CANADIAN **PARTNERSHIP** AGAINST **CANCER**
PARTENARIAT CANADIEN CONTRE LE **CANCER**

Cancer Journey Advisory Group

Return to Work Concerns Faced by People Dealing with Cancer and Caregivers

Literature Review and Consultation

April 2012

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Table of Contents

Executive Summary

The National Survivorship Working Group of the Cancer Journey Advisory of the Canadian Partnership Against Cancer (the Partnership) requested that a literature review and consultations be conducted to determine current Canadian information regarding challenges that people dealing with cancer and their caregivers face when the person with cancer returns to the workplace (as an employee or self-employed) during or after treatment. Up until now the work–life experience for people with cancer and caregivers has been inadequately addressed in Canada. This current project focuses on the survivorship issue of returning to work from the perspective of those most affected by a cancer diagnosis.

This consultation occurred in three iterative phases:

Phase I: Conduct a literature review and interviews to identify, review and assess available information in Canada concerning return to work (RTW) issues for people living with cancer and caregivers to inform the development of a national online survey and focus group protocol.

All Phase I activities were implemented. The recommendations to inform the development of a national online survey and a focus group protocol included that we inquire about relevant demographic information; the health of the individual with cancer (general health and any side effects); work-related information, including whether or not they needed to leave work for cancer treatment (and if so, for how long); and, once back at work, what support/workplace accommodations they received and any recommendations they would suggest. The literature also encouraged that we inquire about the work experience of caregivers, and ask what resources they accessed, what was missing and what they would recommend.

Phase II: Create and distribute a national online survey of people living with cancer and caregivers to identify return to work challenges. Participants were at least 18 years of age, were diagnosed with cancer in the previous 5 years or had been an informal caregiver for someone diagnosed in the previous 5 years, and were working at the time of their diagnosis or caregiving experience.

All Phase II activities were implemented. Four hundred and seventy online surveys were completed (n = 410 individuals with cancer and n = 60 caregivers). We conducted descriptive and bivariate analyses of the data. Of the individuals with cancer who participated, 77% were female, 93% were 25 to 64 years of age at the time of diagnosis and 63% were from Ontario. The individuals with cancer most often had breast cancer, followed next by those who had colorectal cancer. Of the caregivers, 88% were female, 93% were 25 to 64 years of age and 44% were from Ontario. Caregivers had most likely cared for someone with a diagnosis of colorectal cancer.

Phase III: Design, implement and report the results of focus groups in selected locations across Canada to validate and further expand upon survey findings.

All Phase III activities were implemented. Two focus groups were conducted with 16 individuals with cancer (9 women and 7 men) from Montreal, Winnipeg and Vancouver. Focus group participants were working age, most had more than a high school education, most had received chemotherapy and, after treatment, the majority returned to the same work with the same employer.

Assessment Across Phases II and III

Individuals with Cancer

The survey and focus group participants, who were well-educated workers, were typically employed in non-manual work and communicated a wide variety of RTW experiences. Some stayed at work during cancer diagnosis and treatment, some left work during those time periods and, if they left work, they talked about the process of returning back to work. Their cancer diagnosis and treatment affected their work experience in terms of their financial wellbeing, their interaction with their employer and the impact of their health on their work. For the most part, individuals with cancer were well supported by their employers. However, the participants with whom we consulted also talked about the conditions under which returning to work was particularly problematic: a decrease in their income, difficult experiences interacting with their employer and coworkers, and returning to work with deleterious side effects that interfered with doing their work.

Income and Income Supports

- In the 12 months following diagnosis, 60% of survey respondents reported a decrease in their income. Those who continued to work through their cancer treatment or who needed to return to work early cited financial need as the reason.
- During treatment, over three-quarters of the survey participants derived their income from income supports: short-term disability (STD), long-term disability (LTD) and Employment Insurance (EI). The process of receiving disability insurance and EI can be difficult because of waiting periods or gaps in time between applying and receiving benefits. Furthermore, some participants indicated that the period that EI covers was not sufficient for lengthy ongoing cancer treatment.

Interaction with Work/Employer

- Of the survey respondents, 40% left work for more than 6 months to undergo treatment. Some respondents (50%) returned to work gradually; others (18%) returned immediately to full-time work.
- Nearly three-quarters of the survey participants reported returning to work for the same employer, 8% had employment with a different employer and 9% were self-employed.

- Once they returned to work, participants who worked for large organizations (over 500 employees) were more likely to receive workplace accommodations such as working from home or having paid time off for medical appointments than were those in smaller organizations.
- Most focus group participants reported telling their employer about their diagnosis, although some did not. Disclosing their diagnosis negatively affected a few employees.
- Individuals with cancer who returned to work reported work changes such as working less, reducing workload, reducing stress at work by commuting less, better work–life boundaries or changing perspective on work to have it mean less than it did prior to diagnosis.

Health Affecting Work

- A large majority of survey and focus group participants reported that their main work-related issue was experiencing side effects following treatment and while at work — particularly fatigue and loss of energy, as well as cognitive problems — and difficulties trying to manage these issues. Those who experienced deleterious side effects were more likely to report that:
  - they could not work the same way that they did before diagnosis;
  - they were no longer able to work full time;
  - they needed flexible scheduling of work hours, a gradual increase in work schedule and workload, and reduced hours;
  - they needed paid time off for medical appointments, and emotional support from coworkers and their supervisor/employer, and also wanted their employers to understand how side effects negatively affected their work performance.

Caregivers

Overall, the survey participants, primarily women who were well-educated and non-manual employees, communicated similar experiences of caring for an immediate family member or close friend who was more likely to be diagnosed at a later stage of cancer and who was most likely to have received chemotherapy.

Caregiving Role

- Over 40% of caregivers who responded fulfilled this role for over 6 months and the type of care they were mainly providing (other than emotional support) included tasks that required their physical presence and time away from their place of employment (transportation, help with activities of daily living, home management).
- Caregivers reported that they experienced stress and not only needed time off to provide care for others, but also time away from work to take care of themselves.

Caregiving and Work

- Of respondents, 15% reported leaving full-time work, though the majority retained their positions over time. However, 90% reported missing some work and experienced a decrease in income. Caregivers did not leave work if they could not afford to or did not receive their employer's support (63% did not receive support to leave or to work flexibly). To leave work, caregivers used sick days, adopted a flexible schedule or reduced their hours.
- The main work-related issues were loss of concentration and productivity, stress and lack of support from colleagues, which, respondents believed, would have helped to ease the situation.

Limitations

Since this project was not intended to be statistically representative of the cancer population in Canada but designed to provide information for program design, we relied on convenience sampling through the Partnership's relationships with cancer-related community-based and national organizations. Our findings were influenced by this recruitment strategy in the following ways:

- Of survey respondents, 60% reported that they heard about the survey from a community-based cancer support organization, which could be responsible for the bias in participation from those who are well-resourced, well-educated, female, breast cancer survivors from Ontario. Since 46% of the survey respondents had breast cancer, we could not perform any meaningful bivariate analyses by cancer type.
- There is also a bias in this respondent sample regarding education and labour type. Most respondents had more than high school education and were non-manual labourers.

Recommendations

The following recommendations focus on resources, partnerships, advocacy and future research. We recommend that consultation with all stakeholders occur to consider the most meaningful resources to create, offer and distribute. RTW resources should focus on both those who leave work and those who stay at work. RTW content must be created to be delivered across the cancer trajectory.

Resources

Overall, the findings of the research have led us to suggest the following resources be created and offered to individuals with cancer or caregivers:

- Create a website or an information pamphlet about income supports.
- Create awareness about critical illness and/or disability insurance for the self-employed.

- Create workplace accommodation information for employers in small companies.
- Develop information about the possible side effects individuals might experience that could affect their work and direct them to existing rehabilitation programs.
- Create rehabilitation programs and/or resources (web-based or in-person) to address concerns about side effects.
- Enlist a working group of individuals with cancer, insurance representatives, employers and cancer care professionals to create resources for all stakeholders about workplace accommodations and side effects for individuals with cancer to assist with the development of resources.
- Create workplace accommodation information for employers of caregivers.

Partnerships and Advocacy

Partnerships should be developed with organizations interested in improving 1) the eligibility criteria and length of EI benefits and 2) the eligibility criteria and length of Compassionate Care benefit. These partnerships should begin to strategize about how to effect policy change.

Future Research

We recommend that future consultation research be implemented with participants recruited through cancer centres, and that those who have only a high school education or less be recruited to participate.

Phase I: Literature Review and Key Informant Interviews

Introduction

Nitkin, Parkinson and Schultz (2011) produced a report for the Canadian Association of Psychosocial Oncology to “gain a broad understanding of the work–life experience, services and needs of persons with cancer in Canada in order to discuss the implications for clinical practice, policy and research” (p. 5). Until now the issue of cancer and work has been inadequately addressed in Canada (though the Partnership’s Cancer Journey Advisory Group has identified RTW as a concern for those with cancer and their caregivers, as evidenced in several resources and publications[1]). This issue is critically important because nearly half of all individuals with cancer are of working age, and the majority of survivors return to work a year following diagnosis (Spelten et al., 2002). Nitkin et al. point out that, while many individuals with cancer return to

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[1] A Pan-Canadian Clinical Practice Guideline: Assessment of Psychosocial Health Care Needs of the Adult Cancer Patient (2009); Supportive Cancer Care Programs (2009); Environmental Scan of Cancer Survivorship in Canada (2008); National Invitational Workshop: Towards an Agenda for Cancer Survivorship (2008); National Psychosocial Oncology Education Framework (2007).

work, few studies have sought to understand their experience of returning. Additionally, psychosocial research into the impact and experience of RTW interventions from the perspective of individuals with cancer is also lacking. The following outlines what the Nitkin et al. (2011) review of the RTW research revealed.

- Individuals with cancer in Europe and the United States are more likely to be unemployed than are healthy individuals.

RTW Barriers

- Of the women with breast cancer, 16% reported having had their jobs terminated and 20% needed to quit their jobs due to work restrictions, side effects or treatment difficulties. An additional 12% could not return to their same job or salary because of medical concerns and reorganized workplace issues.
- RTW barriers were associated with physical or cognitive tasks that survivors could no longer complete due to side effects and long-term effects of treatment (such as fatigue), and also included an unsupportive work environment, job termination, demotion, perceived employer discrimination and layoffs.

RTW Facilitators

- Individuals with cancer who more successfully negotiate return to work cite work accommodations provided by their employers such as flexible work hours and duties, supportive colleagues, paid time for medical appointments and a gradual RTW schedule.
- Individuals with cancer want to return to work because of financial need and access to health insurance, and they “consider work to be healthy activity that offers structure, purpose, social support, distraction, sense of identity and signifies ‘getting back to normal’” (p.9).

This current literature review and consultation builds from the literature reviewed above by Nitkin et al. and informs the development of an online survey and draft focus group protocol for Phases II and III of this project.

Literature Review

A review of the academic RTW literature about challenges for people who have been diagnosed with cancer and caregivers was undertaken between June and July 2011. A number of searches were conducted using the electronic databases PubMed/Medline, EMBASE, PsycINFO and CINAHL. A targeted hand search of the *Journal of Cancer Survivorship* was also conducted but revealed no resources that were not already included. Given the limited number of Canadian resources about RTW, survivorship reports from the United States, the United Kingdom, Norway, Finland, the Netherlands, Germany and Australia were examined.

Limits relevant to each search are outlined below, but we included studies published from January 2000 to present (with the exception of search #1), written in English and regarding adults (18+ years).[2] In total we conducted the following five searches (for the full literature review strategy, including all search terms, see Appendix A):

1. RTW articles published in Canada from January 1, 2009, until the time of the search (June/July 2011).
2. International RTW sources between January 1, 2000, and the time of the search.

Note: Searches 1 and 2 were combined because of the dearth of Canadian articles.

3. RTW articles about the caregiver experience published in Canada between January 1, 2000, and the time of the search.
4. RTW articles about the caregiver experience published internationally between January 1, 2000, and the time of the search.

Note: Searches 3 and 4 were combined because of the dearth of Canadian articles.

5. Review articles about HIV and mental health and RTW published in Canada between January 1, 2000, and the time of the search. The search was expanded beyond Canada because of the lack of Canadian articles.

The review did not assess the quality of articles but rather their relevance to RTW challenges as experienced by individuals with cancer and caregivers. Regarding individuals with cancer, a total of 61 articles remained from a literature search that garnered 283 articles (duplicates and irrelevant articles were removed). Regarding caregivers of individuals with cancer and chronic disease, 34 articles remained of 515. For the literature search concerning mental health and HIV, 16 articles remained after duplicates and irrelevant articles were removed. Highlights are summarized below. See the end of the Phase I section for a summary of all recommendations derived from the literature review. Please also review Appendix B for specific literature review findings.

Themes

To categorize the issues found within the research articles concerning the RTW challenges faced by individuals with cancer, caregivers and individuals with HIV or mental health issues, we use the following themes:

- General Information
- Barriers
- Facilitators
- Recommendations

[2] The focus of this literature review was not interventions, programs and policies, and the review did not include articles that focus on employer perspectives or RTW for individuals who had childhood cancers.

Since the literature review was conducted to inform the development of the online survey and focus group protocol, only the highlights of the literature review will be presented here.

Findings

Individuals with Cancer and RTW

Most of the RTW literature about individuals with cancer focused on the length of, and reasons for, time away from work, demographics associated with stopping and returning to work, the type of cancer and return to work issues, and the barriers faced by those leaving, contemplating returning or having returned to work. Less often did the literature focus on what made it easier for individuals with cancer to return to work.

General Information

- RTW issues are relevant for almost 60% of survivors.
- Females are less likely to return to work than males.
- Older adults (50-60 years) or ethnic minorities or those with a vocational education are most at risk for unemployment or work changes following cancer diagnosis and treatment.
- Changes to work following a cancer diagnosis and treatment are more common for those who are self-employed.
- Two-thirds of individuals with cancer return to work; one-third do not.
- The less serious the type of cancer (i.e., thyroid vs. lung) or the cancer treatment (surgery only vs. surgery, chemotherapy, radiation), the more likely the individual is able to stay at work or return to work more quickly.
- Among the leading cancers for men and women (prostate or breast, lung and colorectal) (Medicinenet.com, 2011), those with breast, lung and colorectal cancer are more likely to leave work for longer periods of time or stop working altogether.
- Most individuals with cancer leave work 6 months after diagnosis and return 12 to 18 months after diagnosis. The mean duration of absence across cancers is slightly less than 6 months.
- A sizable minority of survivors quit their jobs because of the cancer or cancer treatment, take early retirement and are at risk of unemployment or re-employment.

RTW Barriers

- Being off work for cancer treatment erodes confidence and increases one's sense of vulnerability.
- A substantial number of women with breast cancer encounter physical and then cognitive disability in the year and a half following treatment. Substantially fewer men with prostate cancer report the same.

- Symptoms and side effects, including physical impairments, cause loss in worker productivity for individuals returning to work following cancer treatment.
- Particularly concerning side effects preventing or making return to work difficult for those survivors with the more common cancers include physical impairment, cognitive impairment (including concentration and memory), fatigue, emotional distress (depression and/or anxiety), hot flashes, lymphedema and incontinence.
- Individuals who are at work after cancer have greater physical ability than those who do not return to work.
- Work ability at 6 months predicts ability at 18 months.
- Having had chemotherapy, being at an advanced stage or dealing with blood cancers lowers work ability.
- Men treated for prostate cancer return to the work ability of their non-cancer peers whereas women with breast cancer have decreased work ability compared to both their non-cancer peers and men with prostate cancer.
- Those who have lower work ability and who have physically or psychologically demanding jobs are more likely to encounter work changes.
- Survivors encounter communication challenges about RTW issues.
- Unsupportive work settings can negatively affect physical health and quality of life and decisions about returning to or staying at work.
- Some survivors experience job discrimination.
- Having private health insurance is associated with returning to work.
- Financial challenges and loss of health insurance are aspects of returning to work for cancer survivors.

RTW Facilitators

- Work changes can be socially enhancing.
- Survivors are finding ways to experience less stressful work.
- Those who return to work are physically more able than those who do not.
- Accommodation, flexibility in scheduling, support from employers and colleagues, and services like retraining or counselling assist the return to work.
- Working during treatment can feel very meaningful for some survivors.

RTW Recommendations

- Offer rehabilitation programs.
- Offer legal, on the job and rehab services tailored to unique needs.
- Cancer care professionals should directly assist with RTW by screening or helping with work-related physical and mental limitations.

- Health professionals need to prepare individuals with cancer for the possibility that they will need time off of work.
- Increase communication between all RTW stakeholders.
- Stakeholders need evidence-based guidance to know how to intervene concerning especially salient issues like dealing with side effects or RTW issues for marginalized communities of men and women.

Caregivers of Individuals with Cancer and Chronic Disease and RTW

The literature search did not identify many published articles that were specifically focused on work-related issues from the perspective of informal caregivers of individuals with cancer or how caregiver burden affected work or employment over the course of the illness. The caregiver literature focused primarily on the quality of care provided, training and skills needed, caregiver burden (often focusing on anxiety and depression) and promoting caregiver's emotional and physical wellbeing. This literature was also often within the context of providing care at the palliative and end-of-life stages of care. The caregiver literature identified factors that influence or predict caregiver distress and documented the range of unmet caregiver needs, some of which were work or finance-related.

General Information

- Caregivers are more likely to take time off work if the patient needs chemotherapy or has advanced cancer.

RTW Barriers

- Caregivers who are working have much higher unmet needs (especially financial need, job interruption or stopping work, or multiple role strain) and higher stress.
- Caregivers of persons with cancer experienced greater impact on their normal activities of daily living.
- Caregivers with inflexible job schedules experience greater stress.
- Caregiver burden increased and mental health decreased as the patient's functional status decreased.

RTW Facilitators

- Employed caregivers have better mental health if patient's functional status is healthier.
- Most employers are flexible and offer support when caregiver informs them about cancer diagnosis of loved one.
- More employer flexibility results in less perceived stress.

RTW Recommendations

- Flexible work arrangements are needed for caregivers.
- Information, mental health programs and the provision of helpful skills are needed for caregivers.

Mental Health and HIV and RTW

- Individuals are mentally healthier when they are employed.
- Depression is the most common mental health issue affecting employment.
- Of those who leave work for mental health reasons, 50% to 75% return to work within 6 months.
- It is unknown which risk factors related to mental health issues affect job absence or loss.
- Mental illness is more likely if the individual is single, has a lower level of education or is addicted to a substance (smoking, drugs or alcohol, food).
- Workplace factors that can create or exacerbate mental illness include stress, low job grade, threats to unemployment, workplace injury.
- Providing information about job search or counselling is helpful.
- Survivors of mental health issues benefit from employer and colleague support.
- Directly responsible supervisors and their communication with relevant professionals can facilitate RTW.
- Those with HIV who stop work do not return to work.
- Fear of disclosing HIV status and workplace discrimination are two major concerns for people diagnosed with HIV.
- HIV treatments have side effects that interfere with work.
- Referrals to mental health services assist people with HIV/AIDS (PHAs) to return to work.

Interview with Individuals with Cancer and Caregivers

The second part of Phase I was interviews conducted with people living with cancer and caregivers to inform, along with the literature review, the development of a draft online survey and focus group protocol.[3] See the end of the Phase I section for a summary of all recommendations derived from these interviews.

Methods

Individuals who were recruited to participate were at least 18 years of age, had been diagnosed with cancer in the previous 5 years or were a caregiver of someone who had been diagnosed in the previous 5 years, and were knowledgeable about return to work issues either as an individual with cancer or as a caregiver.

The Partnership recruited participants with the assistance of partners across Canada, including Ovarian Cancer Canada, Young Adult Cancer Canada, Laval University, CancerCare Manitoba, Hope & Cope, British Columbia Cancer Agency and Canadian Cancer Action Network. In an email, potential participants received a description of the study and its purpose, were provided the consent forms (see Appendix C) and were encouraged to contact the research team by email if they were interested in being considered for the study. Written consent was received from all participants.

Eight participants (one caregiver and seven individuals with cancer) contacted the researchers; all met the eligibility criteria. All interviews were conducted by telephone, digitally recorded and transcribed verbatim. Seven interviews were conducted in English and one in French. Interview questions focused on relevant demographics; the participant's past and current employment status and income support;[4] their experience with cancer; their experience of leaving, returning and being back at work (and if they didn't leave, their experience continuing to work through treatment); workplace accommodations; returning to original capacity; gaps in services and resources; and what resources they could have used (see interview guides in Appendix C).

Any identifying information (e.g., names of individuals) was removed during the transcription process to ensure confidentiality. All participants received a $50 gift card as an honorarium.

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[3] Parts 1B, 2 and 3 of this project received Institutional Review Board approval from Institutional Review Board Services.

[4] "Income supports are those non-employment-based financial benefits provided by government and private insurance and pension programs. Persons with disabilities can receive income support from a number of different sources, including the Canada Pension Plan, private disability insurance, workers compensation and provincial income assistance programs."

(Retrieved 01/12/12: http://www.gov.mb.ca/dio/citizenship/challenge.html#inc)

Analysis

These interviews were analyzed using the qualitative description of phenomenon proposed by Sandelowski (2000) and were coded using a QSR NVivo 7.0 qualitative software package. The transcript data were reviewed by the research team and grouped into overall themes and subthemes using a priori data (gathered from the literature review) and other themes emerged. Please see Appendix D for the characteristics of the interview participants and see Appendix E for the list of themes, detailed findings and illustrative quotes. The highlights of these interviews are summarized below.

Findings

- Individuals with cancer do not know in advance what they will need from their employers regarding leaving work or when they will feel ready to return to work.
- Because the work/cancer treatment trajectory is so changeable, the best way to navigate this path is to acknowledge its uncertain course and for employers to offer flexible, supportive work arrangements, and health professionals to allow patients to be autonomous in their decision-making about when to return to work.
- Some participants noted that a recommendation that an individual take a prescribed amount of time off work to undergo the treatment and then recover from it, as is done for heart surgery patients, would be very helpful.
- Survivors find RTW information and information about side effects lacking within the health care system, which is, by in large, where they expect to find it.
- Many people with cancer try to work while in treatment and this can offer them meaning, purpose and a sense of normalcy. Some also say that they have no financial choice.
- Employer flexibility and support regarding time away from work for caregiving employees is also desired.

Recommendations for Online Survey and Focus Group Protocol

The following recommendations, which were derived from all the information collected in Phase I, were the basis for the online survey and the focus group protocol.

Demographics

The following characteristics need to be included in the participant group:

- Men and women
- Serious and less serious types of cancer
- Employed and self-employed
- Various income levels

Questions regarding the following characteristics need to be included in the online survey and focus group protocol.

Health Information

- Mental and physical health
- Functional status
- Most prevalent symptoms and side effects

Work-Related Information

- Occupation
- Time away from work
- If stayed at work through treatment, what encouraged them to do so (and whether they felt they had a choice)
- Ways caregivers and individuals with cancer found their employers or coworkers to be supportive or not supportive when off work or back at work
- If already returned to work:
  - how is their work ability and what work changes do they believe are a result of any reduced work ability,
  - what workplace accommodations did they received and were they provided flexible work arrangements, such as time off for medical appointments
- Concerns about losing employer-supported health insurance should they need/want to change jobs

Caregiving-Related Information

- Unmet needs
- Kind of support caregiver provided to patient

Resources

- What people, services, work environment helped respondents return to and/or stay at work
- Which RTW programs, services, resources were missing
- What they would recommend to help them return to work (provide specific examples such as legal resources, resources within the cancer care system, resources within the workplace, job search resources)

Phase II: Return to Work National Survey

Methods

The National Survivorship Working Group of the Cancer Journey Advisory of the Canadian Partnership Against Cancer (the Partnership) requested that a literature review and consultations be conducted to determine current Canadian information regarding challenges that people dealing with cancer and their caregivers face when the person with cancer returns to the workplace (as an employee or self-employed) during or after treatment. A literature review, individual interviews, focus groups and an online survey were conducted.

This section of the report discusses the online survey element of the consultation and presents the survey design, methodology and results for the two surveys (one for individuals with cancer and the other for informal caregivers of people diagnosed with cancer). Results include responses to closed-ended questions with fixed response options and, where appropriate, "quotations" from responses to open-ended questions (here these are presented in italics). Appendices F to K include a copy of the survey questions, a list of organizations that were contacted by the Partnership to circulate the survey links, an overview of the analyses conducted, a flow chart of survey respondents and a breakdown of responses by question.

Objective

To identify challenges related to return to work for people living with cancer and caregivers.

Survey Development and Implementation

Two surveys (one for individuals with cancer and one for informal caregivers of individuals diagnosed with cancer) were developed based on a review of the literature (the first part of Phase I), a review of existing instruments and feedback from eight individual interviews (the second part of Phase I). In addition, the Partnership coordinated a pilot test of the surveys by circulating the draft survey links and a feedback form to members of the National Survivorship Working Group both for their feedback and to circulate the survey to a small sample of respondents. Surveys were revised based on the pilot feedback and translated into French prior to launch (see Appendix F for a copy of the final surveys). The surveys were administered online using Survey Monkey from September 23 to November 18, 2011.

Survey Recruitment

To recruit respondents, the Partnership compiled a list of community-based, provincial and national cancer-related organizations, networks or associations and contacted them by email and follow-up phone calls to raise awareness of the survey and solicit participation among their clients (see Appendix G for a list of organizations).

The survey link, recruitment text and wording for twitter accounts in both English and French were provided to these organizations who then sent email blasts, posted the survey link(s) on their website and/or sent Facebook and Twitter communications.

The majority of individuals with cancer who responded indicated that they heard about the survey through a community-based cancer support organization (60%). Other sources included a national cancer organization (14%); the hospital or cancer centre where they receive treatment (7%); and a partner, spouse, family member or friend (5%). The primary mechanism for receiving the link (as identified in the Other responses) was through email (see Question 41 in Appendix J). Caregivers were made aware of the survey through a number of sources, including a community-based cancer support organization (47%); a national cancer association (14%); a partner, spouse, family member or friend (12%); and a hospital or cancer centre (7%) (see Question 41 in Appendix K).

