs benefit from public health coverage and some said they regretted not planning ahead for health crises. It is unrealistic to expect most patients to assume all costs not covered by their provincial/territorial health services.

In many cases, younger women are not in a position to have large savings because they have not had many years in the workforce to save and they may be spending most of their income on raising a family until they are well into middle age. The cost of living and the need for two incomes to raise and educate a family today make it impossible for most Canadians to have savings adequate to pay for potentially thousands of dollars of drugs and supplies each month, or to live without income during the average of 38 weeks of treatment and the later gradual re-entry period to work. Most of us need public or private health and income coverage in times of crisis.

Public health coverage, Employment Insurance, Canada Pension Plan disability benefits and welfare are public plans intended to help Canadians get through times of disease and disability. As our respondents told us, however, these plans are not enough to prevent severe economic hardship when dealing with cancer. We need to begin by recognizing that breast cancer and other diseases have economic, as well as health, impacts. Because breast and other cancers affect so many patients and families, they have a profound economic and social impact on our country. We need a national dialogue that recognizes that this disease affects more than our health; it affects companies, governments, families and the economy. It can affect all of us.

Many respondents were forced for financial reasons to choose sub-optimal treatments or do without important medications and supplies such as prosthetics. This indicates that:

- Canadians need to be made more aware of what is covered by public health plans and what is not
- Ways must be found to extend public health coverage for important drugs and supplies
- The national dialogue about pharmacare and equity of access regardless of where Canadians live needs to result in concrete action

Salary replacement during treatment and gradual return to work emerged as a widespread concern from our research. The average duration of treatment is 38 weeks, and yet Employment Insurance benefits last for only 15 weeks. This leaves an average of 23 weeks with no income replacement for those without long-term disability insurance, which is the case for many Canadians. In addition, EI benefits amount to 55% of salary, a level that many women found inadequate, forcing them to go into debt or return to work before they were recovered from treatment. Future reviews of EI conducted by the Government of Canada need to take this information into account so that illness benefits can be extended. Our general population survey shows that Canadians support such an extension.

Special provisions for extended leave for family caregivers also deserve attention, possibly through extending Employment Insurance Compassionate Care Benefits beyond end-of-life care.

The shortcomings of private insurance which were identified by survey respondents included a lack of understanding and compassion on the part of insurers. This indicates a need to raise the awareness of insurers about the effects of breast cancer treatments and the length of time needed to recover. The technical problems of transitioning from Employment Insurance to long-term disability payments and income tax deductions could also benefit from dialogue with insurers. The need to have a gradual withdrawal from long-term disability payments as women gradually return to work should also be discussed. Finally, the level of payments, which women often mentioned as being inadequate at 75% of salary, should be a subject of discussion among insurance companies, employers and breast cancer survivors.

Our research reveals that the practices of employers vary greatly with respect to helping workers through their period of treatment and return to work. Some respondents had positive experiences, while many others found their jobs eliminated or downgraded and encountered lack of understanding of the need for a gradual return to work. Respondents working for small businesses appeared to have more problems than those working for large employers with comprehensive group coverage and human resources practices. This indicates the need for special attention to the situation of small businesses. The experience of the 43% of employers who did make accommodations to ease return to work could be gathered and shared with other employers as positive examples. The attitudes of colleagues in the workplace made the return to work difficult for some respondents, indicating a need to develop workplace education and awareness programs about breast cancer and its impact.

The situation of those who are self-employed is more precarious than for those with jobs and benefits. The possibility of extending Employment Insurance benefits to the self-employed and developing group insurance plans for long-term disability and extended health coverage need to be investigated. A similar situation exists for homemakers.

Lymphedema emerged from our research as a challenge to those returning to work. In many cases, no therapy was offered by the health care system to help women deal with this condition. This indicates the need for recognition of lymphedema as a consequence of breast cancer treatment and for appropriate publicly funded treatment, therapy and help with adjusting to working conditions. The availability of no-cost or affordable compression sleeves and gloves also needs to be improved.