Survey Eligibility Criteria

Individuals were eligible to participate in the survey if they met each of the following three criteria:

- 18 years of age or older AND
- Diagnosed with cancer in the previous 5 years OR had been an informal caregiver (i.e., not providing care in a professional capacity) for someone who had been diagnosed with cancer in the previous 5 years[5] AND
- Working at the time of their cancer diagnosis OR caregiving experiences

Analyses

Three analyses were conducted:

- Qualitative analyses of all open-ended survey responses
- Descriptive analyses of quantitative responses using the Statistical Package for the Social Sciences (“SPSS”) version 20.0
- Bivariate analyses using SPSS on the survey responses from individuals with cancer (see Appendix H for an overview of the comparisons conducted) to identify potential factors that were related to return to work challenges experienced by respondents (only results that were statistically significant at $p \leq 0.05$ are reported)

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[5] The rationale for the 5-year timeframe was

- treatment regimens change over time, causing different recovery, side effect experiences and time away from work etc.;
- to minimize recall bias;
- to reflect more current employment and work accommodation-related policies and procedures;
- to reflect the time within which the majority (although not all) of cancer patients complete treatment and return to work.

Please note that responses from English and French participants were not compared due to the low overall response rate for French surveys; the French-language survey responses were merged with the English responses into one dataset for analysis. No bivariate analyses were conducted on the caregiver dataset due to the small number of respondents. Individuals with cancer and caregiver survey responses were not compared, as this was outside the scope of this project. All quantitative findings are reported in Appendices J and K.

Findings: Individuals with Cancer[6]

Respondent Characteristics

Demographics (Q1–7)

- 457 individuals were eligible and consented to participate in the survey: 410 surveys were completed (90%) and 47 were incomplete (10%) (Appendix I).[7]
- 77% of respondents were female. Note: there were a high proportion of individuals with a breast cancer diagnosis who responded to the survey (Figure 1) and this accounts for some of the bias in the overall proportion of women to men.[8]
- 93.3% of respondents were between 25 and 64 years of age.[9]
- The majority of respondents (83%) had more than a high school education (i.e., non-university certificate or diploma, Bachelor's degree or a university degree above a bachelor's).[10]
- 63% of respondents lived in Ontario, 8% in Nova Scotia, 8% in Alberta, 6% in Manitoba, 6% in Quebec, 3% in British Columbia, 3% in Saskatchewan, 2% in New Brunswick and almost 1% in Prince Edward Island or the Northwest Territories.
- 67% lived in towns/cities with 100,000 or more residents.
- 71% were married or living common-law.
- 19% had a personal income (not household) in the previous 12 months of $30,000 or less, 24% had income between $30,001 and $50,000, 27% between $50,001 and $80,000, and 24% had an income of over $80,000; 7% choose not to answer the question.[11]

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[6] Percentages may not equal 100 due to rounding.

[7] A survey was considered complete if at least 50% of the questions were answered.

[8] A higher proportion of female respondents is typical of health-related surveys.

[9] A higher proportion of individuals of working age was expected due to the return to work focus.

[10] People with higher education (at least completed high school) are more likely to complete health-related surveys.

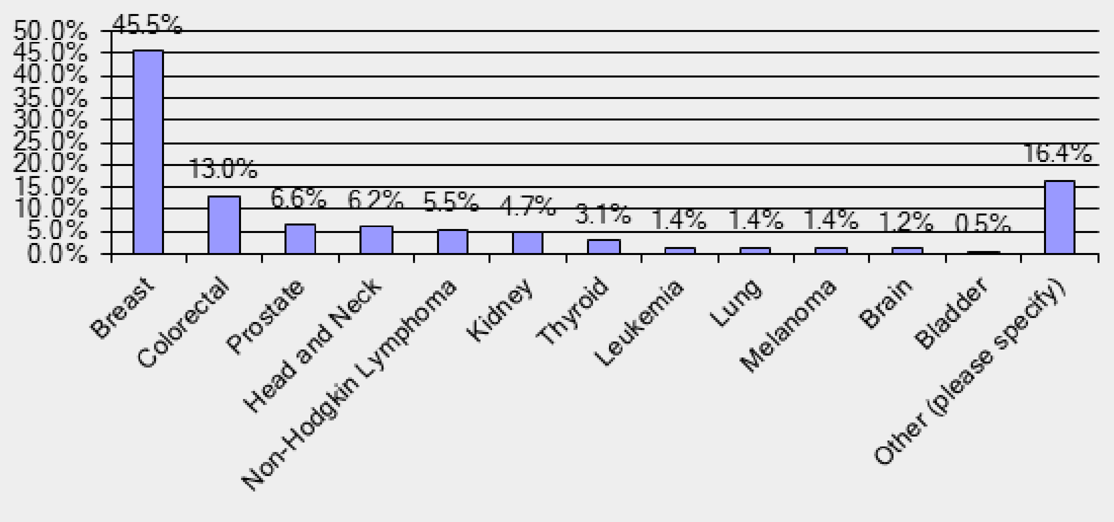
[11] Income was measured as a categorical variable and therefore no mean or median is available.

Cancer Experience

Diagnoses, Cancer Type and Cancer Stage (Q9–11)

- 13% of individuals had been diagnosed in 2006, 11% in 2007, 18% in 2008, 18% in 2009, 25% in 2010 and 12% in 2011.[12]
- Approximately half of the respondents had a breast cancer diagnosis (46%), followed by colorectal cancer (13%) (Figure 1). Note: respondents may have reported more than one cancer diagnosis.
- The distribution of respondents by cancer type does not reflect the 5-year tumour-based prevalence in Canada in 2007 and more likely reflects the channels that were used to raise awareness of, promote and distribute the survey nationally. The top four cancers based on the 5-year tumour-based prevalence in Canada in 2007 (that make up 61% of all 5-year tumour-based prevalence) were 19% prostate, 18% breast, 13% colorectal, 6% lung and 5% bladder.[13]
- The distribution of respondents according to cancer stage at time of diagnosis was: 0 (3%), I (23%), II (27%), III (23%), IV (9%) and don't know (15%).

Figure 1. Q10: What cancer(s) were you diagnosed with?*



**Other cancers include ovarian, liver, cervical, oral, testicular, myeloma, soft tissue sarcoma, pancreatic.*

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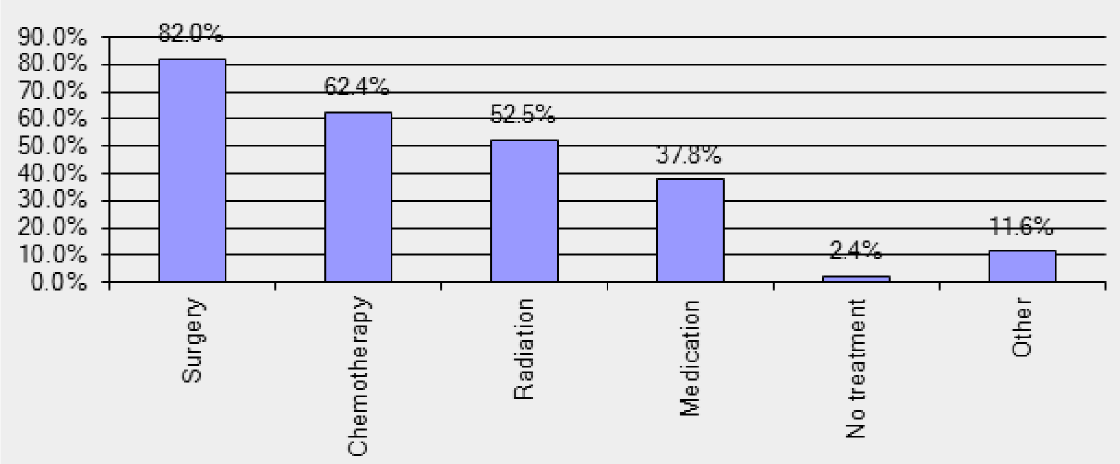
[12] 16 individuals indicated that they had been diagnosed prior to 2006; however, there were two screening questions in the survey that asked if the individual had been diagnosed in the previous 5 years that were answered "yes" by these respondents, so they may have had a recurrence and provided the date of their initial diagnosis.

[13] 49.5% of 5-year tumour-based prevalence of all cancers were in women in Canada in 2007. Of new cases, 56% are between the ages of 30 and 69, and 42% are 70+ years of age. Distribution of new cancer cases in Canada: 38% Ontario, 3% Nova Scotia, 9% Alberta, 3% Manitoba, 26% Quebec, 12% British Columbia, 3% Saskatchewan. (Canadian Cancer Society, 2011)

Cancer Treatment (Q12–14)

- In terms of the types of treatments survey participants may have received for their cancer, the majority of respondents had surgery (82%) and/or chemotherapy (63%) and/or radiation treatment (54%); only 2% indicated that they had not received any treatment following their cancer diagnosis (Figure 2). Treatment referred to surgery, chemotherapy, radiation and medication (e.g., prescribed medications, including pain control, hormonal therapy, anti-emetics, etc.).
- 58% of respondents indicated they had completed treatment (including surgery, radiation, chemotherapy and medication); 42% had not yet completed treatment.
- 5% completed treatment in 2006, 13% in 2007, 13% in 2008, 22% in 2009, 24% in 2010 and 23% in 2011.

Figure 2. Q12: What type(s) of treatment did you have following your diagnosis?



Income Supports and Employment Status

Pattern of Employment (Q15)

- The pattern of employment of respondents changed between three time periods (time of cancer diagnosis, during cancer treatment and employment status at the time of survey completion) (Table 1):
  - The majority of respondents were full-time employed at the time of diagnosis and slightly more than half of this original number indicated they are currently employed full-time.[14] A similar pattern emerged for those self-employed full-time.
  - The number of individuals who indicated they were working part-time decreased during cancer treatment but remained the same for current status.

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[14] The denominator includes all survey respondents regardless of whether they had returned to work or not at the time of completing the survey.

- 28% of survey respondents (n = 114) indicated that they were not currently working (i.e., they were full-time students, not employed, homemakers, on disability benefits or had retired from paid work).
- 36% of the sample continued to be employed during treatment.
- 38% of the sample received income support from their disability insurance during treatment.

Table 1. Q15: What was your employment status during each of the following periods?

Answer options	At time of diagnosis		During cancer treatment		Current employment status		Response count	
Employed full-time by an organization (≥ 30 hours/week of paid work)	327	80.1%	106	26.0%	172	42.2%	332	81.4%
Employed part-time by an organization (≤ 30 hours/week of paid work)	47	11.5%	17	4.2%	49	12.0%	81	19.9%
Self-employed full-time (≥ 30 hours/week)	26	6.4%	9	2.2%	14	3.4%	31	7.6%
Self-employed part-time (≤ 30 hours/week)	18	4.4%	13	3.2%	15	3.7%	29	7.1%
Full-time university or college student	4	1.0%	1	0.2%	4	1.0%	8	2.0%
Not employed	1	0.2%	33	8.1%	16	3.9%	45	11.0%
Homemaker	1	0.2%	3	0.7%	3	0.7%	7	1.7%
On disability benefits	3	0.7%	155	38.0%	66	16.2%	173	42.4%
Retired from paid work	2	0.5%	6	1.5%	25	6.1%	29	7.1%
Other (please specify)							51	12.5%
						answered question	**408**	
						skipped question	**2**	

Level of Position and Type of Work (Q16–17)

- Approximately 40% of respondents held either a management (i.e., manager, supervisor, leader or foreman) or senior management (CEO, VP, Director) position at the time of their diagnosis; 52% held no managerial or supervisory role; and 9% were self-employed.
- 75% of respondents described their work as non-manual (e.g., office work, desk job), 18% described it as a combination of both non-manual and manual work, and 7% indicated that their job was manual (e.g., heavy lifting, trade, manufacturing). The Other responses for this question indicated that the respondents were unable to work, had stopped working or had not yet returned to work.

Physical Requirements of Work (Q18)

- The majority of respondents (71%) indicated that there was no change in the physical requirements of their work following their diagnosis. This is not surprising since the majority of respondents indicated their work was predominantly non-manual prior to diagnosis. Approximately 14% of respondents indicated that their work had become less physical. An additional 13% provided an Other response, the majority of whom indicated that they had stopped work, were unable to work or had not yet returned to work.

Size of Organization (Q19)

- The number of employees in the organization where respondents reported working at the time of diagnosis varied considerably (Table 2).[15]

Table 2. Q19: Approximately how many people were employed at the company where you worked at the time of your cancer diagnosis?

Answer Options	Response Percent	Response Count
Self-employed	6.2%	25
Less than 5	3.7%	15
5 to 10	7.1%	29
11 – 20	8.1%	33
21 to 50	15.0%	61
51 to 100	8.4%	34
101 to 500	14.5%	59
Over 500	33.5%	136
Don't know/Not sure	3.4%	14
	answered question	**406**
	skipped question	**4**

Sources and Level of Income (Q20–23)

- At the time of diagnosis, the majority of respondents reported their compensation came from wages, salaries or self-employment income. During cancer treatment, sources of income shifted to more insurance-related sources (i.e., short and/or long-term disability insurance through work and/or EI) and personal savings. Current sources of income were reported to include wages and salaries; long-term disability; support from partner, spouse, family member and/or friend; personal savings; and CPP or QPP (Table 3).

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[15] The answers for Q19 were recoded into 4 categories for the bivariate analysis: Very Large = over 500 employees, Large = 101-500 employees, Medium = 21-100 employees and Small = ≤20 employees. Note that Table 2 shows the original breakdown of the information.

Table 3. Q20: What were your personal income sources (*not* household) during each of the following time periods?

Top Five Sources of Income at Each Time Period[16]

Answer options	At time of diagnosis	During cancer treatment	Current employment status
Wages and salaries	85%	38%	53%
Self-employment	13%		
Personal savings	9%	21%	13%
Support from partner, spouse, family, friends	7%		13%
Employment insurance	7%	21%	
STD through work insurance		29%	
Long-term disability through work insurance		28%	14%
CPP or QPP			12%

- 60% of respondents indicated that in the 12 months following their cancer diagnosis their personal income decreased compared to the 12-month period before diagnosis.[17] The decrease in income is illustrated in Table 4.[18]
  - Respondents who were either self-employed or in non-managerial or non-supervisory positions were more likely to self-report that their income had decreased than those in a management or senior management position at time of diagnosis (p = 0.007).

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[16] Respondents were allowed to select more than one source of income so the values presented represent the percent of respondents that selected each income source.

[17] Respondents were asked to report income based on ranges. As such, we cannot calculate mean or median income values.

[18] Table 4 illustrates data for only those respondents who indicated a decrease in income and provided data in both the before and after time period (i.e., 12 months before and 12 months after diagnosis).

Table 4. Q21 and Q23: Number of Respondents by Income Range, Before and After Cancer Diagnosis

	Personal Income (not household) in 12 months before diagnosis		Personal Income (not household) in 12 months after diagnosis	
Answer Options	Response Percent	Response Count	Response Percent	Response Count
Less than $5,000	1.7%	4	7.3%	18
$5,000 to $10,000	1.3%	3	5.7%	14
$10,001 to $15,000	1.7%	4	6.5%	16
$15,001 to $20,000	2.1%	5	8.1%	20
$20,001 to $30,000	9.7%	23	14.2%	35
$30,001 to $40,000	13.4%	32	15.4%	38
$40,001 to $50,000	13.9%	33	13.4%	33
$50,001 to $60,000	11.8%	28	9.3%	23
$60,001 to $70,000	11.3%	27	2.0%	5
$70,001 to $80,000	7.6%	18	4.1%	10
$80,001 to $90,000	5.9%	14	2.0%	5
$90,001 to $100,000	5.0%	12	2.4%	6
$100,001 to $150,000	5.5%	13	1.2%	3
Over $150,000	5.0%	12	2.0%	5
Don't remember/Not sure	0.0%	0	2.4%	6
Prefer not to answer	4.2%	10	3.7%	9

Health Conditions (Q24)

- In response to the question *"Did you have any other health conditions (i.e., other than those related to your cancer diagnosis and treatment) that influenced your work status and/or income at each of the following time periods?"* 93% of respondents indicated that they did not. This percentage dropped to 82% who did not during cancer treatment and 77% who did not at the time they completed the survey. The issues that were identified by respondents across the three time periods were extremely broad and the most common issues mentioned included stress, anxiety, depression, arthritis, pain, fatigue and low energy, cardiovascular disease (including heart attacks, high blood pressure), diabetes, lymphedema, headaches and poor cognitive functioning.[19]

Time Away from Work (Q25)

- 26.3% of respondents were away from work for less than 3 months following their cancer diagnosis, 19.1% were away for 3 to 6 months, 39.4% (the majority) were away more than 24 weeks (~6 months) and 16.4% indicated that they had not yet returned to work.

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[19] Though respondents were specifically asked about health conditions other than those related to their cancer diagnosis and treatment, it is possible that some of the issues listed were related to their cancer.

Factors Influencing Time Taken or Not Taken Away From Work (Q26)

In response to the open-ended question "What influenced the amount of time that you did or did not take off from work following your cancer diagnosis?" respondents (n = 367) noted several factors (Table 5).

- Financial concerns, health issues, feeling a sense of responsibility for their work or concerns about job security kept most of them at work or encouraged them to return to work more quickly.
- Many respondents indicated that health-related factors (i.e., side effects, receiving treatment, or concerns about immunity) influenced taking time away from work.
- Having access to financial resources enabled some individuals to remain off work for longer periods of time.
- Some respondents also indicated that they wanted to maintain a sense of normalcy and therefore returned to work.

> *"Work responsibility ... I am the only one in the department that can do my job."*
>
> *"Finances led me to return to work possibly earlier than I should have."*
>
> *"I wanted to keep my life as normal as possible during treatment."*
>
> *"...balancing taking necessary time off with a desire to feel like I was doing things other than focusing on my health, that I still have goals, priorities and structure in my life."*
>
> *"I had income from a spouse to rely on plus my employer provided some sick day benefits and long-term disability benefits. I did not have finances to worry about, my priority was taking the time off so that I could focus on fighting cancer, get healthy and then back to work."*
>
> *"There were days I would love to have worked in between treatments but long- and short-term disability disallowed this."*

Table 5. Q26: What influenced the amount of time that you did or did not take off from work following your cancer diagnosis (e.g., finances, work responsibilities, personal issues)?

	What influenced time away from work	What influenced returning to work sooner
Financial Factors	• having sufficient income while off work • length of time eligible to receive income support • amount of income (income support, income from family, from health insurance) • presence or absence of income supports (e.g., short- or long-term disability, EI)	• loss of income
Work-Related Factors	• work responsibilities (cause problems for work if could not perform tasks) • employer did not accommodate • stress of the job • job termination • concerns about lack of immunity/ exposure at work • supportive coworkers	• personal work ethic • work responsibilities (e.g., only person doing that job) • love for job • self-employed – no one else to do job • didn't want to let coworkers down • job security
Health Factors	• general physical and mental health/recovery • side effects • actively being in treatment • impaired ability to perform work tasks	• felt well during treatment
Personal Factors	• unknown when "should" return	• wanting a sense of normalcy • distract self from thoughts about cancer

Return to Work Process (Q27-28)

- Respondents typically reported they returned to work gradually or on a flexible schedule (i.e., returning to work in terms of the numbers of hours worked or the number of days worked per week). A sizable minority (18%) returned to full-time work immediately (Table 6).

Table 6. Q27: What was your return to work schedule like?

Answer Options	Response Percent	Response Count
I gradually returned to work in terms of the numbers of hours worked or the number of days worked per week	40.6%	166
I immediately went back to work full time	18.3%	75
I have not yet returned to work in any capacity	15.9%	65
I had flexible scheduling of hours worked each day or the location of work (e.g., work from home)	12.2%	50
I never stopped working during treatment	8.1%	33
I immediately returned to work on a part-time basis	6.6%	27
I retired after I was diagnosed	2.7%	11
I was dismissed from my job after I was diagnosed	2.0%	8
I quit after I was diagnosed	1.5%	6
Other (please specify)	11.7%	48
	answered question	**409**
	skipped question	**1**

- Bivariate comparisons of return to work schedules looked at the potential unique effects of gender, marital status, type of treatment, level of position and size of employer:
  - Males were more likely than females (p = 0.005) and respondents who indicated that they were a manager, supervisor, leader or foreman or were self-employed (p = 0.02) were more likely to have immediately gone back to work full time.
  - Women (p = 0.05) and respondents who had received at least surgery (p = 0.05) were more likely to gradually return to work.
  - Respondents who had chemotherapy (p = 0.001) and those who held a non-managerial position at the time of diagnosis (p = 0.003) were more likely to not have returned to work in any capacity.
- The majority of respondents (64%) returned to the same job with the same employer; an additional 7% returned to the same employer but in a different job; 8% had employment with a different employer following their diagnosis or treatment; and 9% were self-employed.

> *"I did not have a formal "back at work" plan or any guidance — those would have been VERY helpful. I returned to work too soon and experienced various challenges related to that."*

Challenges Experienced with Return to Work

Cancer and Health-Related Problems Affecting Work (Q29)

- More than two-thirds of respondents reported that fatigue (74%) and reduced energy (69%) were responsible for work-related challenges.[20] Other concerns that were identified by slightly less than half the respondents were reduced physical ability (48%), personal stress (47%), reduced cognition (45%), sleep problems (45%) and anxiety (43%) (Table 7). In open-ended feedback for this question, some respondents indicated that it is because of the health-related issues that they have not yet returned to work.

Table 7. Q29: Which of the following cancer or health-related problems resulted in work-related challenges following your diagnosis or treatment (check all that apply)?

Answer Options	**Response Percent**	**Response Count**
Fatigue	73.5%	297
Reduced energy	69.3%	280
Reduced physical ability	47.8%	193
Personal stress	47.3%	191
Reduced cognitive ability to manage work demands	45.3%	183
Sleep problems	45.0%	182
Anxiety	43.3%	175
Job-related stress	39.4%	159
Pain	37.1%	150
Body image and appearance	28.0%	113
Depression	25.2%	102
Concern about infection	21.5%	87
Nausea	15.8%	64
Bowel or urinary incontinence	15.1%	61
Loss of appetite	12.4%	50
Shortness of breath	10.1%	41
Lymphedema	9.9%	40
I have not experienced any cancer or health-related problems that influenced my work	6.4%	26
Other (please specify)	11.6%	47
	answered question	**404**
	skipped question	**6**

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[20] Respondents were allowed to select more than one cancer or health-related problem that resulted in work-related challenges so the percentages represent the percent of overall respondents that indicated each problem.

- We analyzed the cancer or health-related problems that resulted in work-related challenges:
  - Respondents were more likely to indicate that they were unable to work in the same way they did before their cancer diagnosis if they reported fatigue ($p = 0.0001$), reduced cognitive ability to manage work demands ($p = 0.0001$), reduced energy ($p = 0.0001$), anxiety ($p = 0.0001$), pain ($p = 0.0001$), sleep problems ($p = 0.0001$), shortness of breath ($p = 0.005$), body image and appearance ($p = 0.007$), depression ($p = 0.0001$), concern about infection ($p = 0.04$), job-related stress ($p = 0.0001$), personal stress ($p = 0.006$) or reduced physical ability ($p = 0.0001$).
  - Respondents were more likely to indicate that the priority that work has in their life changed if they were also experiencing reduced cognitive ability ($p = 0.0001$), anxiety ($p = 0.002$), bowel or urinary incontinence ($p = 0.05$), depression ($p = 0.006$), concern about infection ($p = 0.02$), job-related stress ($p = 0.0001$) or personal stress ($p = 0.005$).
  - Respondents were more likely to indicate that they were unable to work full time now if they were experiencing fatigue ($p = 0.001$), reduced cognitive ability ($p = 0.001$), reduced energy ($p = 0.001$), anxiety ($p = 0.03$), pain ($p = 0.01$), sleep problems ($p = 0.006$), nausea ($p = 0.006$), loss of appetite ($p = 0.05$), depression ($p = 0.008$), concern about infection ($p = 0.02$), job-related stress ($p = 0.0001$) or reduced physical ability ($p = 0.0001$).
  - Respondents were more concerned about not being able to work if they were to become ill again if they were experiencing fatigue ($p = 0.003$), reduced cognitive ability ($p = 0.0001$), reduced energy ($p = 0.008$), anxiety ($p = 0.02$), sleep problems ($p = 0.001$), concerns about infection ($p = 0.001$), job-related stress ($p = 0.0001$), personal stress ($p = 0.0001$) or reduced physical ability ($p = 0.01$).

Cancer Experience and Work (Q30)

- Work provided a sense of normalcy (44%), the work priority shifted (40%) and individuals with cancer benefited from co-worker support (39%).
- On a negative note, 27% of respondents indicated they were no longer able to work "in the same way they did before their cancer diagnosis" and one-fifth of these respondents indicated that they have stayed in their job for fear of losing work-related health benefits (13%) and/or life insurance (8%), 18% indicated that ongoing cancer- or treatment-related symptoms interfered with their work, and 26% expressed concern about not being able to work if they were to become ill again. Other responses included having to return to work for financial reasons. A large number of respondents wrote that work was not negatively affected by the cancer experience.

Table 8. Q30: Please indicate the ways in which your cancer diagnosis or treatment has affected your work (check all that apply).

Answer Options	Response Percent	Response Count
My work provided me with a sense of normalcy*	43.7%	176
I have changed the priority that work has in my life*	40.0%	161
I had coworkers support me at work because of my cancer diagnosis*	39.2%	158
I am unable to work in the same way I did before my cancer diagnosis	27.0%	109
I am concerned about not being able to work if I were to become ill again	26.3%	106
Ongoing cancer- or treatment-related symptoms interfere with my work	18.4%	74
I am unable to work full-time now	16.1%	65
I have earned increased respect at work*	14.1%	57
I have stayed in my job because I do not want to lose my health insurance	13.2%	53
The quality of my work has decreased	11.9%	48
I no longer wish to work*	10.7%	43
My supervisor and/or employer have not been very supportive	10.7%	43
I worry about being forced to retire or quit work before I am ready	10.7%	43
I have experienced a decrease in pay	9.7%	39
I chose to make a career change*	8.2%	33
I have stayed in my job because I do not want to lose my life insurance	7.9%	32
My job was reorganized (e.g., job responsibilities changed)	7.4%	30
I was not able to return to my same job because of medical concerns or reduced physical ability	7.2%	29
I am unable to work at all now	7.2%	29
My coworkers have not been very supportive	7.2%	29
My employer did not make reasonable changes or accommodations in my job to help me	6.0%	24
The terms of my employment were changed	5.5%	22
I have experienced employment discrimination	5.0%	20
I chose to return to a job at a lower level (e.g., fewer responsibilities, less pay)	5.0%	20
I was passed over for a promotion	4.7%	19
My job was terminated	4.5%	18
I have felt that I did not get a job because of my cancer diagnosis	4.2%	17
I left a job that I did not like*	3.0%	12
I had to take on a second job because of debt due to cancer	1.7%	7
My employer demoted me	0.7%	3
None of the above	5.5%	22
Other (please specify)	20.6%	83
	answered question	**403**
	skipped question	**7**

** denotes potentially positive ways in which the cancer diagnosis and/or treatment has affected their work*

Workplace Accommodations or Supports (Q31)

- The top workplace accommodations or supports that respondents required following their cancer diagnosis or treatment were (in order of frequency): support from supervisor and/or employer (52%), paid time off for medical appointments (48%), support from coworkers (46%), flexible scheduling of work hours (45%), gradual increase in work schedule (41%) and gradual increase in workload (33%). Overall, the majority of respondents (>88%) indicated receiving these accommodation or supports (Table 9).

- We analyzed possible factors that might influence responses to the accommodations or supports individuals with cancer indicated that they required:
  - Respondents were more likely to indicate that they required flexible scheduling of work hours if they self-reported fatigue (p = 0.01), reduced cognitive ability (p = 0.001), reduced energy (p = 0.002), lymphedema (p = 0.04), depression (p = 0.03), job-related stress (p = 0.01) or personal stress (p = 0.004).
  - Respondents were more likely to indicate that they required a gradual increase in work schedule if they reported fatigue (p = 0.003), reduced cognitive ability (p = 0.002), reduced energy (p = 0.02), lymphedema (p = 0.005), job-related stress (p = 0.008) or reduced physical ability (p = 0.04).
  - Respondents were more likely to indicate that they required a gradual increase in workload if they reported fatigue (p = 0.001), reduced cognitive ability (p = 0.0001), reduced energy (p = 0.002), anxiety (p = 0.05), pain (p = 0.03), sleep problems (p = 0.02), lymphedema (p = 0.02), depression (p = 0.05), job-related stress (p = 0.0001) or personal stress (p = 0.002).
  - Respondents were more likely to indicate that they required reduced or part-time hours if they reported fatigue (p = 0.001), reduced cognitive ability (p = 0.003), reduced energy (p = 0.002), pain (p = 0.02), nausea (p = 0.03), body image and appearance (p = 0.0001), depression (p = 0.001), concern about infection (p = 0.004), job-related stress (p = 0.01) or personal stress (p = 0.04).
  - Respondents were more likely to indicate that they required paid time off for medical appointments if they reported reduced cognitive ability (p = 0.01), nausea (p = 0.04), depression (p = 0.05), concern about infection (p = 0.01), job-related stress (p = 0.001), personal stress (p = 0.005) or reduced physical ability (p = 0.01).
  - Respondents were more likely to indicate that they required support from co-workers if they reported reduced cognitive ability (p = 0.01), reduced energy (p = 0.05), anxiety (p = 0.01), sleep problems (p = 0.03), job-related stress (p = 0.04), personal stress (p = 0.004) or reduced physical ability (p = 0.05).
  - Respondents were more likely to indicate that they required support from a supervisor and/or employer if they reported reduced cognitive ability (p = 0.05), anxiety (p = 0.02), body image and appearance (p = 0.02), job-related stress (p = 0.005) or personal stress (p = 0.003).

- Analysis was also conducted concerning workplace accommodations or supports received. We looked at the size of employer and the ability to work from home (p = 0.04) and paid time off for medical appointments (p = 0.009) all which were more likely to be received by respondents who indicated they work for a very large company (over 500 employees).

- Five accommodations or supports that were indicated as required by considerably fewer respondents also ranked low in terms of these needs being met, including retraining to perform different work, which was met for only 36% (5 of 14) of the individuals who expressed this need, the need for assistive devices (56%, or 9 of 16), and redesign or adjustment of workplace (56%, or 15 of 27) (Table 9).
- Other responses included not accessing workplace accommodations because they were self-employed, they had retired or they did not leave work during treatment, or they are not currently working.

Table 9. Q31: Which of the following workplace accommodations or supports did you require following your cancer diagnosis or treatment and for each of these please indicate whether you received the accommodation/support?

Answer options	I required this accommodation or support		I received this accommodation or support		Response count	
Support from supervisor and/or employer	166	51.7%	162	50.5%	212	66.0%
Paid time off for medical appointments	155	48.3%	137	42.7%	180	56.1%
Support from coworkers	148	46.1%	171	53.3%	205	63.9%
Flexible scheduling of work hours	144	44.9%	135	42.1%	169	52.6%
Gradual increase in work schedule	131	40.8%	120	37.4%	150	46.7%
Gradual increase in workload	106	33.0%	95	29.6%	126	39.3%
Reduced or part-time hours	97	30.2%	83	25.9%	113	35.2%
Return to work meeting with supervisor/employer	91	28.3%	92	28.7%	121	37.7%
Ability to work from home	84	26.2%	71	22.1%	102	31.8%
Additional breaks or rest periods	66	20.6%	41	12.8%	77	24.0%
Unpaid time off	65	20.2%	60	18.7%	83	25.9%
Modified work tasks	61	19.0%	56	17.4%	78	24.3%
Reduced physical tasks	55	17.1%	39	12.1%	66	20.6%
Redesign or adjustment to workspace	27	8.4%	15	4.7%	31	9.7%
Assistive devices	16	5.0%	9	2.8%	17	5.3%
Retraining to perform different work	14	4.4%	5	1.6%	17	5.3%
Other (please specify)					72	22.4%
				answered question	**321**	
				skipped question	**89**	

Work-Related Changes Respondent Chose to Make Following Diagnosis/ Treatment (Q32)

- Of the 312 individuals who answered this question, the vast majority of respondents reported making changes once they returned to work. The changes were both work-related and personal. These included changes in behaviour (e.g., length of time at work) and in their attitudes about and values associated with work (Table 10).

- A minority of respondents (n = 45 or 14%) reported making no changes, indicated that this question did not apply to them and/or had not yet returned to work.

> *"I chose to try to get a job that would make me happier."*
>
> *"I chose to be assertive with my employer, which resulted in a job re-structuring for the better."*

Table 10. Q32: Thinking about your work experience following your cancer diagnosis or treatment, what changes, if any, did you choose to make?

Theme	Subtheme	Description
Work-Related Changes	Modifications at work	• work that accommodates new abilities after treatment • change work responsibilities/job restructuring • take on less challenging work/reduce work load • work from home • do not commute during peak hours • voluntary demotion
	Time at work	• work less (# of days/week) • stop work/retire/career change • no or less overtime/leave on time each day • do not apply for promotions • reduce travel • take breaks • change time of work (e.g., mornings, no nightshift, no shift work) • less volunteering for extra projects
	Interaction with work environment	• more assertive with employer/colleagues (i.e., better boundaries) • disengage from work politics • distance self from unsupportive colleagues • more efficient/organized • have positive attitude • no longer workaholic/no overtime • minimize workplace stress
Personal Changes	Work–life balance	• get work that would make self happier • get new work that is less stressful/lower profile • family is priority • priority for exercise/healthy behaviours/wellbeing • create new life separate from work • less commitment to work

Work-Related Changes that Were Beyond Respondent's Control (Q33)

- Of the 266 individuals who answered this question, 50% reported that no changes were made beyond their control (e.g., because of a very supportive employer or they were self-employed) or they had yet to return to work.
- Of the 50% of respondents who did report that changes to their work had been made beyond their control, these changes were mainly focused on the process of returning to work and on their job description (Table 11).

> *"My employer was exceptional and supported my focus on my health and treatment."*

Table 11. Q33: Thinking about your work experience following your cancer diagnosis or treatment, what changes, if any, were beyond your control (e.g., made by the employer)?

Themes	Work Changes Made beyond Respondents Control
Process of returning to work	• no choice when to start gradual return to work • no choice in return to work schedule • no choice in degree or type of employer accommodations/support
Modifications to job	• increased volume of work • no flexibility in hours or location of work (no more work at home), workload or travel • work station space adjusted causing stress • modified duties (increased or decreased) • modified job description
Changes to existence of job	• job given to co-worker • fired because of request for unpaid leave • job terminated • demotion/seniority status affected
Changes to work environment	• coworkers let go/new hires • change in work systems • increased scrutiny by management • change in work policies (e.g., unable to bank overtime) • restructuring of office • pressure to work more hours • reporting structures changed • no longer personal privacy about health issues

Main Work-Related Issue Following Cancer Diagnosis/Treatment (Q34)

- Of the 343 individuals who answered this question, over half reported that side effects from their cancer or treatment, particularly fatigue and loss of energy, as well as cognitive impairment, were the main work-related issues. A smaller number encountered unsupportive colleagues. (Table 12)

> *"The demotion (they called it a re-organization) while I was off work was much worse for me than the cancer treatment. The problems have persisted, causing stress for me, two years later."*
>
> *"My biggest challenge was dealing with my long-term disability insurance provider. They fought me every step of the way. I am bitter that I had to waste so much of my time and precious energy fighting with them…"*
>
> *"My main work-related issue was the lack of support I received for a gradual return to work, and then ultimately the termination of my contract after working at this clinic for over 20 years. I felt devalued, betrayed, angry and disillusioned. This added a great deal of distress to my life and has been the biggest area of emotional turmoil and the cause of the majority of my tears through this whole cancer experience."*

> *"I did not have an adequate understanding of how long I could remain away from work; I returned too early and experienced a lot of fatigue. Thankfully I received support from my organization and manager."*

Table 12. Q34: What was your main work-related issue, concern or challenge that you have experienced following your cancer diagnosis or treatment?

Theme	Description
Health	• side effects from treatment, including fatigue, cognitive impairment, memory loss, concentration, incontinence, lymphedema, pain • experiencing stress, anxiety about work load • lost ability to maintain performance • no consideration of health issues in RTW plan • compromising health for the job • adapt job responsibilities to new disability
Work-Related	• unsupportive coworkers and/or employer • looking for new environment/job that suits new abilities • came back too soon/no graduated return/no assistance to navigate • job security/insecurity • feel like am letting down colleagues/employer • missed out on promotion due to diagnosis • exhausting commute to work • feel have to prove capability • reduced hours of work • manage large workload • restructured out/not choice to retire/terminated • miss work • time off to attend medical appointments • disclosure concerns about the diagnosis, health-related issues, treatment, etc. • no workplace accommodations • reduced interest in job • systems changed when gone • job lock to keep benefits • worried about no benefits at new job
Income Support	• insurance pressures • gap in receipt of short-term disability (STD) • dealing with long-term disability (LTD) insurance provider • EI confusion rendering unable to collect, delay in receipt, not enough money • lack of information re: company benefit entitlement
Personal	• sense of self/image diminished • reinvent/prioritize self/work boundaries • meet own expectations of work performance
Financial	• loss of income • keeping money coming in created stress • affording assistive devices that are not covered
No Work Concerns	• employer very supportive

Return to Work Resources and Recommendations

Work-Related Information, Resources and/or Support (Q35)

- Of the 55 respondents who answered this question (13% of the sample), the vast majority who cited sources of work-related information, resources and/or support included family physician (37%), cancer support group (35%), oncologist (34%), immediate work supervisor (26%) or online information (25%).

> *"Access to the breast health nurse who helped me be realistic about what I could expect to be able to do at work."*
>
> *"My supervisor is awesome! Though he did not know what resources we BOTH could have benefited from, he was incredibly flexible with time off, allowing me to maintain links with office while away, etc. He and my coworkers made an effort to ensure that I still felt included in the workplace team."*

- 16% mentioned a return to work program and 6% a back at work program.
- In response to Other work-related sources of information, participants named family and friends, physiotherapists, psychiatrists and alternative health practitioners, other patients, church and career counselling at non-profit organization.
- 21% of respondents indicated that no one provided them with any work-related information, resources and/or support.

Specific Return to Work or Survivorship Program (Q36)

- Respondents were asked to indicate their participation in a return to work or survivorship program. Of the 64 participants (14%) who answered this question:
  - 35 (55%) respondents had participated in a program/group at Wellspring, 9 had attended a program or group at Princess Margaret Hospital and 4 had attended a Canadian Cancer Society program.
  - The remaining responses focused on working with health professionals, support groups, community organizations, societies and a survivorship conference.

> *"Wellsprings programs (Money Matters and Returning to Work). Both programs dealt with specific lived experience and assistance in practical matters in terms of accessing financial support, assessment of employability, and common emotional and physical aspects associated with paid work during and after recovery."*

Return to Work Information or Support that Would Have Helped (Q37)

- The types of information or support that would have helped individuals with cancer manage the return to work experience included guidance on how much time to plan to take off from work (44%), the impact cancer and treatment might have on work (44%), managing the pressure to meet work demands (40%), knowing employment rights (37%) and information on sources of income support (35%) (Table 13).

- Other responses included wanting their supervisor to ask how s/he was doing, help navigating the insurance system and legal support.

Table 13. Q37: What information or support would have helped your work-related concerns and return to work experience following your cancer diagnosis?

Answer Options	Response Percent	Response Count
What the impact of my cancer and treatment might have on my work	44.2%	160
Guidance on how much time I should have planned to take off from work	43.9%	159
Managing the pressure to meet work demands	39.5%	143
Knowing what my employment rights are	36.5%	132
Information on sources of income support	35.4%	128
How to manage my symptoms	31.8%	115
How to talk with my coworkers about my cancer diagnosis and treatment	30.7%	111
How to talk with my employer about my cancer diagnosis and treatment	28.7%	104
Access to income support (e.g., long-term disability)	28.2%	102
How to negotiate workplace accommodations with my employer	22.4%	81
What workplace accommodations could be made	22.1%	80
None of the above	18.2%	66
Other (please specify)		44
	answered question	**362**
	skipped question	**48**

- Bivariate comparisons were conducted on the type of information or support respondents indicated would have helped with their work-related concerns and return to work experience, including size of employer, reported change in income, marital status and type of treatment received:
  - Respondents were more likely to want guidance on how much time they should have planned to take off from work if they were in a non-managerial or management position (p = 0.02) than those who were self-employed or in senior management and if they had received at least radiation treatment (p = 0.01).
  - Respondents were more likely to want information on what the impact of their cancer and treatment might have on their work if they were married (p = 0.01), had radiation therapy (p = 0.04) or had reported a decrease in income in the 12 months following their diagnosis (p = 0.02).
  - Respondents were more likely to want information on how to talk with their employer about their cancer diagnosis and treatment if they were in a non-managerial or management position (p = 0.01) than if they were self-employed or senior management at time of diagnosis.

  - Respondents were more likely to want information about how to talk with their coworkers about their cancer diagnosis and treatment if they were in a non-managerial or management position (p = 0.01) than if they were self-employed or senior management.
  - Respondents were more likely to want to know what their employment rights were if they were in a non-managerial or management position (p = 0.001) than if they were self-employed or senior management.
  - Respondents were more likely to want information on income supports if they were married (p = 0.03), in a non-managerial or management position (p = 0.03), or had reported a decrease in income in the 12 months following diagnosis (p = 0.0001).
  - Respondents who reported a decrease in income or indicated that their income had remained the same in the 12 months following diagnosis were likely to want access to income support (p = 0.004).
  - Respondents who were in a non-managerial (p = 0.02) or management position (p = 0.004) were more likely to indicate that they would like to have information on what workplace accommodations could be made than respondents who were self-employed or held a senior management position.
  - Respondents were more likely to want information or support in negotiating workplace accommodations with their employer if they were in a non-managerial or management position (p = 0.03) at time of diagnosis and if they had radiation (p = 0.01) or chemotherapy (p = 0.04).
  - Respondents were more likely to want information or support in managing the pressure to meet work demands if they were in a non-managerial or management position at the time of diagnosis than those who were self-employed or senior management.

Most Helpful Information or Support for Work-Related Issues that Was Received (Q38)

- Work-related information or support that was most helpful to respondents (n = 292) included knowledgeable people and programs focused on dealing with recovery from treatment and side effects. Less often participants cited resources related to work hardening (progressively rebuilding skills to get back to work) or financial help and assistance related to the process of leaving work for treatment or assistance with the process of returning to work (Table 14).
- The information received was delivered in-person in treatment centres or in community organizations or gathered online (Table 14).

Table 14. Q38: What was most helpful to you in managing work-related issues following your cancer diagnosis (e.g., resource, program, person, source of information)?

Themes	Helpful to manage work-related issues
Resource person	• health professional to explain symptoms, nurse educator, family doctor, breast health nurse • social worker, therapist, psychologist • peer who has been through disability modification/cancer treatment/time off • cancer agency counsellor • work or health consultant from insurance company • union representative • supervisor • vocational rehabilitation counsellor • disability insurance representative • family or friends • labour relations representative • return to work coordinator
Program/ service	• support group or program • Brain Fog program • Community Care Access Centre (CCAC) • Canadian Cancer Society (CCS) • help with application for disability benefits • physiotherapy, relaxation classes, yoga, meditation • financial help (Return to Work and Money Matters at Wellspring)
Work-related changes/ resources	• reduced # of days and/or # of hours, flexible hours, work from home • generous sick leave benefits • Employee Assistance Program • senior management • Workplace Safety and Insurance Board (WSIB) • supportive direct employer, coworkers, clients • knowing workplace contract related to illness
Type of information	• delivered in-person by health professionals, community organization staff or other agency staff • written material • online research, blogs

Recommended Information, Services or Programs (Q39)

- Work-related information or support that was recommended by respondents (n = 280) included information for individuals with cancer on managing side effects and a gradual return to work, and information for employers on expected recovery times and how to support a returning employee. Many other respondents wanted more emotional support from colleagues and peers or those who really understood their experience. They also made mention of helpful programs, advocacy and practical supports. (Table 15)

> *"Someone (or a program, or even an online course) that can clearly and accurately explain how everything works (e.g., paperwork, the patient's rights, what types of financial support a patient might be eligible for, etc.), as well as give guidance about the emotional aspect of it."*

> *"If employers knew more about cancer and the potential side effects, they could better support the employee. For the person returning to work, understanding what could arise and suggestions to address them. Being aware and alert to potential problems can speed up resolutions."*

> *"Information about the long-term effects of cancer treatments (e.g., lymphedema, changes in energy level), how they affect your work and how to deal with them."*

Table 15. Q39: What would you recommend is needed (e.g., information, service, program) to facilitate a positive return to work experience for other individuals diagnosed with cancer?

Recommend	Description
Information (on website: forums or FAQs, written material, seminars delivered online or by health professionals, social workers, a RTW liaison or advocate)	• managing side effects and expectations for recovery for individuals with cancer, employer, coworkers • to employers/coworkers about how best to support individual with cancer • encourage employers/individuals with cancer to return to work gradually or have flexible work arrangements • for insurance adjudicators regarding experience of individuals with cancer and RTW • about expected/average rates of recovery for both individual with cancer and employer and how much time to take off from work • on rights/labour law/legal information/duty to accommodate • shopping for best insurance policies on which treatments can be covered • on income support options (STD, LTD, EI) • on how to manage return to work and work/life balance • on financial matters • how protect self on the job once back at work • how to deal with insurance companies • about companies health policies • on disclosure about the cancer diagnosis, health-related issues, treatment, etc.
Emotional Support	• support group to discuss RTW issues • from employer/coworkers for time to integrate back into workplace (respecting pace of the affected individual) • mentor/peer in the workplace/outside workplace who has gone through same • therapist/counsellor/social worker on negotiating emotional roller coaster • personal follow-up support re: how being back at work is proceeding • personal consultation with health professional about RTW • for self-employed individuals
Advocacy	• an advocate or navigator to deal with insurance company and employer • legal advice • for longer EI sick benefit • for improved labour laws to enforce duty to accommodate
Programs	• RTW program • Back at Work program when workers can attend • yoga, exercise • work hardening programs • to deal with side effects affecting RTW • how to deal with gaps in resume/job search
Practical Support	• income assistance for employed and self-employed • meeting with vocational counsellor or career coach

Findings: Caregivers[21]

Respondent Characteristics (Q1-7)

- 76 caregiver surveys were started: 60 complete (79%), 16 incomplete (21%).
- 88% of respondents were female (n = 52) and 93% were between 25 and 64 years of age (n = 56).[22]
- The majority of respondents (85%, n = 50) had more than a high school education (i.e., non-university certificate or diploma, bachelor's degree or a university degree above bachelor's).
- 44% (n = 26) of respondents lived in Ontario, 19% (n = 11) in Manitoba, 10% (n = 6) in Nova Scotia, 9% (n = 5) in Alberta, 7% (n = 4) in Quebec, 5% (n = 3) in New Brunswick and 6% (n = 5) in another province or territory.
- 60% (n = 36) lived in towns/cities that had more than 100,000 residents.
- 58% (n = 35) were married or living common-law and 22% (n = 13) were widowed.
- 22% (n = 13) had a personal income (not household) in the past 12 months of $30,000 or less, 24% (n = 14) had income between $30,001 and $60,000, 24% (n = 14) between $60,001 and $90,000, and 22% (n = 13) had an income of over $90,000; 9% (n = 6) choose not to answer the question.[23]

Cancer and Caregiving Experience

Relationship to Individual with Cancer (Q8)

- Approximately half of the respondents (52%, n = 31) had cared for a spouse/partner, 30% (n = 18) for a parent, 8% a sibling (n = 5), 3% a child (n = 2) and 7% other (n = 4) (e.g., friend, other family member, boyfriend).

Diagnosis, Cancer Type and Cancer Stage (Q9–12)

- The individuals who were receiving care from the caregivers were diagnosed with cancer in the following years: 11% (n = 6) had been diagnosed with cancer in 2006, 12% (n = 7) in 2007, 19% (n = 11) in 2008, 21% (n = 12) in 2009, 19% (n = 11) in 2010 and 18% (n = 10) in 2011.[24]
- The top three cancers that the individuals they were caring for had been diagnosed with were colorectal (35%, n = 21), lung (8%, n = 5) and leukemia (8%, n = 5) (Figure 3).

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[21] Percentages may not equal 100 due to rounding.

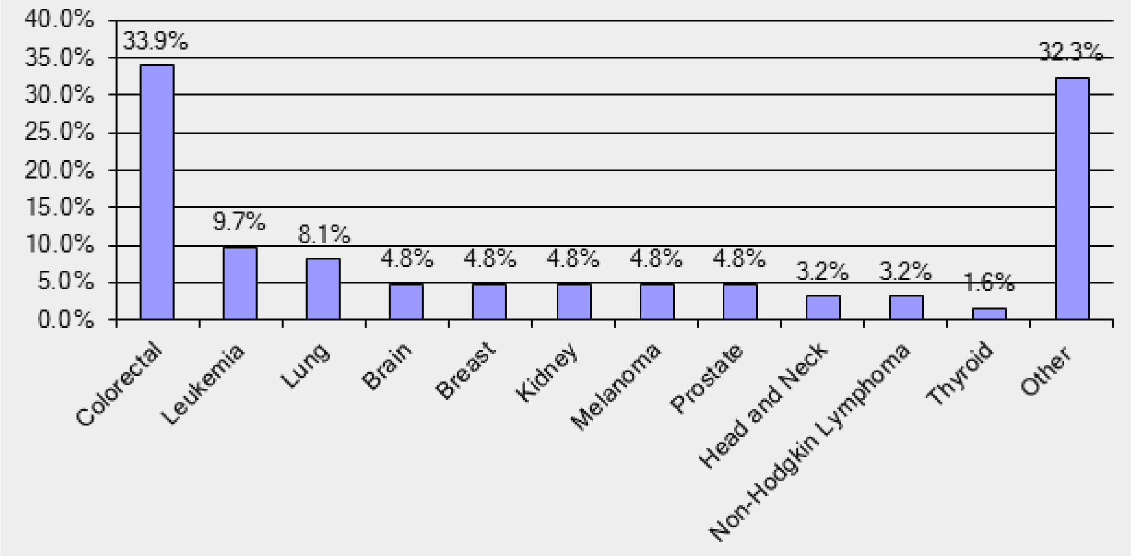
[22] A higher proportion of female respondents and people with higher education (at least completed high school graduation) are typical for health-related surveys.

[23] Income was measured as a categorical variable and therefore no mean or median is available.

[24] Three respondents indicated that the date of diagnosis was prior to 2006.

- The stage of cancer at time of diagnosis varied: 0 (3%), I (10%), II (3%), III (30%), IV (32%) and don't know (22%); it is worth noting that some caregivers were providing care during end-of-life.

Figure 3. Q11: What cancer(s) was the individual you provided care for diagnosed with?*



** Other cancers include ovarian, liver, testicular, myeloma, pancreatic, stomach, spleen, esophageal and mesothelioma.*

Cancer Treatment (Q13–15)

- The majority of individuals had received chemotherapy (77%, n = 46) and/or surgery (58%, n = 35) and/or medication[25] (38%, n = 23) and/or radiation treatment (36%, n = 22); only 2% (n = 1) indicated that they had not received any treatment following their cancer diagnosis (Figure 4).
- 68% (n = 41) of the individuals being cared for had completed treatment (3% in 2006, 8% in 2007, 15% in 2008, 23% in 2009, 23% in 2010, 28% in 2011).

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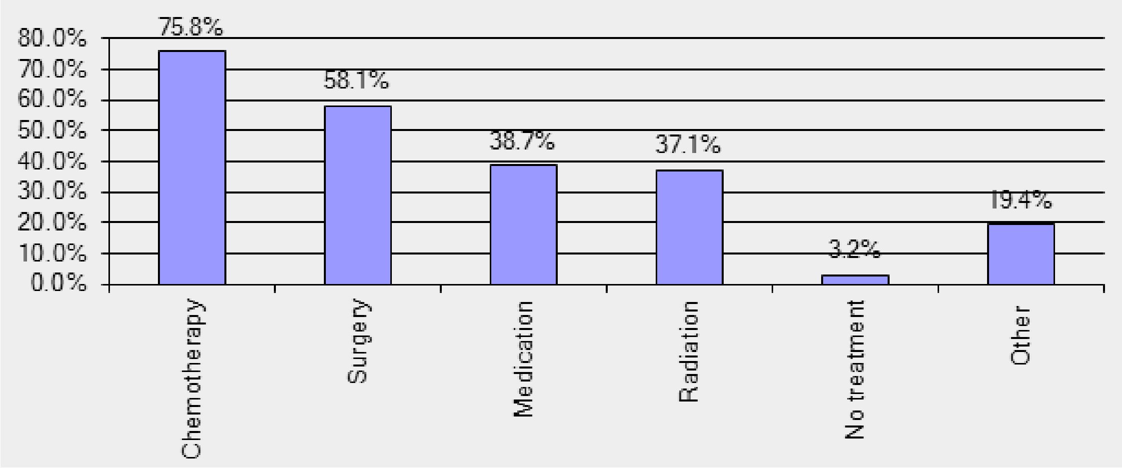
[25] Medication was defined as prescribed medications, including pain control, hormonal therapy, anti-emetics, etc.