Important new evidence emerged from our research about the great impact of chemotherapy on economic burden and return to work. Chemotherapy was linked to the greatest drop in household income, being more likely to quit a job, taking more than 16 weeks off work, decreased mental ability and greater amount of time taken off work by family members providing care. This evidence shows that special attention must be focused on counteracting the effects of chemotherapy through drug and other therapies which are affordable for patients. It also indicates that the return to work after chemotherapy needs dialogue and accommodation between the employer and the worker.

Our research shows that not much has changed since our 2004 study. The same problems recurred in our 2009 study: travel costs; childcare; financial access to treatment; dealing with lymphedema; impact on jobs and return to work; impact on families;

and inadequate Employment Insurance coverage. The more complete and updated information from our 2009 research gives us a deeper understanding of the devastating financial impact effect of breast cancer and leads to a call for action.

The political and social climate may be favourable to change. Our general population survey shows that Canadians realize that a breast cancer diagnosis results in financial burden and that close to 75% of Canadians support a longer period of Employment Insurance sickness benefits (an average of 42.5 weeks, or almost three times the present length of benefits) for persons living with breast and other cancers. The time is ripe for action.

11.0 Recommendations

The Canadian Breast Cancer Network recommends the following action plan for CBCN and its partners.

Governments

At the Federal Level:

- Engage Members of Parliament and government officials in dialogue involving breast cancer and other disease-specific organizations to review Employment Insurance eligibility requirements, income replacement levels, and weeks of payment to better reflect the reality of treatment and work force re-entry. Public opinion will likely support a longer period of benefits for breast and other cancer patients.
- Advocate for extension of the Employment Insurance Compassionate Care Benefit to cover family caregivers providing care for those with breast cancer and other long-term conditions.
- Work with government officials to raise the awareness of Employment Insurance agents (Service Canada) about the realities of breast cancer and its health and economic impact. This could help staff to be more sensitive and realistic in dealing with Employment Insurance sickness claimants.
- Encourage the Federal government to continue dialogue with the provinces and territories to develop extended drug coverage to cover all treatments, including those for efficacy and side-effects of chemotherapy. Advocate for the same coverage for all patients regardless of where they live in Canada.
- Continue to participate in advocacy for a National Pharmacare Program.
- Encourage the Federal government to dialogue with the insurance industry, employers and employees about ways of ensuring that all working Canadians are eligible for long-term disability and extended health coverage. Improve the availability of group insurance for small companies and the self-employed by encouraging the creation of associations of small businesses and self-employed persons.

- Encourage the Federal government to raise the awareness of Canadians about the full economic cost of breast cancer and other cancers as an economic issue as well as a health issue. Engage the Federal government (e.g. Industry Canada, Health Canada and the Public Health Agency of Canada), policy organizations (e.g. Conference Board of Canada, Canadian Council on Social Development, Public Policy Forum) and foundations (e.g. McConnell Family Foundation) to frame breast cancer and other diseases as economic and psychosocial, as well as health, issues. This will contribute to realistic ways of seeing the full economic and social cost of breast cancer and other diseases and developing innovative ways to reduce their negative effects. It will also frame the economic and psychosocial impact of the disease as a population health policy issue

At the Provincial/Territorial Level:

- Encourage Provincial/Territorial governments to continue involvement in discussions with the Federal government about a national pharmacare program to provide full and equitable coverage to all Canadians
- Advocate for full coverage of all drugs and medical equipment needed for breast cancer treatment
- Advocate for coverage of travel expenses required for treatment
- Advocate for help with child care and its expenses
- Advocate for recognition of the high toll taken by chemotherapy and the need for coverage for all treatments and medications to counteract side-effects
- Advocate for recognition of the long-term challenges created by lymphedema and the need for therapy and supplies such as compression sleeves and gloves

Insurance Industry

- Dialogue with the insurance industry (e.g. Canadian Life and Health Insurance Association) to address issues related to long-term disability and extended health benefits. Include the need for education about the realities of breast cancer treatment and recovery and sensitivity training for insurance staff who deal with patients