Figure 4. Q13: What type of treatment did they have following this diagnosis?



Provision of Care (Q16-21)

- The majority of caregivers (43%, n = 26) had provided care for 6 months or longer, 32% (n = 19) indicated that they were still providing care, while the remainder provided care for less than 6 months.
- The amount of time spent providing care varied considerably and ranged from a few hours a week to 24 hours per day (Table 16). The majority of respondents provided care for a few or more hours a day on most days and, for 90% (n = 53) of respondents, their caregiving role occupied them often or all the time.

Table 16. Q17: During this time, on average how much time do/did you provide care to this individual?

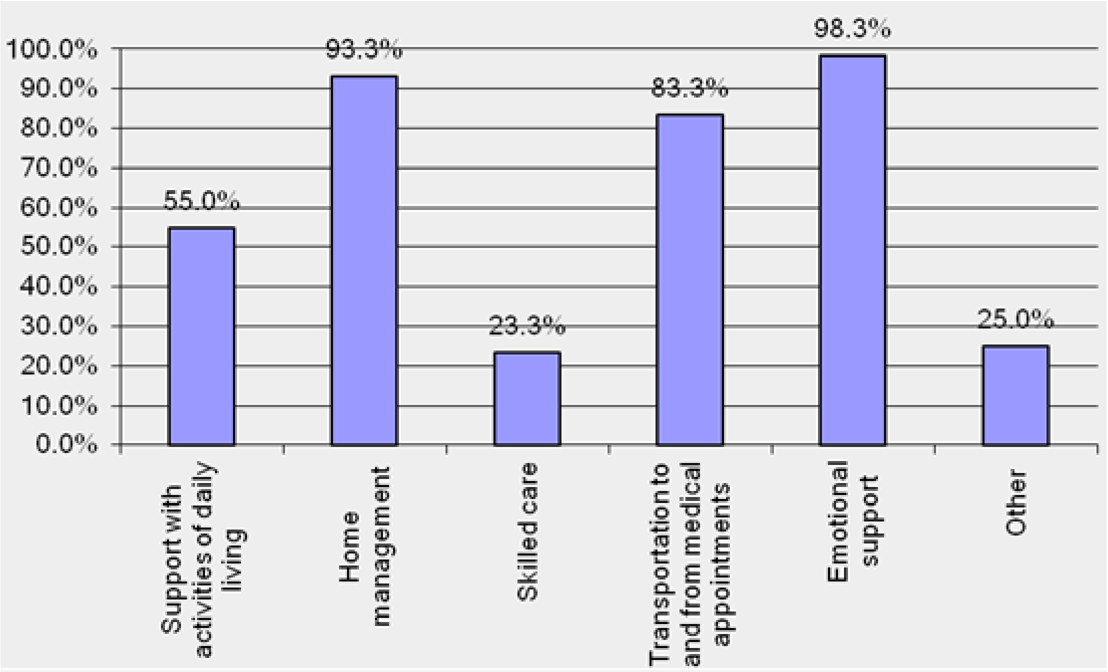
Answer Options	Response Percent	Response Count
A few hours a month	1.7%	1
A few hours a week	15.0%	9
Less than an hour a day most days	10.0%	6
A few hours a day most days	26.7%	16
A number of hours a day most days	26.7%	16
24 hours a day	8.3%	5
Other (please specify)	11.7%	7
	answered question	**60**
	skipped question	**0**

- Respondents provided care at the time of cancer diagnosis (75%, n = 45), during treatment (83%, n = 50) and during palliative care (42%, n = 25).
- 70% (n = 42) of caregivers live/lived in the same residence with the individual for whom they are/were caring.

Type of Care Provided (Q22)

- The majority of respondents provided emotional support (98%, n = 59), home management (93%, n = 56), and transportation to and from appointments (83%, n = 50); a smaller, yet still significant proportion provided support with activities of daily living (55%, n = 33) and 23% (n = 14) provided skilled care (Figure 5).

Figure 5. Q22: What types of care do/did you provide?



Income Supports and Employment Status

Pattern of Employment (Q23)

- The pattern of employment of respondents changed between the three time periods (at the time of cancer diagnosis, during cancer treatment and current employment status) (Table 17):
  - The majority of individuals were in full-time employment at the time the individual was diagnosed.
  - The number of individuals who indicated they were working part-time increased slightly during the treatment period.
  - More individuals indicated that they were not employed, on disability benefits or were retired currently than at the time of the cancer diagnosis.
  - 15% left full-time work between diagnosis and treatment. The numbers of those in full-time work at diagnosis were still lower than those in full-time work at the time of survey completion.

Table 17. Q23: Which of the following best describes *your* employment status during each of the following time periods?

Answer options	**At time individual you are/were providing care was diagnosed**		**During individual's cancer treatment**		**Your current employment status**		**Response count**	
Employed full-time by an organization (30 or more hours a week of paid work)	46	76.7%	39	65.0%	38	63.3%	49	81.7%
Employed part-time by an organization (less than 30 hours a week of paid work)	9	15.0%	12	20.0%	10	16.7%	15	25.0%
Self-employed full-time (30 or more hours a week)	3	5.0%	1	1.7%	1	1.7%	3	5.0%
Self-employed part-time (less than 30 hours a week)	1	1.7%	2	3.3%	2	3.3%	3	5.0%
Full-time university or college student	1	1.7%	1	1.7%	1	1.7%	2	3.3%
Not employed	0	0.0%	3	5.0%	2	3.3%	5	8.3%
Homemaker	0	0.0%	1	1.7%	0	0.0%	1	1.7%
On disability benefits	0	0.0%	3	5.0%	3	5.0%	5	8.3%
Retired from paid work	0	0.0%	0	0.0%	2	3.3%	2	3.3%
						answered question	**60**	
						skipped question	**0**	

Level of Position (Q24)

- 37% of respondents held either a management (i.e., manager, supervisor, leader or foreman) or senior management (CEO, VP, Director) position at the time of their diagnosis, 57% held no managerial or supervisory role and 5% were self-employed.

Size of Organization (Q25)

- The size of the organization individuals worked at the time they provided care varied considerably (Table 18).

Table 18. Q25: Approximately how many people were employed at the company where you worked at the time the individual to whom you are/were providing care was diagnosed with cancer?

Answer Options	**Response Percent**	**Response Count**
Self-employed	5.2%	3
Less than 5	10.3%	6
5 to 10	5.2%	3
11 to 20	8.6%	5
21 to 50	19.0%	11
51 to 100	8.6%	5
101 to 500	10.3%	6
Over 500	29.3%	17
Don't know/Not sure	3.4%	2
	answered question	**58**
	skipped question	**2**

Sources and Level of Income (Q26-29)

- At each of the three time periods (time individual they cared for was diagnosed, during treatment and currently) most respondents had salaries as a source of income, although this proportion declined during each period. More respondents indicated using personal savings and support from others during cancer treatment and currently (Table 19).
- 48% (n = 28) of respondents indicated that their income stayed the same in the 12 months after they began providing care, 42% (n = 25) indicated that it declined and 7% (n = 4) increased; 3% (n = 2) could not recall what change, if any, took place.

Table 19. Q26: What was *your* personal income (*not* household) during each of the following time periods?

Top Five Sources of Income at Each Time Period[26]

Answer options	At time individual you are/were providing care was diagnosed	During individual's cancer treatment	Your current sources of income
Wages and salaries	90%	78%	72%
Self-employment	12%	10%	10%
Child tax benefit	12%	14%	10%
Personal savings	9%	21%	16%
Employment insurance	9%		
Support from partner, spouse, family, friends		12%	12%
Dividends and interest		10%	

Time Away from Work (Q30)

- 29% (n = 17) of caregivers were away from work for 3 weeks or less to provide care, 34% (n = 20) were away 4 to 12 weeks, 24% (n = 14) were away more than 3 months, 5% (n = 3) retired or quit to provide care and 5% (n = 3) were not sure how much time they were away from work. Only 5% indicated not missing any work to provide care. (Table 20)

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[26] Respondents were allowed to select more than one source of income so the percentages represent the respondents that selected each income source.

Table 20. Q30: What was the total amount of time you were away from work to provide care?

Answer Options	Response Percent	Response Count
<1 week	15.3%	9
1 - 3 weeks	13.6%	8
4 - 8 weeks	20.3%	12
9 – 12 weeks	13.6%	8
13 - 16 weeks	8.5%	5
17 - 20 weeks	1.7%	1
21 - 24 weeks	3.4%	2
More than 24 weeks	10.2%	6
I did not miss any work during the time I provided care	5.1%	3
I retired from my job to provide care	1.7%	1
I quit my job to provide care	3.4%	2
I was dismissed from my job because of my caregiving responsibilities	0.0%	0
Don’t know/not sure	5.1%	3
I have not yet returned to work. Please specify the amount of time you have been away from work to date.	5.1%	3
	answered question	**59**
	skipped question	**1**

Factors Influencing the Amount of Time Taken or Not Taken Away From Work (Q31)

- The 52 responders stated they were influenced to take time away for work if they were not worried about finances, had a flexible work arrangement, the health of the other was a clear priority or if they needed to for personal reasons. Survey participants were more likely to return to work because of financial stress or feeling bad about being away. Taking time away from work or not was most often influenced by work-related factors. (Table 21)

Table 21. Q31: What influenced the amount of time that you did or did not take off from work following the cancer diagnosis (e.g., finances, work responsibilities, personal issues)?

Theme	What influenced time away from work	What influenced returning to work sooner
Financial Factors	• Had expenses covered	• Stress of lost income • Needed health benefits • Could not get STD
Work-Related Factors	• Flexible work arrangement • Used sick leave, vacation, compensation time, leave of absence, quit • Reduced work load • Self-employed so flexible	• Personal work ethic • Work responsibilities • Feel bad letting coworkers down
Health Factors	• Personal health reasons • Family responsibilities priority • Loved one dying was the priority • Provide relief for other caregiver	• Wanted to save days for priority health issues of loved one
Personal Factors	• Personal issues • Not state of mind to look for new work as was self-employed	• Work was close to treatment centre • Others cared for loved one while working • Stay at work to maintain normalcy

Adjustments Made to Paid Employment (Q32)

- When asked about the adjustments or changes the caregivers made to their paid employment, the top three adjustments or changes that respondents made 'often' as a result of caregiving responsibilities were using vacation time or sick days for care responsibilities (42%, n = 25), changing work schedule/time (41%, n = 24) and reducing work hours (34%, n = 20).

Work-Related Challenges Experienced

Work Place Accommodations Needed but Not Received (Q33)

- In this open-ended question, 63% of caregivers (n = 38) reported that they needed but did *not* receive reduced work hours, flexible time, support from their employer or coworkers when they needed to leave, time off with pay, personal time to deal with distress, the ability to take unpaid leave and the time away to not affect the possibility of promotion.

> *"Reduced hours or days off for chemo appointments would have helped. We scheduled chemo for late afternoon to accommodate my work."*

- Ten respondents (17%) indicated that they did get the accommodations they needed to provide care.

> *"My workplace was very accommodating as they allowed me to work from home and use vacation time to take my husband to the hospital for his treatments for that month of intensive chemo."*

Main Way Work Has Been Affected (Q34)

- Caregivers indicated that the main way that their work was affected ‘often’ during their caregiving experience was lack of concentration (59%, n = 35) followed by being less productive than usual (49%, n = 29), absences (42%, n = 25) and interruptions (34%, n = 20).

Main Work-Related Issue as a Caregiver (Q35)

- The main work-related challenges identified by caregivers (n = 53) included health issues (49%) and work concerns (42%), including loss of productivity and lack of support from their employer.

> *I was not prepared for the emotional toll it took on me, which led to me having to reduce hours and finally stop working. This led to further emotional stress as I was self-employed and not eligible for EI payments. Returning to work has been an emotional challenge for me.”*
>
> *“Working while my mother was battling cancer was the hardest thing I’ve ever done.”*

Table 22. Q35: What was your main work-related issue, concern or challenge that you have experienced as a result of providing care for the individual with cancer?

Main Work-Related Issue	Description
Health	• could not concentrate/focus at work • emotional health took toll (worry, stress, over-identifying)
Work	• could not maintain productivity • needed flexibility/shorter work day to help with responsibilities • lack of support from coworkers/employer • leaving work early/missing work • could not give to my job • travel • threatened job security
Financial	• maintaining financial stability
Personal	• sacrificed home responsibilities/juggling responsibilities

Return to Work Resources and Recommendations

Work-Related Information, Resources and/or Support (Q36–38)

- The primary sources of work-related information identified by respondents included family physician (28%, n = 16), oncologist (28%, n = 16), immediate work supervisor (26%, n = 15), online information (24%, n = 14), cancer support group (16%, n = 9) and nurses (16%, n = 9).
- 35% (n = 20) of respondents indicated that no one provided them with any work-related information, resources and/or support.

- Of the 10 caregivers who responded to the open-ended question about which RTW programs they participated in, only two mentioned that they had participated in any program. One participated in a program at Wellspring: Chingacousy (program not specified) and the other a program through Manulife Insurance. The remaining respondents to this question stated they knew of no such program.
- The top five information or supports that would have helped manage work-related concerns while providing care were how to manage caregiving and work demands (58%, n = 32), what employment rights are (53%, n = 29), information on potential sources of income support (49%, n = 27), impact providing care might have on work (47%, n = 26) and how to talk with employer about caregiving role (46%, n = 25).

Resources Most Helpful in Managing Work-Related Issues (Q39)

- Caregivers (n = 41) identified those resources/programs that were most helpful to them in managing work-related issues. Nearly one-half found that an employer offered the most help in the form of time off work and emotional support.
- A large minority of respondents stated that assistance was received from health care professionals, family and friends, and fellow caregivers and/or a self-care program (yoga, meditation).
- Nearly one-third mentioned that resources had not been offered or were unhelpful.

Table 23. Q39: What did you find to be the most helpful to you in managing work-related issues during your caregiving experience (e.g., resource, program, person, source of information)?

Resource	Description
Work-related	• understanding supervisor and colleagues/emotionally supportive • time off work • flexible schedule • ability to work from home
Resource Person	• health care professional (GP, nurse, social worker, psychiatrist) • peers • family/friends
Program	• yoga • meditation • Reiki • visualization • support group

Recommended Resources for Caregivers (Q40)

- 43 caregivers (72%) provided recommendations about the resources needed to alleviate or assist with their workplace issues.
- One-quarter of participants wanted more emotional support from employers, other caregivers and mental health professionals.

- The same number wanted income support from Compassionate Care (at a level they could live on) or another government-funded program.
- The remaining respondents recommended that information/programs be developed to inform caregivers and employers about the issues surrounding the workplace when someone in the caregiver's life has cancer.

> *"Some sort of emotional support would be amazing. As I said, I've been fortunate enough to have a work schedule with the flexibility to accommodate things like Mom's doctor's appointments. But even with that flexibility, I feel so worn out and alone sometimes, like there are just too many people expecting too many things from me at once, and it would be helpful to have other people to talk to about this, other people who are in similar situations."*
>
> *"The time and guidelines for EI Compassionate Care just don't fill the need. By the time you are eligible for Compassionate Care Benefits you are already overwhelmed and exhausted. Advocating for some legislated additional leave for caregivers — additional sick time or perhaps partly paid if it's for a long time. Ensuring health benefits continue for the caregiver if they are off work — this wouldn't be the time to take away health benefits."*
>
> *"I'm not sure that any one service can really provide what is needed. However, there is a need for nursing care in the home to give the caregiver a break and to assist when he/she has to leave the house."*

Table 24. Q40: What would you recommend is needed (e.g., information, service, program) to reduce work-related issues for caregivers of individuals who have been diagnosed with cancer?

Resource Needed	Description
Emotional Support	• provided by employers/insurance companies to caregivers that demonstrates grief is normal reaction • caregiver group • therapist
Income Support	• compassionate leave with income supplement • paid days off • not having to use sick days to help at home
Information	• about RTW provided by heath care professionals to coworkers, employees of caregivers • about extent of work disruption • about emotional support • about financial support
Program	• educate employers about needs of caregivers
Practical Support	• affordable assistance with home-based care services

Phase III: Focus Group Consultations

Methods

A draft focus group protocol was developed based on the findings from the literature review and individual interviews described in Phase I of this study. The protocol included an introduction, discussion of confidentiality, focus group purpose, a consent form and the questions to be asked (e.g., what kind of return to work arrangement was made with the employer and/or insurance company, how the return to work transition was experienced, gaps in resources and any recommendations for helpful resources). The draft protocol was approved by the Partnership and the final protocol is available in Appendix L.

The Partnership staff recruited participants with the assistance of their partners from across Canada, including the British Columbia Cancer Agency (which sent the recruitment flyer [see Appendix L] to their community partner organizations, and advertised it generally) and the Canadian Cancer Society (which attempted to recruit participants through the Montreal, Hamilton, Halifax, Toronto and Winnipeg offices).[27]

Individuals recruited to participate in the focus groups had to be at least 18 years of age, diagnosed with cancer in the previous 5 years, working at the time of diagnosis and had attempted to return to work. Potential participants were informed about the study's description and purpose in an email, were provided the consent forms and short demographic survey (see Appendix L), and were encouraged to contact the research team by email if they were interested in participating.

Sixteen participants contacted the researchers. All met the eligibility criteria, completed the consent forms, participated in the focus groups and completed the short demographic survey. Because of low numbers of participants in Vancouver and Winnipeg, the scheduled in-person groups were combined into one teleconference (n = 7). A second group was held in Montreal, with seven participants in-person and two on speaker phone (n = 9). The teleconference group was conducted by two facilitators and the in-person group was conducted in French by one facilitator.[28] Both groups were 1.5 hours in length, were digitally recorded and transcribed verbatim. Any identifying information (e.g., names of individuals) was removed during the transcription process to ensure confidentiality. All participants were given a $50 gift card honorarium.

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[27] Please note that, due to time and budget limitations, we did not recruit participants through cancer centres.

[28] The Canadian Cancer Society assisted with the logistics of the Montreal focus group and provided a staff member to take notes.

Analysis

The transcripts of the two focus groups were analyzed by the researchers and a coding framework was developed (Patton, 2001). Initial themes were anticipated from the literature (such as, *disclosure of diagnosis* and *income support*) and constituted a priori codes. The remaining emergent data was grouped into overall themes and subthemes and a detailed coding was carried out using QSR's NVivo 7.0.

Please note that the aim of a focus group is to draw out experiences regarding a particular event or phenomenon from a homogeneous group of participants (Patton, 2001). The data was coded into themes based also on the relative importance of that issue to the participants as demonstrated by the volume of data as well as importance based on the intensity of comments (Krueger, 1998). The final coding framework, broken down into chronologically ordered sections and themes and subthemes, is as follows:

Prior to Returning to Work

- Work and treatment
- Interaction with employer before RTW
    - Disclosure of diagnosis
    - During treatment
- Income support

Returning to Work

- Return to work process
    - Facilitators
    - Barriers

Reflections on Returning to Work

- Impact of cancer and RTW experience
- Resources
- Gaps and recommendations

The researchers then expounded on the meaningful patterns found in the data and supported these patterns with illustrative participant quotes.

Findings

Participant Demographics

All 16 focus group participants completed the demographic information (see Appendix M for complete information). Participants were between 25 and 64 years, 7 were male and 9 were female, most held a bachelor's degree or non-university certificate. Nine participants were living common-law or were married and 7 were single. Participants had experienced a variety of cancers. More than one participant had one of the following types of cancer: bladder, breast, ovarian, colorectal, lymphoma. The remaining participants had cancers such as testicular or lung. Most had received chemotherapy (n = 13) and most (n = 13) were no longer receiving treatment. Six participants held at least managerial positions, 8 were not in a position of management and 2 were self-employed. After treatment the majority returned to the same work with the same employer (n = 10).

Prior to Returning to Work

Work and Treatment

A good portion of the discussion in both focus groups was concentrated around the topic of what experiences people had with their work in general between the time they were diagnosed and treated for cancer and when they returned to work. As mentioned above, the participants underwent a variety of cancer treatments and were off work for various amounts of time. Some participants stopped work before diagnosis; others worked between surgery and diagnosis and then stopped until treatment was over; some worked through treatment (taking days off at a time to recover from chemotherapy); and some had surgery only and then returned to work. Those who continued to work cited the need to do so for financial reasons: they were self-employed and/or were the sole source of income for their families.

> *Because I was self-employed — I'm also a single parent — I didn't have the luxury of just not working. What I had to do was work around my treatment knowing that I would be taking a week off for chemo and a week off to recover from chemo.*

Some participants discussed their frustration with undergoing treatment while working. A few tried to arrange doctor's appointments around their work schedule; others needed to keep from their employer that they were undergoing cancer treatment for fear of losing their job.

Several participants noted that they encountered no difficulties managing cancer treatment and work.

> *…my immediate manager, who was a woman a little older than I am…knew what was ahead. She said…you're off for 6 to 8 weeks for abdominal surgery. So, she made preparations for that and then as we found out upon surgery that it was cancer she knew that I was going to be away for a long time. They looked after things and it was very easy for me.*

Interaction with the Employer Before RTW

A large amount of the conversation in both groups focused on more specific interactions with their employers while they were undergoing diagnosis and treatment.

Disclosure of Diagnosis

Participants felt differently about disclosing their illness to their employer or future employers. A few participants who did not leave work for cancer treatment talked about how they feared disclosure would negatively impact their job security. Others, whether or not they left work for treatment, spoke about how disclosing negatively affected their relationship to their employer or job.

> *I was self-employed. I hid my treatment for half of it…my supervisor at the time would have forced me out if he knew. Halfway through my treatment he was forced out and I could come clean about it…*
>
> *I pretty much waited a couple of weeks before actually telling my employers. They kept asking, asking, how the surgery went and I just kept putting it off…I work for a very small company…I didn't know what to do. Anybody I had spoken to all worked for large companies...I phoned the Labour Board and asked what I should do. They recommended that I be openly honest and tell my employer everything, which I regret doing because they ended up kind of using that information against me. They weren't really supportive.*

A few other participants shared positive outcomes.

> *…once I was diagnosed after the surgery and I was home again, I actually wrote quite a widespread email. I used it as a teaching lesson of what I was going through and why I'd be gone for so long and what I'd be fighting and by the way, here are the symptoms, as an educational piece. And the response to that email I sent to my colleagues…there's probably 100 people on the list. I got great feedback. For me it was a way of being proactive about my disease…*

This participant added that as she was returning to work she wondered about the wisdom of her widespread disclosure and how that disclosure could threaten her job security given her workplace was laying off employers.

> *…one of the reasons I encouraged myself to go back when I did, was that they did some serious layoffs. And it struck me, I thought, "oh god, why did I tell everybody?"*

During Treatment

A second area of discussion concerned what went well and did not go well when directly interacting with the employer. One participant was in a position to take unpaid time from work to receive treatment and had an employer who demanded to see her medical records.

> *In August, they phoned Cancer Care demanding my medical record behind my back, asking for the same medical records that the insurance company was getting.*

Most participants relayed positive stories of interacting with their employer during treatment. Employers were perceived as emotionally supportive, flexible and demanding little from employees during this period of time.

> *It was phone calls and paperwork. I didn't really have to go in to work to do much of anything. They just needed more information about what was going on. They didn't ask for a lot of details.*
>
> *My part-time job was very supportive. They were very open. It was a retail operation but they were more than flexible. I'm not allowed to go on leave with them so I just had to do one shift a month, three hours just to keep my status. But honest, sometimes I've gone four months without working a three-hour shift and they don't say anything. They understand.*
>
> *My sister actually recalled that when I was in the recovery room, that I kept shouting, "Thank god for (names employer)." I have two kids in university. Boy was I glad that I was working for a big company with good benefits. They have been very good in helping me to find what works.*
>
> *…I had a fairly positive situation… I did have a return-to-work coordinator working with me. They had kept in contact, mainly through email through the recovery process. (How was that interaction?) It was very good.*

Income Support

Participants in both focus groups experienced several concerns related to income support. With EI, participants encountered delays in receiving money due to employer error or due to the mandatory systemic delay between applying for and receiving EI and/or between finishing EI and starting long-term disability, found the period of time to receive EI was not long enough, found the amount of EI insufficient to cover expenses and suffered financially with the deductions made by EI if that individual made money elsewhere.

> *You're covered for 15 weeks maximum, that's it. What they pay you as a medical leave is even less than if I would have been laid off. And so, for a whole month, I had no income because once my EI benefits cut off I had to wait for the long-term disability to kick in.*

> *For August, I basically got $69.00 from EI. And I knew I had some other clients for September and October that I already had agreed to their business. I thought well, I can't be on EI because I'm going to end up losing money if I stay on EI, which kind of forced me to go back to work.*

Participants also expressed exasperation at confusion when applying for and receiving short- and/or long-term disability benefits. Some were unsure about whether they would be approved to receive this form of income support, others were deemed ineligible. One participant shared his frustration at not knowing he could have topped up his CPP had he known he could have taken early retirement, which he then immediately did.

> *They finally told me that if I do earn any extra money from retirement — CPP — they would top me up to within a certain percentage of what I was making when I was working full-time. Nobody ever tells you this when you go on disability. I could have been making $1000 more a month if I had known that I could have taken early retirement and they'd have topped me up to that percentage. That's the key thing that I'd like to get across if I get anything across (at the focus group).*

Returning to Work

The discussion in both groups mainly centered on the return to work process.

Facilitators

Factors that facilitated the RTW process included a gradual or flexible work schedule; an emotionally and instrumentally supportive employer; an employer that paid for time away for medical appointments, bought new work equipment to accommodate a cancer-related disability and offered work coverage to support gradual return so the work could still be completed.

> *…they gave me the opportunity to come back however many days, however many hours I wanted. And they often said to me…you look tired. Why don't you just go home? Why don't you work from home?...giving me that option, actually allowed me to come back quicker because it took so much pressure off of me. I could come back according to how I felt. For me it was a real positive.*

> *Yes, I work in the high tech industry so it was possible to work from home by computer. And after the six months it was rather gradual, or progressive, a few days a week, a few hours a day. I had the flexibility of working from home so it would really depend on how I felt at the time.*

> *My employer has been very good about allowing me to take off time to go to things like brain fog class or Pilates for cancer patients and stuff like that. They see it as being part of the health insurance. Even*

> *though they don't pay for it but they see it as a way of working toward my health, keeping me healthy, them allowing me to do that during their hours while they're paying me, that's really, really supportive.*

Physical Barriers

The biggest barrier associated with returning to work was trying to adjust to the enormous impact of cancer treatment side effects, including fatigue, cognitive dysfunction (memory and concentration lapses), neuropathy, aches and a variety of other problems. A few participants felt that they should have taken more time to recover from side effects before going back to work, and many talked about returning to work and not feeling as competent because of also dealing with side effects.

> *It was basically once you're in the door the job is the job. I could have pushed it to the point of staying off more probably. It's the same thing as what I've heard other people saying is you're extremely tired. You don't have the stamina that you had before and that type of thing. The first couple of weeks I did the half-days and three-quarter days. In hindsight, I probably should have done a month or two of that before I got back into it because I still definitely was not back to the way I was prior to my diagnosis.*

> *…like the brain fog. It's the awareness. It's the focusing. It's the concentration. A simple task… you're making sure you're not making a mistake. And that's what I felt like. I couldn't make a mistake because if I made a mistake then like oh my god, heaven forbid.*

> *It is for real. That when you're going back to work, it takes longer for you to do your job. You're concentrating twice as hard because you're using that extra energy. You're twice as fatigued, three times more fatigued. It's having someone acknowledge that it's actually a disability or actually a problem.*

One gentleman developed physical problems from lifting once he returned to work and had to retire because of it. (Retiring put him further ahead financially compared to being on long-term disability but further behind compared to receiving a full-time salary).

> *Right after my healing from that surgery, I went back to work. I was there for about nine months and developed three hernias on the same scar tissue. I was taken off work. They did surgery on the scar tissue and then I was put on permanent disability. The (employer) said they couldn't retrain me so I've been forced to retire.*

Financial Barriers

Members of both groups spoke about financial issues (less income from benefits plans and other sources compared to work-related compensation) and having no choice but to return to work early because of them. The conversations in each focus group suggested that several factors may have influenced how people described the impact of financial concerns. These financial concerns seemed a particular worry for those who lived alone, were from a single income family, were self-employed, or who used up their savings to pay for treatment or living expenses.

> *And I knew that I didn't have much of a choice and (the doctor would) say, "be careful, be careful, you can't go back right away." But it's the obligation of going back to work that is the most difficult to manage, and it was a financial pressure more than anything else.*
>
> *And due to financial pressure I went back to work in a lab (with carcinogenic substances)…I try to be careful but it is a concern or worry every day.*

Other Barriers

Other barriers included unrealistic expectations — the employer or health professional (in one situation the surgeon suggested a faster RTW time than the individual with cancer was comfortable with) or the employee expects to be able to go back and be able to function at a level similar to prior to cancer; the employer not abiding by the plan to return gradually; hassling the employee about attending follow-up doctor's appointments or threatening job security; work environment changes that were difficult to adapt to; and disclosure fears related to searching for new employment.

> *And they thought that after the amount of time that the doctor had granted that everything would be perfect, that I'd come back in top shape within five months. I'd been down and out, flat out, for at least one year, so it's impossible. And instead of informing themselves and looking into this, there's even somebody in HR who was a nurse and, no, they said, we're going to hire somebody to replace you, that's it.*
>
> *(Did [the surgeon] tell you to go for fewer days per week?) Three days. And that's when my employer exerted pressure and caused me problems because he felt that I was taking advantage of the system…And such was not the case at all. And that's where the break occurred with my employer.*
>
> *…to be asked every time for a doctor's paper to confirm the whys and wherefores and why I was taking time off for my follow-up appointments. I found that very, very difficult. It was a very heavy burden on my shoulders.*
>
> *I mean we can't disclose that we have cancer because, legally they're not allowed to turn you down, but when looking for a job they're going to say we don't fit the profile.*

Reflections on Returning to Work

Impact of RTW/Cancer Experience

Members of both groups reflected on the impact of cancer, cancer treatment and side effects in the context of returning to work. Some members felt that the impact was deleterious, such as their perception of being passed over for a promotion, feeling less self-confident and using up their sick time.

> *I was up for promotion and for quite a substantial one and because of my sick leave and getting sick more often, I haven't been. I've been passed over.*

Others reported that the experience was a positive one. This experience encouraged them to conserve energy and delegate more, reduce their workload, take better care of themselves, risk more by going after a desired promotion, and judge themselves less and distract them from thinking of the disease.

> *I was promoted. (Was it based on your diagnosis of cancer that made it such that you applied for other positions?) Yes, indirectly. Psychologically. Because it enabled me to leave my comfort zone and to simply say, no, I can do it and I lived through cancer I can certainly live through many other things and far more minor things, so I can certainly put myself through this.*
>
> *…returning to work helped me psychologically, got my mind off things, because then we get to think of other things, other than disease…*

Resources

Only a few members in each of the two groups talked about RTW resources they accessed. Two individuals accessed a return to work coordinator (offered by their employer), two accessed mental health resources through the cancer centre or community organization, and two talked about knowing of resources but not using them for fear of negative repercussions.

> *So for the return to work we must deal with Health Canada who comes to your office and evaluates the ergonomy, the level of stress, fatigue and everything. And it causes an additional level of stress and also labels you with top management, because we cause trouble… So I decided to not use the services and to go back to work full-time.*

Gaps and Recommendations

Though only a few knew about and used resources, many weighed in on what would have been important to access had they had the opportunity. Drawing from what they found lacking in their own RTW experience, the most often repeated recommendation was to have information or a program available to employers about the physical and emotional side effects of cancer treatment.

> *But I would have liked them to have had a program to help employers understand patients after such significant treatments.*
>
> *The key part of it is just in education (about side effects from treatment). Just because your treatments are done doesn't necessarily mean you're ready to go back to work.*

Other recommendations focused on having information about income support or financial issues. Specifically participants suggested increasing the amount of and the time one can receive EI, eliminating any gaps in receiving money from income support programs, receiving information from the insurance company or cancer agency about what's available to help financially, and a navigator to help with accessing insurance benefits.

> *I would have expected more information from my insurance company and even the cancer agency. I would have liked more information about what was available, especially financially.*

Limitations of the Research Process

This project was designed to provide information for program design (and was not intended to be statistically representative of the cancer population in Canada). As such, we relied on convenience sampling through the Partnership's relationships with cancer-related community-based and national organizations. Our findings were influenced by this recruitment strategy in the following ways:

1. The recruitment was conducted by the Partnership and based on its relationships, mainly with cancer-based community organizations. We therefore heard from people affected by cancer who are more likely to have accessed helpful resources. Their concerns might not reflect the concerns of those who are not likely to seek this kind of support.
2. Of the survey respondents, 60% reported that they heard about the survey from a community-based cancer support organization. We noticed that when Wellspring Toronto promoted this survey to its members, we had a spike in the response rate and Wellspring's programs were most often referred to in the qualitative survey responses. This could have been one of the main reasons this survey is biased to represent the needs of Ontario respondents.
3. Our recruitment also did not extend to those individuals currently accessing cancer treatment centres across Canada. The budget and timeframe of this project precluded us from working over long periods with each cancer centre's ethics review board. We therefore might not have the perspective of those who are still receiving treatment, have returned to work or never left work.

4. Women are more likely than men to complete surveys and as such there is a bias in our survey responders by gender and by cancer type. Nearly half (46%) the respondents had breast cancer, so when we undertook the bivariate analysis, we could not conduct a meaningful comparison by cancer type. The remaining respondents reported they were diagnosed with different cancers, which resulted in the numbers in the other cells being too small. This was not intended to be a study of return to work challenges for breast cancer patients and how these issues and concerns compared to people diagnosed with other cancers. There is also a bias in both the survey and focus group participants regarding education and labour type. Most respondents had more than high school education and were non-manual labourers.
5. We were only able to conduct 2 focus groups because of timing; 3 to 5 would have been ideal.

Assessment Across Phases II and III

These consultations were conducted to determine current Canadian information on the challenges that people dealing with cancer face when they return to work (as an employee or self-employed) during or after treatment. The consultations also looked at the effect caring for a person with cancer had on the caregiver whether they continued to work or took time off work for caregiving.

Individuals with Cancer

Overall, the survey and focus group participants — well-educated employees typically employed in non-manual work — communicated a wide variety of return to work experiences. Some stayed at work during cancer diagnosis and treatment, some left work during those time periods and, if they left work, they talked about the process of returning to work. Having received cancer treatment affected their work experience in terms of their financial wellbeing, their interaction with their employer and the impact of their health on their work.

For the most part, individuals with cancer were well supported by their employers during all phases of their cancer experience and received workplace accommodations to assist them to reintegrate. However, the participants with whom we consulted also talked about the conditions under which returning to work was particularly problematic: some experienced a decrease in their income, some had difficult experiences interacting with their employer and coworkers, and some returned to work while experiencing deleterious side effects that interfered with their work.

Highlights of Phases II and III focus on the challenges of income and income support, difficult interactions with employers and the impact of health on work as reported by the survey respondents, the focus group participants or both.

Income and Income Supports

- Those who continued to work through their cancer treatment or who needed to return to work early cited financial needs.
- In the 12 months following diagnosis, 60% of survey respondents experienced a decrease in their income, especially those who were either self-employed or in non-managerial positions.
- During treatment, 78% of income was derived from income supports: STD, LTD and EI. For those who are self-employed or who work for companies where STD and LTD is not available, the issue of accessing EI for a longer period of time was salient and finding financial resources for the self-employed is very concerning.
- The process of receiving disability insurance and EI can be difficult because of waiting periods or gaps in time between applying and receiving benefits. Furthermore, EI is not offered for a long enough period of time (15 weeks vs. the 38 weeks typically needed to undergo surgery, chemotherapy and radiation, and then recovery time). (Canadian Breast Cancer Network, 2009).
- **What is needed:** information about financial resources and more income support, especially for those who are in non-managerial positions, who need to leave work in the 12 months following diagnosis or who are self-employed.

Interaction with Work/Employer

- A large number of individuals (40%) who participated in this research left work for more than 6 months to undergo cancer treatment. Though half of the responders returned to work gradually, almost 20% returned to full-time work immediately (mainly men, managers and supervisors, and the self-employed).
- The ability to work from home and have paid time off for medical appointments was more likely received by those working for employers with over 500 employees (not the situation for 66% of survey respondents, so attention must be paid to encourage employers in smaller companies to offer these accommodations).
- 50% reported work changes beyond their control, such as changes to job description, no choice in RTW process or change in environment at work.
- Almost three-quarters of survey participants reported returning to work for the same employer.
- A small number of survey respondents told us that their job had either terminated (4.5%) or they were not able to return to it (7.2%).
- Most individuals with cancer tell their employer about their diagnosis, although some do not (those who do not leave work for treatment). Disclosing their diagnosis affected a few employees negatively.
- Once individuals had returned to work, they reported changes through accommodations such as working less, reducing workload, reducing stress at work by com-

muting less, better work/life boundaries or changing perspective on work to have it mean less.

- **What is needed:** information to employers and individuals with cancer about:
  - what to expect regarding average recovery times when returning to work, especially for those employees in non-managerial positions;
  - the best ways to manage the RTW process (knowing about and negotiating gradual and/or flexible work return arrangements and, for employees only, how to talk to the employer or coworkers, managing work demands), especially for those employees in non-managerial positions;
  - the best ways for employers/coworkers to support the returning employee;
  - information on employment rights, especially for those employees in non-managerial positions.

Health Affecting Work

- A large majority of survey and focus group participants reported that their main work-related issue was side effects following treatment and while at work — particularly fatigue and loss of energy, as well as cognitive problems — and trying to manage them. This is not surprising considering 63% of survey respondents received chemotherapy (although only 40% left work for more than 6 months), which can cause loss of energy and affect cognitive function. Even more concerning, respondents who had chemotherapy and who were in non-managerial positions were more likely to not have returned to work in any capacity.
- Almost one-third of the survey sample said they could not work the same way that they did before diagnosis. This was more likely the situation for those who reported fatigue, reduced energy, reduced cognitive ability, anxiety, pain, sleep problems, shortness of breath, body image and appearance, depression, concern about infection, job-related stress, personal stress or reduced physical ability.
- Respondents were more likely to indicate that they were unable to work full-time now if they were experiencing the problems reported in the previous bullet (other than shortness of breath and body image and appearance) as well as nausea, loss of appetite.
- Fatigue, loss of energy and cognitive concerns (among others) were also more likely to be reported with needing a flexible schedule of work hours, a gradual increase in work schedule and workload, or reduced hours.
- Cognitive concerns (among other concerns) without fatigue were associated with being more likely to want paid time off for medical appointments, and support from coworkers and their supervisor/employer.
- Many returning employees are concerned that their employers do not understand how side effects negatively impact their work performance.

- **What is needed:** information or a program for employers about the side effects of cancer treatment and how to help individuals with cancer manage side effects at work.

Caregivers

Overall, the survey participants — primarily women who were well-educated and non-manual employees — communicated similar experiences of caring for an immediate family member or close friend who was more likely to be diagnosed at a later stage of cancer and who was most likely to have received chemotherapy.

For many, managing the caregiving and the employee role over an extended period of time (e.g., over 6 months) and experiencing a decrease in income was a great burden.

Highlights of Phase II focus on the challenges of the caregiving role and on the effect of that role on the caregiver's employment.

Caregiving Role

- Almost all caregivers reported being occupied by this role often or most of the time and over 40% of these caregivers fulfilled this role for over 6 months.
- The type of care they were mainly providing (other than emotional support) included tasks that required their physical presence, and thus they needed to be away from their place of employment (transportation, help with activities of daily living, home management), and for the majority of respondents these tasks were required a few or more hours per day.
- Caregivers reported that they experienced stress and not only needed time off to provide care for others but also time away from work to take care of themselves.
- **What is needed:** Income support and respite care for the caregiver.

Caregiving and Work

- To carry out this role, 15% reported leaving full-time work, though the majority retained their pattern of employment over the time of the caregiving experience.
- 90% reported missing some work, a decrease in income, and needing to use their personal savings.
- To leave work, caregivers used sick days, adopted a flexible schedule (over 40%) (the same hours just completed on a flexible schedule) or reduced hours.
- Caregivers left work if they could afford to do so without pay or if they had their employer's support to do so with pay. Caregivers did not leave work if they could not afford to or didn't receive their employer's support (63% did not receive support to leave or to work flexibly).

- The main work-related issue was loss of concentration and productivity, stress and lack of support from colleagues, which if offered would help ease the situation.
- **What is needed:** Information on how to manage work and caregiving, how to talk to the employer about caregiving and working, and employee rights. Concerning the employers, the caregivers wanted their support and wanted information provided to them about how the workplace might support caregivers of someone with cancer.

Recommendations

The following recommendations focus on resources, partnerships, advocacy and future research. We recommend that all stakeholders are consulted to consider the most meaningful resources to create, offer and distribute.

Resources

- Create flexible content to address a wide variety of RTW experiences: staying at work or leaving work, being self-employed or working for an employer.
- Offer RTW resources to participants over the cancer trajectory — from diagnosis to recovery. Resources at diagnosis could include how to disclose diagnosis to an employer. Resources during treatment could include information about and links to income support, and where to find assistance completing STD, LTD and EI forms. Resources during recovery could include expected average recovery times and how to manage side effects to prepare for work or once the person with cancer has returned to work.

Income and Income Supports

- Create a website and/or an information pamphlet referring individuals with cancer and caregivers to financial resources (federal and provincial government programs, and resources offered by community organizations or foundations).
- Create an awareness campaign for those who are self-employed about accessing critical illness insurance and/or private disability insurance.

Interacting with Work/Employer

- Create a webpage, instructional video, in-person program and/or brochure about disclosing cancer diagnosis and treatment to a current and/or future employer.
- Enlist a group of caregivers and employers to create resources for these stakeholders about workplace accommodations during a caregiving experience.
- Create and distribute information to individuals with cancer regarding their rights to workplace accommodation.

- Work with employers of less than 500 employees to create workable workplace accommodation processes.

Health Affecting Work

- Develop information for individuals with cancer about side effects they might encounter that could affect their work, and direct them to existing rehabilitation programs.
- Create rehabilitation programs and/or resources (web-based or in-person) to address how to manage side effects such as fatigue and reduced cognitive function.
- Investigate the creation of guidelines and timescales for returning to work — recognizing that uncertainty is always part of cancer and cancer treatment outcomes — and develop a guideline or criteria that would assist health professionals and employees decide when they are fit to return to work during or following treatment.[29]
- Enlist a group of individuals with cancer, insurance representatives, employers and cancer care professionals to assist with the development of resources for all stakeholders regarding workplace accommodations to handle, among other challenges, medical appointments, side effects and changes in work abilities.
- Organize respite care for caregivers.

Partnerships and Advocacy

- Partner with organizations interested in improving 1) the eligibility criteria and length of EI sickness benefits and 2) the eligibility criteria and length of Compassionate Care benefit, and begin to strategize about how to effect policy change.

Future Research

These research participants were recruited through community-based organizations. Individuals with cancer who are in contact with these organizations are presumably more likely to access resources and so we have not yet heard about the RTW experiences of those who do not readily access help. Because of this study limitation and because of the low numbers of focus group participants in particular, we recommend that future focus groups be implemented with participants recruited through cancer centres.

Because the current sample of individuals recruited to participate in Phases II and III was well-educated, we also recommend that future research include participants with a broader range of educational experience.

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[29] Macmillan Cancer Support. Retrieved 01/14/2012 from http://www.Macmillan.org.uk/Home.aspx

Appendix A: Search Strategy

Scope

To identify return to work challenges for persons who have been diagnosed with cancer and caregivers. The focus will not be on interventions, programs and policies and will not include articles that focus on the employer's perspective. The review will not assess the quality of articles but rather will assess articles included based on their relevance to RTW challenges as experienced by individuals with cancer and caregivers.

Search Strategy

A number of searches will be conducted using the electronic databases PubMed/Medline, EMBASE, PsycINFO and CINAHL. A targeted hand search of the *Journal of Cancer Survivorship* will also be conducted. In addition, survivorship reports from the countries listed below will be reviewed. Limits relevant to each search are outlined below but will include studies published from January 2000 to present, English language, country (Canada, the United States, the United Kingdom, Norway, Finland, the Netherlands, Germany and Australia), human subjects and adults (18+ years). Where appropriate, both MeSH and text-word terms will be used to maximize retrieval. The bibliographic software tool RefWorks will be used to manage the search results.

RTW and Individuals with Cancer Searches

Search #1: An update of Nitkin et al.'s review report (2011) to identify additional articles on RTW and individuals with cancer in Canada (for the topics related to RTW issues, specifically functional and personal impact of cancer on work, factors associated with positive RTW experiences and barriers to RTW as described on page 4 of the Nitkin et al. report). The search will be limited to years 2009 to mid-2011.

Key terms: Cancer survivor OR cancer OR cancer patient OR neoplasm AND employment OR work OR workplace OR work environment OR unemployment OR return to work OR work ability OR work performance OR work retention OR work demands[30]

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[30] Cancer patient terms and RTW terms were identified based on review article Feuerstein et al. (2010).

Limits to search:

Time	2009 to mid-2011
Country	Canada
Discipline	Health
Gender	Male and female
Age	Working Age
Type of Materials	Journal articles

Search # 2: A review of RTW issues in cancer for individuals with cancer in the United States, the United Kingdom, the Netherlands, Germany, Norway, Australia and Finland. Articles from these jurisdictions that have been published in the past 10 years will be identified.

Key Terms: Cancer survivor OR cancer OR cancer patient OR neoplasm AND employment OR work OR workplace OR work environment OR unemployment OR return to work OR work ability OR work performance OR work retention OR work demands

Limits to search:

Time	2000 to mid-2011
Country	United States, United Kingdom, Netherlands, Germany, Norway, Australia and Finland
Discipline	Health
Gender	Male and female
Age	Working age
Type of Materials	Journal and review articles

RTW, Cancer and Caregiver Searches

Search #3: A review of caregiver-specific literature related to cancer in Canada published in the past 10 years.

Key Terms: Cancer OR neoplasm AND employment OR work OR workplace OR work environment OR unemployment OR return to work OR work ability OR work performance OR work retention OR work demands AND caregivers OR carers OR caregiving[31]

Limits to search:

Time	2000 to mid-2011
Country	Canada
Discipline	Health
Gender	Male and female
Age	Working age
Type of Materials	Journal articles

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[31] Caregiver terms were identified by reviewing caregiver literature and considering appropriate synonyms.

Search # 4: A review of RTW issues in cancer for caregivers in the United States, the United Kingdom, the Netherlands, Germany, Norway, Australia and Finland. These will be limited to review articles if needed.

Key Terms: Cancer OR neoplasm AND employment OR work OR workplace OR work environment OR unemployment OR return to work OR work ability OR work performance OR work retention OR work demands AND caregiver OR carers OR caregiving

Limits to search:

Time	2000 to mid-2011
Country	United States, United Kingdom, Netherlands, Germany, Norway, Australia and Finland
Discipline	Healthcare, employment
Gender	Male and female
Age	Working age
Type of Materials	Journal and review articles

RTW and Chronic Diseases Canada

Search #5: A review of RTW issues in other chronic diseases (specifically HIV and mental health) in Canada, the United States, the United Kingdom, the Netherlands, Germany, Norway, Australia and Finland in the past 10 years. Limited to review articles only.

Key terms: Chronic disease OR HIV OR mental health AND employment OR work OR workplace OR work environment OR unemployment OR return to work OR work ability OR work performance OR work retention OR work demands[32]

Limits to search:

Time	2000-2011
Country	Canada, United States, United Kingdom, Netherlands, Germany, Norway, Australia and Finland
Discipline	Health—chronic diseases
Gender	Male and female
Age	Working age
Type of Materials	Review articles

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[32] Cancer patient terms and RTW terms were identified based on review article Feuerstein M et al 2010

Appendix B: Literature Review Findings

Individuals with Cancer and RTW

A total of 61 articles remained from a literature search that garnered 283 articles (duplicates and irrelevant articles were removed); highlights are summarized below.

Articles were excluded for the following reasons: the findings were from the perspective of formal/professional caregivers (e.g., health care professionals), they focused on specific issues not related to work and/or financial issues, they focused on childhood cancers and RTW, or they focused on interventions and RTW.

Most of the RTW literature for individuals with cancer focused on the length of and reasons for time away from work; the demographics associated with stopping and returning to work; the type of cancer and return to work issues; or the barriers faced by those leaving, contemplating returning or having returned to work. Less often did the literature focus on what made it easier for individuals with cancer to return to work.

🇨🇦 = Canadian source

General Information

Demographics and RTW

- Almost 60% of individuals with cancer are of working age (Oberst et al., 2010).
- Female survivors are less likely to return to work than males (Kirchoff, Leisenring and Syrjala, 2010).
- Individuals with cancer are at a small increased risk of unemployment following cancer treatment, especially if they are between the ages of 50 and 60 years at diagnosis, if they are engaged in manual work at a medium-income level and have a vocational education (Carlsen et al., 2008).
- Older age, more than one co-morbid condition and receiving chemotherapy predicted work changes after cancer (Mols et al., 2009).
- Younger age, higher education, being male, fewer days of sick leave are significantly associated with a greater likelihood of returning to work (Mehnert, 2011) and survivors were less likely to encounter work changes if they had a medium educational level (Mols et al., 2009).
- Racial or ethnic minority women are more likely to stop working altogether after a diagnosis of breast cancer (Mujahid et al., 2010).
- Individuals with cancer who were employed in high occupational classes returned to work earlier, but time to return to full-time work did not differ across occupa-

tional classes. Those who were employed by large companies returned to work more quickly than those in small companies (Roelen et al., 2010).

- In a survey of men and women with the 10 most invasive cancers, 84% of those who had a cancer diagnosis were still working and 24% had made work changes because of the cancer. These changes were more common among those who were self-employed and those with a lower level of education (Torp et al., 2011).
- In a study to understand what prevented women with breast cancer from returning to work 2 years post-diagnosis, age, educational level, matrimonial status and presence of under-age children were not significantly associated with return to work (Johnsson et al., 2007).

Type of Cancer and RTW

- A review of the cancer and RTW literature found that overall, 63.5% of individuals with cancer returned to work (Mehnert, 2011).
- Having a breast cancer diagnosis and treatment negatively affects employment (Bradley, Bednarek and Neumark, 2002); stopping work is more likely, especially following chemotherapy (Mujahid et al., 2010); and 80% leave work after diagnosis but return to work after treatment (Molina Villaverde et al., 2008).
- Of long-term survivors of prostate cancer, endometrial cancer, non-Hodgkin's lymphoma and Hodgkin's lymphoma, 49% experienced no changes in their work situation after their diagnoses, 17% worked fewer hours and 34% stopped working or retired (Mols et al., 2009).
- Of the 50% of men with prostate cancer who had open radical retropubic prostatectomy and then returned to work, those who returned part-time returned two weeks post-surgery and those that returned full-time went back three weeks post-surgery (Sultan et al., 2006).
- 🇨🇦 One-sixth of cancer patients with non-metastatic lung or colorectal cancer leave the workforce following treatment, particularly those who have a poor prognoses or lower socioeconomic status (Earle et al., 2010).
- Among working adults who were diagnosed with colorectal cancer, 33% of men and 40% of women were not working at one year post-diagnosis (Gordon, Lynch and Newman, 2008).
- Of men and women with meningiomas, 86% returned to work at a pre-diagnosis level of functioning (Kalkanis et al., 2000).
- At five years post-diagnosis, 60% of disease-free hematologic malignancy patients were working full-time and 32% were working part-time (Kirchoff et al., 2010).
- Regarding work, those with thyroid cancer reintegrate well (Schultz, Stava and Vassilopoulou-Sellin, 2003).

- Of the allogeneic hematopoietic stem cell transplant patients who were in remission, 60% returned to work — 31% returned part-time and 29% returned full-time (Bieri et al., 2008).
- Of disease-free hematologic malignancy survivors, 84% had returned to work by 5 years post-diagnosis (Syrjala et al., 2004).
- Of those with head and neck cancers, 38% were not working at diagnosis and this was more likely the case for those who were older or had a lower education level. Of those who were employed at diagnosis, 83% returned to work over 2 years, with a median time to return of 6 months (Verdonck-de Leeuw et al., 2010).
- Survivors of cancer of the central nervous system, head and neck, or Stage IV blood and lymph malignancies had the highest adjusted risk of disability or quitting work (Short, Vasey and Tunceli, 2005).