Employers

- Dialogue with large employers who employ women (perhaps choose a large corporation such as the Royal Bank – RBC) about coverage and ways of re-integrating women after treatment. Large corporations can act as models for other corporations

- Identify employers among those who did provide accommodation for employees returning to work in order to learn what was done and how this experience could be shared as a positive example with other employers
- Dialogue with small business associations about these issues. Small businesses are least likely to have adequate benefits and coverage for their employees – how can they work together to improve this situation?
- Dialogue with human resources professional associations to make them aware of the financial burden and challenges of re-entry to work and the need to develop ways to improve the situation
- Develop workplace education and awareness programs to make employers and co-workers aware of the reality of breast cancer treatment and its impact on their affected colleagues
- Find ways of reaching self-employed women to work with them on these issues, through business and professional women's associations and other partners

Labour Unions and Professional Associations

Labour unions and professional associations represent many in the work force and would understand the economic impact of a disease and the need to develop better income protection and re-integration into the work force. Many survey respondents mentioned that their unions were helpful in negotiating benefits for them.

- Work with labour unions and professional associations to raise awareness of the health and economic issues of breast cancer, especially concerning extended health and long-term disability coverage, workplace accommodation of people returning to work, and more understanding on the part of colleagues

Partners

Many of the issues identified in our research are of interest to potential partners. Partnerships advance advocacy and deepen its reach and impact. Potential partners include:

- Health care providers (e.g. Canadian Medical Association; Canadian Nurses Association). Joint initiatives could include:
 - Awareness of the economic and psychosocial impact of breast cancer
 - Chemotherapy: greater awareness of the impact of side effects and developing ways of reducing impacts
 - Lymphedema: recognizing it as a condition requiring better treatment and rehabilitation
- Other cancer organizations, because the issues of economic impact and work force re-entry are probably experienced by many others living with all forms of cancer. Dialogue with organizations to expand the understanding of cancer as an

economic, as well as a health, condition. Work with them on advocacy efforts (e.g. the current Employment Insurance review) and awareness-raising with the public

- Other chronic disease organizations, which would share many of the challenges associated with economic impact of disease
- Women's groups, including business and professional women's groups, status of women organizations, women's health bureaus, etc., because breast cancer is largely a women's issue

The Public

- Raise public awareness of the complete cost of breast cancer and its economic impact so that people are aware of the facts and become more understanding about the impact that hits individuals and families, which could impact them if they or a close relation receive a diagnosis of breast or other cancer. Some attention could be directed to raising the awareness of men, who are less aware than women of the financial impact of breast cancer, the need for workplace accommodation and longer EI benefits

Researchers

As with most studies, our research answered questions and also opened up new questions for further research. Avenues for more research could include:

- Identifying and counteracting the impact of chemotherapy side-effects with affordable approaches
- Lymphedema
- Health economics:
 - Further investigation of economic impacts; research on ways to lessen economic burden and ease workforce re-entry
 - Innovative ways to provide extended health coverage, especially for small businesses and the self-employed
- Psychosocial research:
 - In-depth studies of the health effects of financial and work stress and the probability of recurrence of breast cancer
 - Studies of workplace programs to help patients return to work and co-workers deal with adjustments



12.0 Conclusion

The women and men who participated in our research had moving experiences to share and strong motivation to share them, indicated by the unusually high response to the patient survey and follow-up questions. Respondents provided information in order to tell us what is happening and to help others. The information makes it clear that breast cancer has a strong economic impact and creates challenges for those re-entering the workforce. This is a concern for all Canadians. The general population survey indicates that Canadians will be receptive to measures to ease the financial burden of the disease.

A diagnosis of breast cancer should be the beginning of a healing journey, not a descent into poverty and despair. The Canadian Breast Cancer Network and its partners will work for change to reduce and eliminate the negative impacts experienced by survey participants and thousands of other Canadians who have been, and will be, diagnosed with breast cancer.