Time Away from Work or Stopping Work

- Most cancer patients have left work 6 months after diagnosis. Many have returned at 12 and 18 months after diagnosis (Bradley et al., 2007).
- The mean duration of time that breast cancer survivors were absent from work was 349 days. Of absences, 37% last longer than a year and 12% last over 2 years, particularly in younger women (25 to 34 years old) (Roelen et al., 2009).
- Individuals with cancer are slower to return to work if they report physical disability (Kirchoff et al., 2010).
- Women with breast cancer were more likely not to return to work at 6 months post-diagnosis if they received chemotherapy, were off sick for more than 30 days during the previous year or had low satisfaction with activities of daily living. They were more likely not to return to work at 10 months if they received irradiation to breast/chest wall and regional nodes, and felt low satisfaction with their job. Women were more likely to feel global life satisfaction at 6 and 10 months if they were working. (Johnsson et al., 2011).
- Among colorectal survivors, radiation therapy among men and chemotherapy among women were more often associated with ending work (Gordon et al., 2008).
- At 2 years, 16% of disease-free patients had not returned to work. Patients were more likely not to return to work if they received adjuvant endocrine therapy (Johnsson et al., 2007).
- Time to return to work was shortest for those with skin cancer (median 55 days) and longest for those with lung cancer (median 377 days) (Roelen et al., 2010).
- Across all cancers, the mean duration of absence from work was 151 days. Survivors were at an increased risk of unemployment or early retirement and were less likely to be re-employed. Between a quarter and a half of survivors lost their pre-cancer jobs or quit their job at 6 years post-diagnosis; between one- and three-quarters of those who lost their jobs found new ones (Mehnert, 2011).

- In the Netherlands, the proportion of women who return to full-time work within a year of diagnosis has decreased since 2002, meaning women with breast cancer are taking a longer period of time to return to work (Roelen et al., 2011).
- Within 4 years of diagnosis, 13% of all survivors quit working for cancer-related reasons. More than half of survivors who quit working did so after the first year, while three-quarters of those who stopped working for treatment returned to work within 4 years (Short et al., 2005).
- For retirees, cancer may not negatively affect their decision to retire or the quality of their retirement (Bednarek and Bradley, 2005).

RTW Barriers[33]

Health and Wellbeing

- Even though breast, prostate and testicular cancer survivors report poorer health and work ability, more physical symptoms and anxiety on returning to work, they are still as engaged in their work as those without cancer (Berg Gudbergsson, Fosså and Dahl, 2008).
- Many individuals with cancer, especially women, report unmet psychosocial needs related to their jobs (Frazier et al., 2009a). Focus groups and surveys with women with gynecologic cancer identified that challenging employment-related tasks (which they encountered throughout the cancer trajectory) included leaving the job or making career plans (Frazier et al., 2009a).
- In a study comparing female and male cancer survivors with non-cancer patients concerning the likelihood of current employment, female survivors were more likely to be self-employed and more likely to feel less confident that if they lost their job that they could find another. Male cancer survivors were less likely than non-cancer patients to be employed, were more likely to be retired and were also less confident about finding another job if they lost their current one (Norredam et al., 2009).
- When off of work, those receiving treatment for colorectal cancer were also participating more frequently in healthy behaviours (James et al., 2006).
- Of the women with breast cancer, 60% reported physical disability at 12 months (compared to 29% of men with prostate cancer). This figure decreased to 36% at 18 months (17% for men with prostate cancer). Of the women with breast cancer, 34% reported cognitive disability at 12 months (12% of men with prostate cancer), which decreased to 22% (7% for men) at 18 months (Oberst et al., 2010).

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[33] For the literature regarding individuals with cancer, the subthemes under RTW Barriers and RTW Facilitators were adopted from Feuerstein et al. (2010) who found that most RTW articles can be divided into 1) health and wellbeing, 2) symptoms, 3) function and work demands, 4) work environment, and 5) policies, procedures and economics.

- Feeling uncertain and vulnerable about their physical appearance, ability to work and potential job loss affected the decision about working during treatment for women with breast cancer (Tiedtke et al., 2010).

Symptoms

- Women with gynecologic cancer reported that they were challenged by managing post-treatment symptoms when back at work (Frazier et al., 2009b).
- Decisions about returning to work for women with breast cancer are affected by side effects of treatment (Kennedy et al., 2007).
- One in five individuals with cancer report having a disability and half of those were working (Short et al., 2005).
- Cognitive impairment is an issue for women with breast cancer (Boykoff, Moieni and Subramanian, 2009; Munir et al., 2010).
- Women with breast cancer had concentration, arm and fatigue problems following treatment (Tiedtke et al., 2010).
- One-quarter of post-treatment women with breast cancer who also had decreased range of motion and slow walking ability were at high risk for functional loss and reported that cancer negatively affected their work (Gerber et al., 2006).
- For individuals with cancer who have finished treatment, fatigue is a major issue when they return to work (Verbeek and Spelten, 2007; Grunfeld and Cooper 2010).
- Breast cancer survivors who are working full-time report a loss of just over one hour of work per week compared to healthy worker norms. At three years post-treatment, fatigue and hot flashes account for 1.6% and 2.2%, respectively, of work performance loss (Lavigne et al., 2008).
- At three years post-treatment, distress, fatigue and job stress were higher in the group of women who had breast cancer than the women who did not have cancer. Women with breast cancer self-reported that cognitive limitations were related to reduced work output (Calvio et al., 2010).
- Patients who did not return to work reported higher scores for pain, anxiety, sleep disorders, depression, impairments in social functioning, and partnership and family life than those who returned to work (Gruber et al., 2003).
- Of patients with allogenic, syngenic and autologous haematopoetic stem cell transplantation (HSCT), 30.7% did not return to work at all, citing concerns with fitness, pain, fear or emotional distress (Gruber et al., 2003).
- In a sample of women who had undergone radical mastectomy surgery, only 20% left their former place of employment citing physical impairments as their major concern (Hinman, 2001).

- Male and female cancer survivors experience work-related disabilities and report that physical disability was more problematic than cognitive dysfunction (Oberst et al., 2010).
- Cancer survivor absenteeism is associated with cancer-related post-traumatic stress disorder (PTSD) (Shelby, Golden-Kreutz and Andersen, 2008).
- Those with PTSD following cancer diagnosis also had more problems with employment and insurance (Smith et al., 2008).
- Incontinence following prostatectomy can cause distress for men who are returning to work (Sultan et al., 2006).
- For survivors of head and neck cancer, anxiety, oral dysfunction, loss of appetite and problems with social eating were significantly associated with impeding return to work (Verdonnk de leeuw et al., 2010).

Function and Work Demands

- Individuals with cancer who reported poorer physical functioning were also more likely to not be engaged in paid work compared to those individuals with cancer who did not report poorer physical functioning (Bowen et al., 2007).
- Cancer patients who return to work experience a decline in work ability compared to non-cancer patients (Mehnert, 2011).
- Five-year survivors of breast cancer were more likely to be functionally limited and needed to reduce their work hours, which lowered their income (Chirikos, Russell-Jacobs and Cantor, 2002).
- Work ability was significantly better in male survivors of prostate or testicular cancer than in female survivors of breast cancer. These male survivors did not differ significantly in work ability from their controls whereas female survivors did (Gudbersson, Fossa and Dahl, 2011).
- Patients with hematological cancers and those treated with chemotherapy showed the lowest work ability scores. Patients with cancer of urogenital tract or gastrointestinal cancer had the highest scores. Demonstrating work ability at 6 months predicted return to work at 18 months (de Boer et al., 2008).
- Disease progression, type of treatment and staging of disease were independently associated with the ability to work after treatment (Molina Villaverde et al., 2008).
- Those survivors who experienced work changes also reported lower physical functioning (Mols et al., 2009).
- For breast cancer survivors who returned to work, the ability to manage work was affected by cognitive functioning following chemotherapy, the awareness of these failures and the impact of these failures on their confidence to perform work tasks (Munir et al., 2010).

- Work changes are more often reported by those with high physical or psychological job demands (Torp et al., 2011).

Work Environment

- Women with gynecologic cancer who returned to work were challenged by communicating with supervisors and coworkers and applying for employer-sponsored benefits (Frazier et al., 2009a).
- Decisions to stop working altogether after breast cancer are influenced by unsupportive work settings (Mujahid et al., 2010).
- The physical health of breast cancer survivors was strongly associated with needed and received support from managers, coworkers and occupational health services (Gudbergsson et al., 2009).
- Breast cancer survivors reported that social support was lower for those women who were sick-listed one year after breast cancer treatment than for those who had returned to work (Johnsson et al., 2010).
- Support from managers and colleagues influenced the decision to return to work for breast cancer survivors (Kennedy et al., 2007).
- Individuals with cancer reported that communication and support from and between occupational health, line managers and colleagues was necessary, particularly during the period of returning to work and the period following the initial return. These interviewees also highlighted the difficulties associated with the lack of support received from colleagues over time, even though difficulties associated with cancer and its treatment had not abated (Yarker et al., 2010).
- Work changes were associated with receiving low supervisor support concerning the cancer (Torp et al., 2011).
- Cancer survivors compared to non-cancer patients experienced temporary or permanent changes in their work schedules, hours and wages (Mehnert, 2011).
- Some women with breast cancer reported feeling discriminated against by their employer on returning to work (Tiedtke et al., 2010) and noted that discrimination affected their quality of life (Schultz et al., 2002).

Policies, Procedures and Economics

- Not surprisingly, a study of breast cancer survivors showed that those who were diagnosed with cancer also suffered reductions in earnings that were not experienced by those not diagnosed with cancer. The study’s authors found that these monetary losses were the result of reduced work effort and not the result of reduced wages (Chirikos et al., 2002).
- Having private health insurance was associated with resuming work for both men and women (Gordon et al., 2008).

- Few women with disease-free, Stage II breast cancer reported a negative impact of breast cancer on employment even though, in the United States, nearly one-fifth were denied life insurance on returning to work (Hensley et al., 2005).
- Women with gynecologic cancer reported that they were challenged by the task of managing their finances and finding solutions to cancer-related job problems (Frazier et al., 2009b).
- Individuals with cancer were economically burdened by lost income, lost unpaid work (household responsibilities) and health care expenses (Gordon et al., 2007), and decisions about returning to work were influenced by financial concerns (Kennedy et al., 2007).
- Cancer survivors' unmet needs in the areas of insurance, employment, information and home care increased between 1987 and 2007 (Barg et al., 2007).

RTW Facilitators

Health and Wellbeing

- Social wellbeing was positively associated with work changes for individuals with cancer (Mols et al., 2009).

Symptoms

- Cancer patients that reported fewer physical symptoms were more likely to return to work (Mehnert, 2011).
- To deal with chemo brain, survivors took lower-paying, less stressful jobs (Boykoff et al., 2009).

Function and Work Demands

- Most individuals who had been diagnosed with and treated for cancer could return to work without residual disabilities (Steiner, Nowels and Main, 2010).
- Individuals with cancer who reported a greater increase in physical quality of life also reported fewer chronic conditions and were more likely to be employed (Bloom et al., 2004).

Work Environment

- Blue or white collar women with gynecologic cancer reported that they felt a strong sense of accomplishment or felt distracted when working during treatment (Frazier et al., 2009a).
- Factors significantly associated with a greater likelihood of being employed or returning to work included perceived employer accommodation, flexible working arrangements, work-related counselling, and training and rehabilitation services (Mehnert, 2011).

- Of breast cancer survivors, 29% (N = 96) noticed that their coworkers and managers tried to be helpful and no one experienced job discrimination (Molina Villaverde et al., 2008).
- Of invasive cancer survivors, 84% found that their supervisor was caring and 90% found that their colleagues were caring (Torp et al., 2011).

Policies, Procedures and Economics

- Though breast cancer had a negative impact on employment among survivors who stayed in the workforce, the number of hours of work and their earnings were higher compared to women in a control group (Bradley et al., 2002).

RTW Recommendations

Resources and Services

- A survivorship care plan should include information about how survivors can protect themselves legally regarding employment and health insurance (Morgan, 2009).
- Supportive work environments need to take into account women's unique needs (Tiedtke et al., 2010).
- Rehabilitation programs are important for those returning to work after cancer (Mols et al., 2009).
- Workplace resources to increase work-related capabilities, reasonable accommodations and improve social support need to be developed (Bieri et al., 2008; Kennedy et al., 2007; Syrjala et al., 2004).
- Individuals with cancer reported receiving most support from their coworkers but hoped for more support from occupational health care personnel (39% of women and 29% of men), especially for survivors treated with chemotherapy (Taskila et al., 2006).
- Health professionals must realistically prepare cancer patients for time off work during treatment (Kirchoff et al., 2010).
- Health providers could assist with the psychosocial needs of individuals with cancer who are considering returning to work by screening for job concerns, helping to create a return-to-work plan, assisting with symptoms, offering rehabilitation services and reaching out to employment specialists (Frazier et al., 2009b; Grunfeld and Cooper, 2010; Gudbersson et al., 2011; Kennedy et al., 2007; Lavigne et al., 2008; Short et al., 2005).
- Communications between survivors, employers, physicians and insurance representatives and the support of professionals need to be increased and improved to allay many concerns of survivors (Tiedtke et al., 2010).

Research

- Evidence is needed to better guide clinicians, survivors and employers about cancer in the workplace (Amir and Brocky, 2009).
- Future research should focus on: 1) collecting workplace issues in cancer studies; 2) the employment outcomes for racial and ethnic minority patients; 3) interventions to curb side effects of treatment that affect employment; and 4) the relationship between health insurance coverage through work and cancer recovery (Bradley et al., 2007).
- A better understanding of how cancer affects working adults and contributes to unwanted work cessation is required to identify individuals who may benefit from occupational rehabilitation programs (Gordon et al., 2008).

Caregivers of Individuals with Cancer and Chronic Disease and RTW

For the literature search concerning the caregivers of individuals with cancer and chronic disease and RTW, 34 articles remained (from 515) after duplicates and irrelevant articles were removed.

Articles were excluded for the following reasons: they were not cancer-related (e.g., traumatic brain injury, dementia, children with disabilities, multiple sclerosis); they were from the perspective of formal or professional caregivers (e.g., health care professionals); they focused on specific caregiver issues not related to work and/or financial issues (e.g., information, training and quality of clinical care provided for and by informal caregivers, pain management, communication and bereavement services).

The literature search did not identify many published articles that were specifically focused on work-related issues from the perspective of informal caregivers of individuals with cancer or how caregiver burden affected work or employment over the course of the illness. The caregiver literature focused primarily on the quality of care provided, training and skills needed, caregiver burden (often focusing on anxiety and depression) and promoting caregiver's emotional and physical wellbeing. This literature was also often within the context of providing care at the palliative and end-of-life stages of care. The caregiver literature identified factors that influence and predict caregiver distress and documented the range of unmet caregiver needs, some of which were related to work or finances.

The issues of work and financial impact experienced by caregivers was often measured and reported on within the literature about quality of life. A detailed review of the standardized instruments and surveys used to measure caregiver concerns is provided at the end of this section.

General Information

- 🇨🇦 Family members of individuals who received chemotherapy were more likely to have to take time off work to provide care (52% versus 34% for those who did not receive chemotherapy) (Canadian Breast Cancer Network, 2009).
- 🇨🇦 Nearly 50% of individuals with cancer reported that a family member or friend took time off work to care for them. Most took less than 4 weeks to provide care, but between 21% and 36% took several days a week for a period of several weeks or months (Canadian Breast Cancer Network, 2009).
- Caregivers of those with a primary malignant brain tumour were more likely to be employed if they were younger. They were more likely to report lost hours from work when care recipients required assistance with instrumental activities of daily living (IADLs) and when care recipients were further from the time of diagnosis (Sherwood et al., 2008).

RTW Barriers

- The mean number of unmet needs among cancer caregivers was higher for those caregivers who were currently working versus those who were not working (Fridriksdottir et al., 2011).
- Role overload predicted secondary stress in cancer caregiving (i.e., how cancer caregiving stress influences other aspects of life such as financial wellbeing, time available to engage in other activities) (Gaugler et al., 2008).
- Of the psychosocial needs of informal carers of cancer patients, “help with financial matters” was identified as a significant unmet need by 39% of respondents (Soothill, et al., 2001) and caregivers reported more unmet needs than those receiving care (Soothill et al., 2003).
- The range of the more than 200 self-reported problems encountered by caregivers of cancer patients included (Stenberg, Ruland and Miaskowski, 2010):
    - Financial difficulties (difficult to pay bills, lack of sick leave, lack of vacation time, loss of income, loss of savings)
    - Work and education (change in employment status, engage in fewer work activities, given up work, hard to concentrate on work, job interruptions, less effective overall at work, long service leave, missed work, reduced work hours, stop work to care, work adjustment)
    - Role strain (balancing multiple roles, changes in responsibilities, difficult to manage many life roles, role changes)
- A recent study using a tool to measure caregiver needs found that (Kim et al., 2010):
    - Caregivers whose financial needs were not being met reported poorer mental health

  - Caregivers whose daily activity needs were not being met reported poorer mental health
  - The authors noted that their finding that caregivers with higher income reported greater daily activity unmet needs may be attributable to their higher paying and demanding occupations and may reflect challenges of balancing occupation and caregiver roles as cancer care becomes less intensive but persists over time
- A study that examined the effect of caregivers' multiple roles (e.g., employment, child care) on their psychological adjustments found that employed caregivers with children reported a higher level of care-related stress than those without children or those who were unemployed without children (Kim et al., 2006).
- Transitions into caregiving (not specific to cancer) resulted in a decrease in labour force participation (Berecki-Gisolf et al., 2008).
- In a study of caregiver burden among individuals caring for terminally ill patients with cancer, the highest burdens reported among caregivers included experiencing more restrictions in their daily activities, especially for those who were younger (Goldstein et al., 2004).
- In a study to understand caregiving-related problems, the authors found that caregiving had led 28.8% of employed participants to stop work temporarily and 2.5% to stop work altogether, and that 37.5% had cancer-related economic problems and 11% reported insufficient income (Ferrario et al., 2003).
- A study comparing the physical and psychosocial health in family caregiving between AIDS and cancer caregivers found that the groups were similar in their experience of depression, grief, symptoms of stress and health but that caregivers of persons with cancer experienced greater impact on their normal activities of daily living, such as work and visiting with family and friends than AIDS caregivers (Stetz and Brown, 2004).
- Workplace factors that inhibited the ability of informal caregivers of cancer patients to provide care and the specific aspects of caregiving that hinder caregivers' ability to meet work responsibilities included (Swanberg, 2006):
  - Providing care sometimes interfered with caregivers' work responsibilities for nearly all employees
  - Overall stress associated with meeting demands of work was higher for caregivers of patients with acute symptoms, those more involved in cancer-related treatments or whose medical status fluctuated
  - Individuals whose jobs were not conducive to flexible scheduling appeared to have greater perceived stress than those with some work flexibility

  - Providing care to cancer patients was challenging due to the unpredictable nature and uncertainty of their caregiving needs, which vary across disease type, duration, progression and prognosis

- Increased economic burden was experienced by 51.3% of caregivers of individuals with cancer, and the majority of caregivers (67%) had difficulty working and thus their income was negatively affected. Pensioners, who did not need to work, were among the individuals who answered negatively regarding low income and job difficulties (Tsigaroppoulos et al., 2009).
- 🇨🇦 Among the employed caregivers (56% were in FT or PT employment) of women with advanced breast cancer, 69% reported some adverse impact on work, 5% had to quit their jobs or declined advancement, and a large proportion reported lost work hours or using special leave or holidays to meet their caregiving responsibilities. More respondents reported missing work because of caregiving responsibilities in the terminal rather than palliative care period (77% versus 53%) as well as an increased inability to work regular hours and more lost work hours in the terminal period. Caregivers' depression and perceived burden also increased as patients' functional status declined (Grunfeld et al., 2004).
- In a study of caregivers, more than half of the participants had a substantial need for financial support and for 42.7% the need was unmet and 30% of those who were employed felt that their caregiver role limited their job performance. Caregivers' unmet needs (for symptom management, financial support or community support) negatively affected the quality of end-of-life care they delivered as well as their workplace performance (Park et al., 2010).
- 🇨🇦 A study to determine the financial and family resources burden (both direct and indirect costs) associated with treatment of cancer found that (Longo et al., 2006):
  - 35.6% of patients required others to take time from work to provide care
  - Caregivers reported a mean of 7 days of lost work in the previous 30 days
  - 59.6% of patients who perceived a high-cost burden had caregivers take time off work which was significantly more than the 29.7% in the low-burden category
  - Findings suggest that lost income (both cancer patient and caregiver) may have a larger financial impact than direct out-of-pocket costs (OOPC)
- A literature review of concerns related to terminal cancer was conducted and found that the proportion of families reporting that someone gave up a job to provide care ranged from 10% to 40% (Hanratty et al., 2007).
- Caregivers were less likely to be working, more likely to miss days of work when they were employed and more likely to lack health insurance (Ho et al., 2005).

RTW Facilitators

- Relatively affluent caregivers reported better mental and physical health and caregivers who were employed reported better physical health 2 years post-diagnosis (Kim and Spillers, 2010).
- A study by Swanberg (2006) identified workplace factors that facilitated the ability of informal caregivers of cancer patients to provide care and the specific aspects of caregiving that hinder caregivers' ability to meet work responsibilities. One workplace factor that assisted caregivers was as follows:
    - On learning of the cancer diagnosis, most caregivers solicited support from their immediate supervisor and most supervisors offered informal or formal support, including flexible and adjusted work schedules and sick and vacation time. Individuals who had flexible job scheduling also had less perceived stress.

RTW Recommendations

Resources and Services

- 🇨🇦 Grunfeld et al. (2004) noted that strategies are needed to reduce the psycho-social, occupational and economic burden associated with caregiving.
- Berecki-Gisolf et al. (2008) suggested that policies need to support flexible working arrangements to maintain labour force participation during caregiving and re-employment programs need to be developed.
- Glajchen (2004) identified four main types of caregiver interventions that have been recognized as promoting emotional and physical wellbeing among caregivers: 1) educational programs to increase knowledge, 2) counselling or psychotherapy to reduce anxiety and depression, 3) hospice or palliative home care to provide medical and psychosocial services for end-of-life care, and 4) problem solving or skill building to improve skills and increase confidence.
- Swanberg (2006) noted that it is important to develop and communicate courses in caregiving, which should be required when someone is diagnosed with cancer. This would help caregivers more effectively plan for caregiving needs and manage these in the context of work and family responsibilities. Swanberg (2006) also indicated that social services agencies that provide care to cancer patients could play a role in assisting employed caregivers to negotiate the demands of work and home (e.g., counselling sessions addressing work-related topics such as planning time off, informing employers about cancer diagnosis and treatment, and identifying who else could assist with caregiving while at work).

Research

- Kim and Spillers (2010) recommended that future research explore the economic impact following treatment, including managing late effects, additional out-of-pocket expenses and lost income related to disability, and the need of caregivers to limit employment to care for the survivor.

- Matthews, Baker and Spillers (2004) noted that it is important to expand the understanding of the impact of a cancer diagnosis on those who will be the patient's informal caregivers because of current demographic trends, medical technological developments and health care policy.
- Sherwood et al. (2008) highlighted the importance of being able to predict which caregivers were at risk of losing hours from work or changing employment to provide care so that targeted interventions could be implemented to balance employment and caregiving demands (e.g., targeting caregivers of persons with functional impairments to provide more coordinated supportive care).

Policy

- 🇨🇦 A recent presentation by Torjman (2011) outlined the policy challenges related to the caregiver/care receiver relationship (not specific to cancer). One key policy challenge identified was the depth and duration of the caregiving relationship and that the employment status of the caregiver is likely to be affected if the caregiving period is expected to be intense or of long duration. Torjman (2011) also noted that caregivers and care recipients are intrinsically linked but that interventions need to recognize the unique needs of both to identify which measures best meet the needs of which individual in the caregiving relationship. This means that some interventions are best targeted at caregivers (e.g., training and information) and some interventions are intended only for caregivers (e.g., respite services).

Measures of Caregiver Quality of Health, Burden and Needs

- Examples of caregiver-related quality-of-life instruments (Edwards and Ung, 2002):
    - Caregiver Quality of Life Index — Cancer Scale (CQOLC) (Weitzner et al., 1999) is a 35-item scale that includes some items relevant to work experiences, including impact on daily schedule, maintenance of outside activities, financial strain, concern about insurance, economic future and change in priorities.
    - Caregiver Quality of Life Index (CQLI) (MacMillan and Mahon, 1994) measures caregiver quality of life along four dimensions: emotional, social, financial and physical.
    - Quality of Life Family Version (QOLT) (Padilla et al., 1990) is a 37-item instrument originally developed for use with cancer patients but adapted for family caregivers. It has four subscales (emotional, physical, social and spiritual) and includes two items under the social wellbeing subscale that are related to work and finances (interference with job and financial burden).

  - Quality of Life Index — Cancer Version (QLI-CV) (Ferrans and Powers, 1985) is a 32-item instrument across four domains: health and functioning, socioeconomic, psychological or spiritual, and family.

- The Stress Process Model was developed to provide a conceptual framework for the caregiving experience. The tension and conflict associated with maintaining other role's in the caregiver's life (e.g., employment) is defined as a secondary stressor in this model (Pearlin et al., 1990).

- 🇨🇦 Keefe et al. (2008) developed an assessment tool to understand caregivers' needs and situations (not specific to cancer). The tool has 10 main sections, with one section (juggling responsibilities: 12 main questions) addressing work-related concerns. The authors acknowledged that caregivers traditionally have not been identified as clients of health and social service agencies and that this tool could be used to inform the development of intervention plans to address caregivers' unmet needs. VON Canada has a Caregiver Best Practice Team that uses the CARE Tool and Caregiver Risk Screen to identify the social and emotional needs of caregivers (Guberman et al.).

- Given et al. (1992) developed the Caregiver Reaction Assessment (CRA) for Caregivers to measure caregiver burden for those with chronic physical or mental impairments. This assessment tool has a four-item subscale that measures the financial impact of caregiving: 1) difficult to pay for care, 2) finances are adequate, 3) there is a financial strain on the family or 4) I stopped work to give care.

- In 2002, the American Cancer Society launched a longitudinal study of the quality of life of caregivers of cancer patients. This study examined caregiver quality of life at 1, 2 and 8 years post-diagnosis.

- Needs Assessment of Family Caregivers — Cancer (NAFC-C) was recently developed to measure caregiver needs on eight dimensions. Three of these dimensions have work or finance-related items: 1) financial unmet needs (e.g., taking care of bills, having enough insurance coverage for him/her, paying for his/her medical expenses); 2) daily activity unmet needs (e.g., taking time off from work); and 3) balancing roles for survivor care (e.g., balancing work/school with caring for him/her) (Kim et al., 2010).

- Glajchen (2004) described the impact of cancer caregiving on four dimensions of quality of life: 1) physical, 2) psychological 3) social (including financial factors, lost salaries and work) and 4) spiritual.

Mental Health and HIV and RTW

For this literature search concerning mental health and HIV, 16 articles remained after duplicates and irrelevant articles were removed (4 regarding mental health and RTW and 12 about HIV and RTW). Articles were excluded for the following reasons: the findings were from the perspective of formal or professional caregivers (e.g., health care professionals), they focused on specific issues not related to work and/or financial issues, or they focused on interventions and RTW.

Mental Health and RTW

General Information

- 🇨🇦 Being employed was found to be mentally beneficial (Kirsch, 2000).
- Half of the individuals off work for 6 months or more for mental health reasons returned to work (Blank et al., 2008).
- Definitions of poor mental health varied widely and mental health is poorly defined (Blank et al., 2008).
- Demographic factors that predicted someone would not return to work after leaving work because of mental health issues included being single, widowed or divorced; older; lower education; under- or overweight; smoking; and drug dependency (Blank et al., 2008).
- Anecdotally, mental health issues are believed to cause sickness absence, but research has not illuminated which risk factors for poor mental health carry the most risk of sickness absence and job loss (Blank et al., 2008).

Barriers

- Having a longer pre-existing condition and having a way to separate mental health and substance abuse benefits from health insurance plans negatively affected the likelihood of returning to work (Blank et al., 2008).
- Depression affected more employees than the more severe mental health disorders. Depression lasted longer and was more likely to recur. At the conclusion of an episode, 75% of employees returned to work within 6 months (fewer men than women returned to work and a greater number of older adults were likely to take long-term disability instead of returning to work). Returning to work predicted fewer depressive symptoms (Blank et al., 2008).
- Work factors that affected returning to work for those who were mentally ill included low job grade, high job or reorganizational stress, threats to employment, workplace injury, the lack of worker's insurance and not attempting to return to work within 16 months (Blank et al., 2008).
- Medical factors that affected returning to work included the presence of a minor psychiatric disorder and the severity of symptoms (Blank et al., 2008).
- Most mental health and RTW studies focused on short-term, frequent absences rather than longer-term sickness absence leading to stopping work or job loss (Blank et al., 2008).

Facilitators

- 🇨🇦 Individuals with mental health issues were more likely to go back to work if their jobs felt meaningful to them, they felt a sense of job satisfaction and security, and they felt supported by supervisors and colleagues (Kirsch, 2000).
- 🇨🇦 Returning to work was facilitated by support from colleagues and managers, an improved job experience (i.e., less stressful conditions), a gradual return to work and better support for the employee when absent due to mental illness (Saint-Arnaud, Saint-Jean and Damasse, 2006). (Note that this assumes work plays a role in mental health deterioration, which this is different from cancer.)
- If supervisors were directly responsible for the return to work and if there was active communication between the employer and other professionals, then the RTW rates were better (Blank et al., 2008).
- Mentally ill clients who used employment support agencies benefited from advice and counselling for their job search, as well as concerning how and whether to disclose and access employer support (Boyce et al., 2008).

Recommendations

No recommendations were presented in these articles but we can surmise after reviewing the facilitators that recommendations might include the following:

- Provide counselling regarding searching for jobs and disclosing about mental illness.
- Create healthy work environments or have as an employee benefit access to mental health services (e.g., Employee Assistance Programs).
- Encourage supervisors to be directly responsible for the return to work of their employees and to communicate with relevant professionals about making this a smooth transition.

HIV and RTW

General Information

- The Centre for Disease Control estimates that of the 400,000 people living with AIDS in the United States in 2003, 96% were of working age. With the advent of antiretrovirals, those who were once disabled with AIDS for long periods of time were re-entering the workforce because of the desire to work, psycho-emotional problems or because of financial pressures (Bravemen et al., 2006; Martin et al., 2006b; Presnell, 2006).
- Despite improvements in health over the course of time while away from work, men with HIV do not return to work (Gorman et al., 2009; Martin, Steckart and Arns, 2006b).
- More women than men lost their jobs after becoming sero-positive (Gorman et al., 2009).

- What kept men with HIV at work was a solid employer structure for disability benefits, lower incidence of depression, high cognitive functioning and higher education (Martin et al., 2006b).

Barriers

- 🇨🇦 What prevented people with HIV/AIDS (PHAs) from returning to work included concerns about growing more disabled, engaging in other more pleasurable activities and losing access to health plans (Ferrier and Lavis, 2003).
- In one study, three-quarters of the sample of PHAs were contemplating returning to work but expected barriers, such as loss of disability income benefits (73%), loss of publicly funded health insurance (67%) and workplace discrimination (66%), as well as concerns about health, physical ability, workplace health concerns and current job skills (Brooks et al., 2004).
- In a qualitative study of HIV and returning to work, all participants experienced a lessened sense of occupational identity, occupational competence (they felt less confident about their abilities and less optimistic about returning to work) and a lessened sense of the ability to navigate occupational environments. Participants also felt a lack of confidence about being able to carry out their work duties should they return to work (Bravemen et al., 2006).
- The most common barriers to returning to work included physical impairments, mental health issues and lack of resources. Other barriers included social problems, substance abuse relapse, motivation issues, incarceration troubles, cognitive dysfunction and a lack of job skills (Martin et al., 2006b).
- For men with HIV, the stigma of being unemployed competes with the stigma of unintentional disclosure of the disease once at work, making it a difficult decision to return (Nixon and Renwick, 2003).
- Combination therapies that introduce side effects such as peripheral neuropathy, nausea and diarrhoea interfere with work activities (Presnell, 2006).
- One of the side effects of HIV treatment and the HIV virus is neurological impairment. Of those with this impairment, 17.5% were unemployed (Gorman et al., 2009).

Facilitators

- 🇨🇦 Interviews with PHAs who had been on LTD for at least 5 years revealed that returning to work was more likely if the opportunity existed for a low-risk trial to be back at work or the guarantee of returning to their old job (Ferrier and Lavis, 2003).
- Accessing the mental health treatment system may have facilitated a return to work for individuals with HIV (DiClementi et al., 2004).
- If PHAs had a more optimistic narrative about returning to work, then they were more likely to become employed (Levin et al., 2007).

- HIV participants felt a heightened sense of occupational identity, competence and ability to navigate occupational settings if they were introduced to and had mastery over new activities while off work. Participants felt more optimistic if they were not struggling as much with health issues (Bravemen et al., 2006).

Resources and Services

- 🇨🇦 Employers, disability plan specialists and AIDS organizations could work together or independently to reduce the barriers to RTW (Ferrier and Lavis, 2003).
- PHAs need assistance to discuss perceived barriers that may prevent them from seeking employment (Brooks et al., 2004).
- PHAs could be psychosocially assessed and then referred to mental health services, which could facilitate returning to work (DiClementi et al., 2004).
- Employers need to offer flexible back to work arrangements so that PHAs can deal with ongoing medical appointments (Martin et al., 2006a).
- Rehabilitation counsellors must realize the real and perceived barriers of PHAs. Information needs to be updated as treatment options and functional limitations change (Glenn et al., 2003).

Appendix C: Interview Consent Form, and Interview Guides for Survivors and Caregivers

Informed Consent: Individual Interview

Understanding the Return to Work Experiences of Cancer Survivors/ Caregivers

You are being asked to participate in a research study. Before you give your consent to be a volunteer, it is important that you read the following information and ask the researcher as many questions as necessary to be sure you understand what you will be asked to do.

Investigators:

Judy Gould, PhD, funded by the Canadian Partnership Against Cancer
Fred Ashbury, PhD, funded by the Canadian Partnership Against Cancer
Cathy Cameron, MHSc, funded by the Canadian Partnership Against Cancer
Manon Labrecque, MA, funded by the Canadian Partnership Against Cancer

Purpose of the Study: The investigators want to learn more about the return to work experiences for individuals who have experienced a cancer diagnosis and treatment and their caregivers. The investigators wish to interview 5 to 10 people who have been diagnosed in the last 5 years and the caregivers of those who have been diagnosed in the last 5 years.

Description of the Study: After you have had an opportunity to review and discuss this research consent form with the interviewer we will ask you on the telephone to provide your consent and we will audio-record your reply. If you consent to participate the telephone interview will commence (about 1 to 1.5 hours in length). In the interview we will be asking both the individual with cancer and their caregiver questions like how long the individual with cancer was away from work, what kind of return to work arrangement did that individual have with the employer and/or insurance company, how the individual with cancer/caregiver experienced the return to work transition, gaps in resources, and any recommendations you might have for helpful resources. At the conclusion of the interview you will be asked a short series of questions about your age, family status, date of diagnosis (if individual with cancer), and education. With your permission, the interview will be audio-recorded and later transcribed. Your interview recording and responses are strictly confidential.

Risks or Discomforts: Because of the personal nature of the questions asked, you may find yourself recalling unpleasant memories while responding to our interview questions. This may be a source of discomfort to you. If you begin to feel uncomfortable, you may stop the interview, either temporarily or permanently. You are not obliged to answer questions about things you do not wish to talk about.

Benefits of the Study: It could be that recalling return to work experiences elicits pleasant memories. However, the investigators cannot guarantee that you will experience any benefit. It is possible that the results of this study will spur the creation and development of programs and resources to help people living with cancer return to work, although again, the researchers cannot guarantee this outcome.

Confidentiality: In all instances, your interview recording and transcriptions are strictly confidential. Your recording and transcription will be identified by number, not by name. The corresponding list of numbers and names will be kept in a secure, separate location. The audio-recordings and transcription will be kept in a secure location and will only be used for the purposes of the research described above. After the completion of the research project, the audio-recording and transcripts will be stored for seven years and then will be destroyed. In the resulting publication, no identifying characteristics and no names will be used. The findings of this study (without your identifying details) will be relayed to the sponsor of this research: the Canadian Partnership Against Cancer. All work will be completed only by the investigators named above. You have the right to check your study records and request changes if the information is not correct. By signing or indicating your audiorecorded agreement with the terms of this information and consent form, you consent to the collection, access, use and disclosure of your information as described above. While every effort will be made to protect the privacy of your information, absolute confidentiality cannot be guaranteed. This does not limit the duty of the researchers and others to protect your privacy.

Incentives to Participate: There will be a $50.00 honorarium for all participants for each interview. The honorarium will be mailed out to you following the interview and will not be withheld if you need to discontinue the interview before all questions have been answered or need to pass on completing any question.

Voluntary Nature of Participation: Participation in this study is voluntary. Your choice to participate will not influence your future relations with the Canadian Partnership Against Cancer or with any individuals involved with the research. If you decide to participate, you are free to withdraw your consent and to stop your participation at any time without penalty or loss of benefits to which you are allowed. At any point in the study, you may refuse to answer any particular question or stop participation altogether.

Questions about the Study: If you have any questions about the research, please ask. If you have questions later about the research, you may contact one of the researchers (Judy Gould at judygould@rogers.com). Please contact the Director, Human Research Protection Program, IRB Services, who is not affiliated with the research or the research team, if you

- have questions about your role and rights as a research participant
- wish to obtain more information about research in general
- have concerns, complaints or general questions about the research, or
- wish to provide input about the research study

You can do so in the following ways:

- In writing: 300-372 Hollandview Trail, Aurora, ON L4G 0A5
- By phone: 1-866-449-8591
- By email: subjectinquiries@irbservices.com

Agreement: Your audio-recorded agreement indicates that you have read the information in this agreement and have had a chance to ask any questions you have about the study. Your audio-recorded agreement also indicates that you agree to be in the study and have been told that you can change your mind and withdraw your consent to participate at any time. You have been given a copy of this agreement. You have been told that by indicating your audio-recorded consent agreement you are not giving up any of your legal rights.

Consent Provided: ☐ Yes or ☐ No Researcher: ___________________________

Date: ______________________

Final Interview Guide: Person with Cancer

Respondent Demographics

1. Age: ________ (years)

2. Sex: ___ Female ___ Male

3. What is the highest level of education you have completed (check one):

- ☐ Some high school
- ☐ Graduated from high school
- ☐ Some college or university
- ☐ Graduated from college or university
- ☐ Some graduate school
- ☐ Completed graduate school
- ☐ Other, please specify ____

4. What province or territory do you live in (check one):

- ☐ Alberta
- ☐ British Columbia
- ☐ Manitoba
- ☐ New Brunswick
- ☐ Newfoundland and Labrador
- ☐ Northwest Territories
- ☐ Nova Scotia
- ☐ Nunavut
- ☐ Ontario
- ☐ Prince Edward Island
- ☐ Quebec
- ☐ Saskatchewan
- ☐ Yukon

5. Community size (check the box that best applies):

- ☐ population of over 500,000
- ☐ population between 100,000-499,000
- ☐ population between 30,000-99,000
- ☐ population of between 15,000 – 29,000
- ☐ population of less than 15,000

6. What is your current marital status?

- ☐ Single/Never Married
- ☐ Married
- ☐ Common-law
- ☐ Separated
- ☐ Divorced
- ☐ Widowed

7. What is your job title? ____

Employment Status/Support

8. What was your employment status **at time of diagnosis** (check box best applies):

- ☐ Full-time (30 or more hours a week of paid work)
- ☐ Part-time (less than 30 hours a week of paid work)
- ☐ Self-employed
- ☐ Unemployed
- ☐ Homemaker
- ☐ On disability benefits
- ☐ Retired
- ☐ Other, please specify ___________________________________

9. What was your employment status **during treatment** (check box best applies):

- ☐ Full-time (30 or more hours a week of paid work)
- ☐ Part-time (less than 30 hours a week of paid work)
- ☐ Self-employed
- ☐ Unemployed
- ☐ Homemaker
- ☐ On disability benefits
- ☐ Retired
- ☐ Other, please specify ______________________________

10. What is your **current** employment status (check box that best applies):

- ☐ Full-time (30 or more hours a week of paid work)
- ☐ Part-time (less than 30 hours a week of paid work)
- ☐ Self-employed
- ☐ Unemployed
- ☐ Homemaker
- ☐ On disability benefits
- ☐ Retired
- ☐ Other, please specify ______________________________

Cancer Experience

11. What cancer(s) were you diagnosed with (e.g., breast): ________________

12. What was the date of your diagnosis: ______ (month) ______ (year)

13. What type of treatment did you have? (check all that apply)

- ☐ Surgery
- ☐ Radiation
- ☐ Chemotherapy
- ☐ Medication
- ☐ Don’t know
- ☐ Other, please specify:______________________________

Interview Questions

1. What was your experience leaving work for treatment/working through treatment? What were the main work-related issues or challenges you experienced?

If You Left Work

Being Away from Work

- Was that your choice to leave work? What factors influenced this choice to leave work?
- How long were you away from work?
- What arrangement did you make with your employer to be away from work? (gradual return, flexible, no arrangement regarding reduced workload)
- What type of income support did you have while away from work?
- What accommodations, if any, were made for you upon returning to work?
- What accommodations, if any, were made for your caregiver re: work?

Returning to Work

- What kind of arrangement did you have with your employer/the insurance company when it came time to return to work? (gradual return, flexible, no arrangement)
- How supported by the employer did you feel to return to work?
- How supported by the insurance company did you feel to return to work (if applicable)?

Back at Work

- What were your expectations of yourself, your colleagues, your managers and were they met when you returned to work? How so, or how not?
- What happened with the arrangements that were made prior to returning to work?
- What made the transition difficult?
- What helped to make that transition easy/easier (people, resources)?

If You Worked Through Treatment

- How did you manage physically, emotionally?
- Was that your choice not to leave work? What factors influenced this choice to stay at work?

Accommodations at Work

- What, if any, accommodations did your employer make? (to salary?, vacation?, other?)
- What, if any, accommodations did you make? (salary? vacation? other?)
- How supported by the employer/others did you feel?

Returning to Original Capacity at Work

- If you have returned to your original capacity at work what were your expectations of yourself, your colleagues, your managers and were they met? How so, or how not?
- What made the transition difficult?
- What helped to make that transition easier (people, resources)/which resources (programs, services & Information) did you access?

2. What were the gaps between what you had and what you needed to make a successful transition back to work/to continue working?
3. What resources would have been helpful to you?
4. Is there anything we haven't yet discussed about working and cancer that you would like to talk about?

Thank you for participating

Final Interview Guide: Caregivers

Respondent Demographics

1. Age: _______ (years)

2. Sex: ___ Female ___ Male

3. What is the highest level of education you have completed check one):

- ☐ Some high school
- ☐ Graduated from high school
- ☐ Some college or university
- ☐ Graduated from college or university
- ☐ Some graduate school
- ☐ Completed graduate school
- ☐ Other, please specify ______________________________________

4. What province or territory do you live in (check one):

- ☐ Alberta
- ☐ British Columbia
- ☐ Manitoba
- ☐ New Brunswick
- ☐ Newfoundland and Labrador
- ☐ Northwest Territories
- ☐ Nova Scotia
- ☐ Nunavut
- ☐ Ontario
- ☐ Prince Edward Island
- ☐ Quebec
- ☐ Saskatchewan
- ☐ Yukon

5. Community size (check the box that best applies):

- ☐ population of over 500,000
- ☐ population between 100,000-499,000
- ☐ population between 30,000-99,000
- ☐ population of between 15,000 – 29,000
- ☐ population of less than 15,000

6. What is your current marital status?

- ☐ Single/Never Married
- ☐ Married
- ☐ Common-law
- ☐ Separated
- ☐ Divorced
- ☐ Widowed

7. What is your job title? ____

Employment Status/Support

8. What was **your** employment status at the time that the **person with cancer was diagnosed** (check box best applies):

- ☐ Full-time (30 or more hours a week of paid work)
- ☐ Part-time (less than 30 hours a week of paid work)
- ☐ Self-employed
- ☐ Unemployed
- ☐ Homemaker
- ☐ On disability benefits
- ☐ Retired
- ☐ Other, please specify ____

9. What was **your** employment status when the **person with cancer was receiving treatment** (check box best applies)?

- ☐ Full-time (30 or more hours a week of paid work)
- ☐ Part-time (less than 30 hours a week of paid work)
- ☐ Self-employed
- ☐ Unemployed
- ☐ Homemaker
- ☐ On disability benefits
- ☐ Retired
- ☐ Other, please specify ______________________________

10. What is **your current** employment status (check box that best applies)?

- ☐ Full-time (30 or more hours a week of paid work)
- ☐ Part-time (less than 30 hours a week of paid work)
- ☐ Self-employed
- ☐ Unemployed
- ☐ Homemaker
- ☐ On disability benefits
- ☐ Retired
- ☐ Other, please specify ______________________________

Cancer Experience of the Person with Cancer

11. What type of cancer(s) was that person diagnosed with (e.g., breast): ________

12. When was the person with cancer diagnosed: ______ (month) ______ (year)

13. What type of treatment did that person with cancer receive? (check all that apply)

- ☐ Surgery
- ☐ Radiation
- ☐ Chemotherapy
- ☐ Medication
- ☐ Don't know
- ☐ Other, please specify ______________________________

Interview Questions

1. What was the **person with cancer's experience** leaving work for treatment/working through treatment?
    - How long was s/he away from work/continue to work during treatment?
    - If s/he left work, what type of income support did the person with cancer have while away from work?
    - If s/he left work, what kind of arrangement did the person with cancer have with his/her employer/the insurance company when it came time to return to work? (gradual return, flexible, no arrangement regarding reduced workload to begin)

2. How did **caregiving impact your work**?
    - What was your work experience like while providing care during/after treatment?
    - What were the main work-related issues or challenges you experienced?
    - What kind of work arrangements, if any, did you make while the person with cancer was undergoing treatment?

3. What was **your work situation** like as the person with cancer was making the transition back to work/after treatment?
4. What were the gaps between what you had and what you needed for the **person with cancer/you** to make a successful transition to work?
5. Which resources (programs, services) **did you or did the person with cancer access** that aided with working through or returning to work after cancer treatment?
6. What resources would have been helpful to **you**?
7. Is there anything we haven't yet discussed about working and cancer that you would like to talk about?

Thank you for participating

Appendix D: Characteristics of Interview Participants

Respondent Type	Individual with cancer	7
	Caregiver	1
Age	<50	2
	50 to 60	5
	>60	1
Sex	Male	3
	Female	5
Education	Some College/University	2
	College/University	4
	Some Graduate school	1
	Completed Graduate school	1
Province of Residence	Nova Scotia	3
	Ontario	1
	Quebec	1
	Saskatchewan	3
Community Size (Population)	<15,000	3
	100,000-499,999	3
	500,000+	2
Marital Status	Married	5
	Separated	1
	Divorced	1
	Single	1
Employment when Diagnosed	Full-Time	6
	Self-employed	1
	Unemployed	1
Employment During Treatment	Full-Time	3
	Self-employed	1
	Part-Time	1
	On disability	2
	Unemployed	1
Current Employment	Full-Time	5
	Self-employed	1
	On LTD	1
	Unemployed	1
Type of Cancer	Breast	3
	Ovarian	2
	Prostate	2
	Uterine	1
Type of Treatment(s)	Surgery	7
	Chemo	5
	Radiation	4
	Medication	1

Appendix E: Detailed Interview Findings

Analysis

Four higher order themes emerged from the data analysis of the interview transcripts.

- General Information
  - Selected demographics and the cancer experience
- Barriers
  - symptoms, side effects
  - interactions with employers/colleagues
  - information from cancer care professionals
  - financial concerns
- Facilitators
- Recommendations

The research team then expounded on the meaningful patterns found in the data and supported these patterns with illustrative participant quotes.

Findings

General Information

All 8 interview participants completed the demographic information (see Appendix D for complete information). Three men and 5 women participated in the interviews; the lone caregiver participant was a male and most participants were between 50 and 60 years old. Of the survivor participants, 2 had breast cancer, 2 had ovarian cancer and 2 had prostate cancer. All of the individuals with cancer had surgery; 5 of 6 had chemotherapy, 4 of 6 had radiation and 1 of 6 had hormone therapy.

Six participants had at least some university or college education. Five participants were married, one was single, one was divorced and one was separated. Five of the 6 individuals with cancer were employed full-time at diagnosis (one was self-employed). Three survivors continued to work full-time during treatment and 2 worked part-time (one of those individuals was self-employed), and 5 of the 6 returned to full-time work following treatment (one woman was still making that transition and one woman was receiving long-term disability). The caregiver participant was unemployed before, during and after his wife’s treatment.

The one woman who was self-employed and who continued to work part-time through her chemotherapy treatments had this to say about doing so:

> *When you have the flu, you're really in terrible shape for maybe four days but after that you can work from home a little bit for a few hours. So it was like that; I was able to keep going….and I didn't miss any (work deadlines) through my chemotherapy treatments…just a personal satisfaction because other people couldn't see how hard it was for me. (My husband) could, but people outside my family couldn't see it, all they could see was well, if you're doing the work, you're able to do the work. They were appreciative but they didn't have the sense that I did of I'm writing this from my bed with a bucket beside me. For me personally it was this satisfaction that I'm still here, still doing this. (Breast cancer, female)*

Another wanted to keep working because to do otherwise was tantamount to dying.

> *I did not want to go off work, so I stayed working…my workplace is very supportive in saying well you need to just go off work and go on long-term disability. But internally to me it was saying you're going to die… So I kept working. And I had never used any of my sick time, so I just used sick time. I had my surgery, like it was ovarian cancer. I did the surgery and then so I was off for a month I think it was. (Ovarian, female)*

Another woman wanted to work but could not sustain her full-time duties once treatment commenced:

> *(My boss) was extremely supportive, extremely supportive. I told her I wanted to continue working because I said I don't want to sit home. And she was very good with that. She said if you want to continue working we'll support you…Then finally I couldn't work anymore. (Ovarian, female)*

Barriers

All of the participants provided information about what they experienced as the barriers associated with work in the context of a cancer diagnosis and treatment. The sub-themes — symptoms and side effects, interactions with employers and colleagues, information from cancer care professionals, and financial concerns — highlight the difficulties.

Symptoms and Side Effects

The most often cited symptom or side effect of cancer treatment, raised by 4 participants, was feeling emotionally low, depressed or stressed once they returned to work.

Three participants also mentioned having no energy and feeling physically fatigued; one participant experienced concerns related to bowel and urine leakage at work.

During the interviews, 2 participants commented on having difficulty with their memories and concentration once they returned to work and another mentioned the difficulty of not being as productive as they once were. One individual with ovarian cancer felt physically depleted from the hormone treatment to the extent that she asked that it be discontinued.

> *You know by 7:30 I was in bed at night. I really didn't do much of anything. I would get up. I would go to work. I would come home and have dinner. My friends knew, like don't call after 7:00 o'clock. I think I managed by sleeping more than anything else. I slept more than anything. And I tried to walk a lot. (Ovarian, female)*
>
> *Fatigue was an issue, like a little bit of an issue but there was also emotional fatigue. I found that even tougher than just the physical side. When I did come back there was one morning where I actually broke down, just moving and the cancer and everything just caught up to me, a brand new job coming back. (Prostate, male)*
>
> *You go through your highs and your lows, but (I) kind of went through that same thing again getting very close to return to work with some emotional things. I went into a depression. Not that I had to go for any type of counselling, but went into quite a deep depression because it just didn't feel that my continence was coming back as quickly as what I thought it should come, even though I was doing everything that they told me I would have to. So there was some emotional and some psychological things went on there. (Prostate, male)*
>
> *I went back to work earlier than expected. It wasn't due to my employer; it was the doctor that wanted me to go back to work…I didn't feel that I had recovered. My doctor did. When you undergo chemo or radiation, you see psychologists and other therapists and they monitor you and they follow you and they know what you're going through. And I was just seeing my surgeon, so other than physically it was difficult to see how I was doing…it was…the psychological impact that it had on me……And then I had to ask for another sick leave almost one year afterwards. (Uterine, female)*

Interactions with Employer and Colleagues

Employers: Four participants encountered barriers with their employers. The participant who currently is off work receiving LTD is finding it difficult to gauge when to return to work and finds it difficult to get information about the stability of her position at work.

> *I was talking to my boss just this week. I avoided calling her because I didn't know what to say. All I could say is no, I know I'm not ready to come back. But I just couldn't and still can't kind of estimate well you know I think in another two months or six months or who knows that I would be able to...And so I said to her… what (would) I need to do or how much time (would) I need to be back so that it would be helpful and not just rock the whole system…And she said well I really need to know that you're back in full steam so that I can go full tilt. And I thought oh dear, because that just made it seem even more distant…So on the one hand I'd like to have a clearer idea of my options, but I'm really fearful of raising the issue too much. (Breast, female)*

Another participant found that when she was working part-time through her treatment her employer applied pressure to perform.

> *There was some pressure on me. I could have left at noon. (My boss) was very uncomfortable about doing the report. That was the one time where I wasn't very happy but it was the only time that I can say that that happened at that time. (Ovarian, female)*

Another women who continued to work part-time through her treatments asked for but did not receive LTD forms when she was initially diagnosed; if she had completed the LTD forms early in her treatment and was approved to receive LTD, she would have left work. Another participant, who was seconded to another position, needed to leave that secondment lest he lose all health benefits offered by his original position in the company. A third participant who wanted to continue to work sporadically (more when she was feeling better and less when she was not) wasn't able to collect any disability pay because she needed to be fully off work for a consecutive 119 days.

> *this was an issue because I know with my work it was you had to be off 119 consecutive days off totally in order to get on (long-term) disability…my supervisors and the director of care at the facility said you know this really is designed really not for people who want to work…It was a hindrance for me. I wanted to work as long as I could…So it didn't allow me to work periodically. (Ovarian, female)*

Coworkers: Three individuals with cancer talked about interactions with their coworkers on their return to work. One participant found that, once she started working half-days during her treatments, her coworkers would become frustrated that she would leave at noon. This same woman felt uncomfortable about questions about her hair and another 2 male participants felt awkward telling colleagues they had had cancer.

> *I found I'd be on my way to the bathroom or something and (colleagues) they'd go, " oh… what happened with the hair?" That sort of annoyed me for a while because I didn't want to keep bringing it up. I*

> *have to say that I found that difficult to deal with all the time. (Ovarian, female)*

> *Probably the biggest thing for me was just the stigma of saying that I've had cancer and I went through treatment. Just not knowing…how they're going to react even though I knew that we've got a pretty accommodating company. (Prostate, male)*

Information from Cancer Care Professionals

Five survivors raised the problem that the information received from cancer care professionals about returning to work was either non-existent or not helpful. Participants needed to know that it was likely they would need to leave work while receiving chemotherapy treatment, that they might encounter side effects and how to treat those side effects.

> *Because if I was going off (of work), then you're into dealing with insurance companies. You need a doctor's letter or whatever. And so I didn't know how that was going to happen because neither the oncologist nor my family doctor seemed to…they weren't saying I think you should stop (work). (Breast, female)*

> *I wasn't told now you should be off work until after your chemo. If a doctor tells me something, I'd listen. But nothing was said so I just bulldozed my way through. (Ovarian, female)*

> *When you ask (names the discharge unit at the treatment centre) does this (incontinence) go away? (They) can't answer that for you because they don't know you the individual (nor) what are you doing (at work). (Prostate, male)*

> *If there would have been one thing that would have made it easier that I couldn't find, would be for example a return-to-work guidelines or recommendations from say the Canadian Cancer Clinic (society?) saying if you have prostate cancer here are some of the things that you should consider when returning back to work. I never did find anything. (Prostate, male)*

> *But there's nothing in there (the cancer centre) that even talks about return to work. What do I have to ask my employer? What should I ask my employer? Should I notify my employer of whatever? It's not there. That message just is not there… The only thing that was mentioned about work was with the surgeon when he said that within two weeks to go back to work. Nobody else (cancer care professionals) mentioned work at all. Any of the contacts we had and processes we went through, nobody talked about work. (Prostate, male)*

> *The oncology nurses are really good if you call them and you talk about your symptoms, but no, not when it comes to returning to work. I didn't have any support for returning to work. (Ovarian, female)*

Financial Concerns

Two participants were quite concerned about their finances and worked as much as possible in order to pay their bills. One of these two was additionally strapped because of the loss of health benefits and her discomfort about seeking income support from the government.

> *…we were very worried about money and I wanted to keep doing my job as much as possible, so that was why I tried, through my treatment, to really plan ahead. (Breast, female)*

Facilitators

All interview participants mentioned several factors that assisted them in working through treatment, leaving work during treatment or returning to work. Those who wanted to or, for financial reasons, needed to continue to work were aided by having a very flexible work situation. Either they were self-employed or they had a part-time flexible work arrangement.

> *Being self-employed was a godsend in that time….Because I had so much autonomy. (Breast, female)*
>
> *After my second chemo treatment I requested to go back to work half-days. The oncologist was okay with that and my boss was okay with that. I worked half-days. Sometimes I did work, like near the end of the three weeks because chemo treatments are every three weeks, I would work a little bit more. But normally I would go in in the morning and then I would come home and I would either work, maybe answer e-mails from home or sleep in the afternoon…(working) just made me feel normal about everything. It gave me a sense of autonomy…I felt supported and it gave me a sense of purpose. (Ovarian, female)*
>
> *I'm really quite independent in my work, so it's not like I had shifts I have to fill or anything like that. I can work flex time. That was important…I could come in when I wanted. So I would book a client in late morning 10:30/11:00. And then I would work into the evening sometime. So I took advantage of that flex time. I still do actually. (Ovarian, female)*

When ready to return, participants were helped by having complete autonomy to decide how much to engage with work, having contact with work while not working and having a gradual back to work plan.

> *My work would have accommodated me to come gradually back to work and where we left it, we'll leave it up to you to decide where you're at…my new oncologist and my general practitioner (said) you know your energy levels better than anybody and if you need time, take time and we'll give you the time…(Interviewer: So it was left up to you and what you felt able to do?)…It was. It was. (Prostate, male)*

> *I was always in contact with folks at work and with my boss…it wasn't like I was completely cut off…I was still looking at e-mails…There were times where I was called to provide…advice from a professional standpoint. We were in contact every week at least…It wasn't hard to go back to work at all because I was keeping in contact with these folks…it was extremely helpful because I wanted to feel a sense of normalcy as well. And so I didn't feel like an outcast and so that was very important for me. (Prostate, male)*

> *(the insurance company told me about) a gradual return to work plan. So I said well okay, what's that? So he made one up that extended over almost close to two months…starting with just a couple of hours, a couple of days and then increasing the amount of time and the number of days, so that by late July I was working full-time. (Breast, female)*

Particular people at work (like immediate supervisors, an occupational health nurse, human resources and coworkers) also helped participants to feel supported, causing them, for the participant below for example, to feel very loyal to his employers.

> *The President and Executive Vice President from our company…came to visit me and my wife, to our home. And that was absolutely first class. They actually took the time…This was just after I had surgery, to drop in to see how I was doing but more importantly what meant a lot to me was they wanted to find out how my wife was doing… So it gave me a sense of belonging or non-abandonment… I tell these guys I'd almost take a bullet for them because that was pretty classy. (Prostate, male)*

> *The employer wasn't phoning on a constant basis begging when are you coming back….I never felt that from my employer…I think to be able to enter back into it psychologically, I knew that there weren't any problems… (Prostate, male)*

> *There are other folks, men and women, who have experienced cancer in our organization. Our company is about 1,000 people. So it's a great feeling when you meet a fellow cancer survivor because you have a tremendous bond with them… (the connection) was informal. So that was a tremendous bright spot. (Prostate, male)*

Other facilitators included having a caregiver at home (or move into the home), having the information that it was not possible to know ahead of time whether or not you needed time off of work, and having a support group to discuss returning to work with.

> *[Interviewer: So it really made a difference. If you were to picture being self-employed without that (caregiver) support, do you feel you would not have been able to continue working?] I would not, my life would have been a thousand times worse. I can't even imagine what it would have been like. (Breast, female)*

Recommendations

The participants who had experienced cancer had several recommendations about how to improve the return to work experience. Three participants suggested improvements in the information and support provided by health care professionals about returning to work. Their suggestions included encouraging them to leave work during treatment, asking questions of patients about side effects, treating side effects when they are reported by the patient and preparing patients with information about, and support for likely physical and emotional side effects of cancer and cancer treatment that could interfere with returning to work.

> *…if I had someone who had said that right off when I was going through cancer, look you need to take nine months off or a year off or just right off the bat, and I was told that this is the protocol, I would have done it…And that's how they worded it after my heart surgery. We want you to come back but we want you to come back well. We want you to take that time off… And not feel guilty about it…it would have been helpful to hear that right from the doctors…But comparing it to the heart surgery when my boss said look we're going to hire someone to cover for you for the next six months. Okay, well I let go of it then. And I could just relax and say I'm going to use this time to get better. (Ovarian, female)*

> *(I would hope that) the health care system would see return to work or rehab as part of their mandate…that they would have a formal commitment to that as part of the care they offer so that for people like me where things did not go smoothly, that (rehab) would be already built in. It would be built into the follow-up just the question how is it going, and paying attention to the answers…You know, what it's like with side effects? (Breast, female)*

> *…give individualized recommendations about return to work… "Given that here's where you are in your treatment, here's your physical response to this, this is your emotional response at this time, and maybe it isn't time yet (to RTW)"… To say, you know, "there could be some challenges here. Why don't you see this person to give you support*

> *along the way." So that instead of me struggling and trying to figure out what's going on, somebody who's got some distance on the situation could be saying you know this is what I see… the right person (to give these recommendations) could have been a nurse, it could have been a social worker, it could have been a psychologist. It could have been any number of different professions who had the right mindset about it… a couple of months before that to say, "Okay well now you've finished this treatment and usually within this timeframe people are getting organized or going back to work. How are you feeling about that? Does that look possible?" And just dealing with it in a very concrete kind of way. (Breast, female)*

> *(the health professionals) should be attuned to your (psychological) needs (Uterine, female)*

One individual with cancer thought it would be helpful to have legal advice about employee rights and sick leave. Another participant recommended that lending institutions offer a low-interest loan to help recover lost income from not working. This same participant hoped that employers of caregivers provide some flexibility in his/her work schedule to more easily assist the loved one with cancer.

> *(my husband) and I often said over the course of the year that if he hadn't been laid off, they would have fired him (because of helping me with the treatment), and I really think that's true…that would have been a huge quality-of-life issue for us that employers really need to be more flexible in terms of accommodating the caregivers and the family members. It's unbelievable to me that his company, if he had been working for them, would not have let him drive me to radiation every day for three weeks but I'm completely certain they would not… (Breast, female)*

Appendix F: Individuals with Cancer and Caregivers Return to Work Surveys

Links to Return to Work Surveys:

English:

http://www.cancerview.ca/idc/groups/public/documents/webcontent/rtw_survey_en.pdf

French:

http://www.cancerview.ca/idc/groups/public/documents/webcontent/rtw_survey_fr.pdf

Appendix G: Survey Recruitment

Text of email sent for first contact

My name is Fay Bennie and I work for the Canadian Partnership Against Cancer. We are currently conducting a study that looks at the concerns, issues and challenges that people diagnosed with cancer and their caregivers experience when the person with cancer returns to work during or after treatment. The feedback we receive from participants through an online survey will help inform future programs, services and resources. We will be asking those who are

- 18 years of age and older

  AND
- Were working and had a cancer diagnosis in the past 5 years

  OR
- Were working and were an informal caregiver to someone who was diagnosed with cancer in the past 5 years

to complete the survey.

The online survey will be ready early October and I'm hoping you would be able to help us by contacting your network of survivors and their caregivers to make them aware of this survey. I will follow up with you by telephone.

I have also attached a file with more details about the *Cancer Journey Action Group, Survivorship Initiative, Returning to the Workplace*.

Organizations that responded to recruitment email

- Cancer Journey advisory groups:
  - Cancer Journey Advisory Group
  - Cancer Journey Guidelines National Advisory Group
  - Cancer Journey National Survivorship Working Group
  - Cancer Journey Palliative Care Working Group
- Alli's Journey
- Brain Tumour Foundation of Canada
- Canadian Breast Cancer Network
- Canadian Cancer Action Network
- Canadian Cancer Society – Ontario, Montreal, PEI Divisions
- Canadian Virtual Hospice
- Colon Cancer Canada
- Colorectal Cancer Association of Canada
- Gilda's Club
- Kidney Cancer Canada
- Lymphedema Association of Ontario
- Melanoma Network of Canada

- Ovarian Cancer Canada
- Prostate Cancer Canada
- ReThink Breast Cancer
- The Canadian Association of Psychosocial Oncology
- The Canadian Testicular Cancer Association
- The Leukemia & Lymphoma Society of Canada
- Thyroid Cancer Canada
- Wellspring
- Willow Breast Cancer Support Canada
- Young Adult Cancer Canada

Text of email with information regarding the survey

Thank you for agreeing to help us with our **Returning to the Workplace** online survey. Here is the wording in English and French that we have posted for the survey on our www.cancerview.ca/vuesurlecancer.ca and website. Please feel free to use it for your posting.

Return to Work Survey

- Are you 18 + years old?
- Have you had a cancer diagnosis OR been an informal caregiver in the last 5 years?
- Were you working at the time?

Help us improve the return to work experience for cancer patients by completing this survey. https://www.surveymonkey.com/s/cancerandworkexperiences

Sondage sur le retour au travail

- Avez-vous au moins 18 ans?
- Vous a-t-on diagnostiqué un cancer OU avez-vous été un aidant naturel pour une personne atteinte d’un cancer au cours des cinq dernières années?
- Travailliez-vous à ce moment là?

En répondant à ce sondage, vous nous aiderez à améliorer l'expérience des personnes atteintes d'un cancer qui retournent au travail.

https://www.surveymonkey.com/s/canceretexperiencesdetravail

Here is a tweet in English and French.

- Improve the return to work experience for cancer patients by completing this survey. http://svy.mk/qdBxCk
- Améliorer l'expérience des personnes atteintes d'un cancer qui retournent au travail en répondant à ce sondage. http://svy.mk/mQeM5H

Thanks again for your help.

Appendix H: Overview of Bivariate Analyses Conducted

Comparisons Conducted[34]

The number of respondents who completed the survivor survey (n = 410) allowed for comparisons of responses regarding their issues and concerns returning to work along a number of dimensions:

- Reported change in income in the 12 months following their cancer diagnosis (Q22) (i.e., increased, decreased, stayed the same) by each of level of position held (Q16), size of company (recoded Q19), respondent demographics (gender, age, population of town/city, marital status).
- The possible influence of employer size (recoded Q19) on workplace accommodations or supports ***received*** (Q31).
- Cancer or health-related problems that respondents indicated resulted in work-related challenges following their diagnosis or treatment (Q29) was compared to the ways in which their cancer diagnosis or treatment affected their work (Q30) (specifically those who indicated they were “unable to work in the same way they did before their cancer diagnosis”, “changed the priority that work has in their life”, “unable to work full-time now”, “concerned about not being able to work if I were to become ill again”).
- Accommodation or supports ***required*** (Q31) by cancer or health-related problems (Q29).
- Return to work schedule (“immediately went back to work full-time”, “gradually returned to work in terms of the number of hours worked or the number of days worked per week”, “have not yet returned to work in any capacity”) by each of respondent characteristics, including gender, marital status, type of treatment, level of position held and size of employer.
- Respondents who were still receiving treatment or not (Q13) by the ways in which their cancer diagnosis or treatment affected their work (Q30) (specifically those who were “unable to work in the same way they did before their cancer diagnosis”, “changed the priority that work has in their life”, “unable to work full-time now, concerned about not being able to work if I were to become ill again”, “work provided me with a sense of normalcy”).
- The accommodation or supports respondents said they ***required*** (Q31) (i.e., flexible scheduling of work hours, gradual increase in work schedule, gradual

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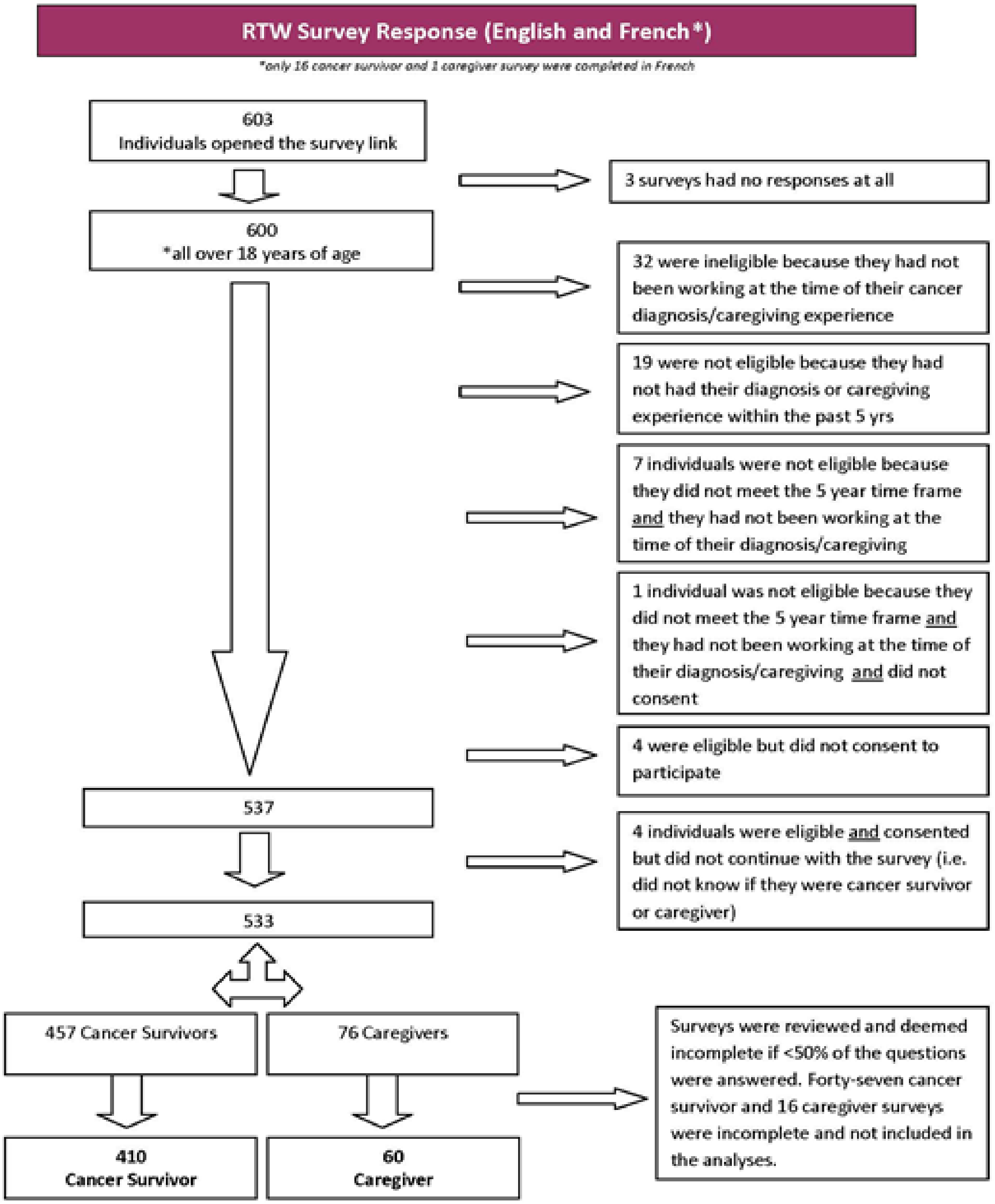
[34] No comparison was conducted by cancer type. Nearly half (46%) of the respondents reported they had a breast cancer diagnosis. The remaining respondents reported they were diagnosed with different cancers, which resulted in the numbers in the other cells being too small. This was not intended to be a study of return-to-work issues and concerns of breast cancer patients and how these issues and concerns compared to people diagnosed with other cancers.

increase in workload, reduced or part-time hours, ability to work from home, paid time off for medical appointments, support from coworkers, support from supervisor and/or employer) were explored based on the possible influence of whether or not the respondents were still receiving treatment (Q31).

- Whether respondents were still receiving treatment or not (Q13) and the types of information or support that would have helped respondents manage their work-related concerns and return to work experience following their cancer diagnosis (Q37).
- The types of information or support that would have helped respondents manage their work-related concerns and return to work experience following their cancer diagnosis (Q37) by size of employer (recoded Q19), marital status (Q6), reported change in income (Q22) and level of position held at time of diagnosis (Q16).

Appendix I: Flow Chart of Survey Responses



RTW Survey Response (English and French*)

*only 16 cancer survivor and 1 caregiver survey were completed in French

603
Individuals opened the survey link

3 surveys had no responses at all

600
*all over 18 years of age

32 were ineligible because they had not been working at the time of their cancer diagnosis/caregiving experience

19 were not eligible because they had not had their diagnosis or caregiving experience within the past 5 yrs

7 individuals were not eligible because they did not meet the 5 year time frame and they had not been working at the time of their diagnosis/caregiving

1 individual was not eligible because they did not meet the 5 year time frame and they had not been working at the time of their diagnosis/caregiving and did not consent

4 were eligible but did not consent to participate

537

4 individuals were eligible and consented but did not continue with the survey (i.e. did not know if they were cancer survivor or caregiver)

533

457 Cancer Survivors

76 Caregivers

Surveys were reviewed and deemed incomplete if <50% of the questions were answered. Forty-seven cancer survivor and 16 caregiver surveys were incomplete and not included in the analyses.

410
Cancer Survivor

60
Caregiver

Appendix J: Individuals with Cancer Detailed Findings

Section 1: Respondent Characteristics

1. What is your age? (check one)

Answer Options	Response Percent	Response Count
18 – 24 years	0.7%	3
25 - 34 years	6.6%	27
35 - 44 years	15.4%	63
45 - 54 years	39.8%	163
55 - 64 years	31.5%	129
65 - 74 years	5.9%	24
75 years of age and over	0.2%	1
	answered question	**410**
	skipped question	**0**

2. Are you…? (check one)

Answer Options	Response Percent	Response Count
Male	23.5%	96
Female	76.5%	312
	answered question	**408**
	skipped question	**2**

3. What is the highest level of education you have completed? (check one)

Answer Options	Response Percent	Response Count
Some elementary school	0.5%	2
Elementary school	0.0%	0
Some high school	0.7%	3
Completed high school	12.0%	49
Non-university certificate or diploma (e.g., college, trade, apprenticeship)	34.6%	142
Bachelor’s degree	29.3%	120
University degree above bachelor’s (e.g., M.A., PhD, medical degree)	18.8%	77
Other (please specify)	4.1%	17
	answered question	**410**
	skipped question	**0**

4. What province or territory do you live in? (check one)		
Answer Options	**Response Percent**	**Response Count**
Alberta	7.6%	31
British Columbia	3.4%	14
Manitoba	6.4%	26
New Brunswick	2.0%	8
Newfoundland and Labrador	0.0%	0
Northwest Territories	0.2%	1
Nova Scotia	7.9%	32
Nunavut	0.0%	0
Ontario	62.6%	254
Prince Edward Island	0.5%	2
Quebec	5.9%	24
Saskatchewan	3.4%	14
Yukon	0.0%	0
	answered question	**406**
	skipped question	**4**

5. What is the population of the town/city in which you live? (check one)		
Answer Options	**Response Percent**	**Response Count**
1 to 1,000	2.7%	11
1,001 to 30,000	13.3%	54
30,001 to 100,000	11.1%	45
100,001 to 500,000	21.7%	88
Over 500,000	45.2%	183
Don’t know/Not sure	5.9%	24
	answered question	**405**
	skipped question	**5**

6. What is your current marital status? (check one)		
Answer Options	**Response Percent**	**Response Count**
Married	62.2%	253
Living Common-law	8.8%	36
Widowed	1.7%	7
Separated	3.9%	16
Divorced	10.1%	41
Single, never married	13.3%	54
	answered question	**407**
	skipped question	**3**

7. What is the best estimate of your personal income (not household income) from all sources, before taxes and deductions, in the past 12 months? (check one)

Answer Options	**Response Percent**	**Response Count**
Less than $5,000	2.5%	10
$5,000 to $10,000	1.2%	5
$10,001 to $15,000	2.5%	10
$15,001 to $20,000	3.7%	15
$20,001 to $30,000	8.9%	36
$30,001 to $40,000	9.4%	38
$40,001 to $50,000	14.3%	58
$50,001 to $60,000	11.6%	47
$60,001 to $70,000	6.4%	26
$70,001 to $80,000	8.9%	36
$80,001 to $90,000	6.2%	25
$90,001 to $100,000	3.5%	14
$100,001 to $150,000	9.1%	37
Over $150,000	4.9%	20
Prefer not to answer	6.9%	28
	answered question	**405**
	skipped question	**5**

Section 2: Cancer Experience

8. Have you been diagnosed with cancer in the past 5 years? (check one)

Answer Options	**Response Percent**	**Response Count**
Yes	100.0%	410
No	0.0%	0
	answered question	**410**
	skipped question	**0**

9. What was the date of your cancer diagnosis?

Year	**Response Percent**	**Response Count**
Earlier than 2006	3.9%	16
2006	12.6%	51
2007	11.3%	46
2008	17.5%	71
2009	18.0%	73
2010	24.6%	100
2011	12.1%	49
	answered question	**406**
	skipped question	**4**

10. What cancer(s) were you diagnosed with? (check all that apply)		
Answer Options	**Response Percent**	**Response Count**
Breast	46.0%	188
Colorectal	12.7%	52
Prostate	6.6%	27
Head and Neck	6.4%	26
Non-Hodgkin Lymphoma	5.4%	22
Kidney	4.6%	19
Thyroid	2.9%	12
Leukemia	1.5%	6
Lung	1.5%	6
Melanoma	1.5%	6
Brain	1.2%	5
Bladder	0.2%	1
Other (please specify)	16.4%	67
	answered question	**409**
	skipped question	**1**

11. What stage was your cancer when it was diagnosed? (check one)		
Answer Options	**Response Percent**	**Response Count**
Stage 0	2.7%	11
Stage I	22.9%	94
Stage II	27.1%	111
Stage III	23.2%	95
Stage IV	9.3%	38
Don’t know/Not sure	14.9%	61
	answered question	**410**
	skipped question	**0**

12. What type(s) of treatment did you have following your diagnosis? (check all that apply)		
Answer Options	**Response Percent**	**Response Count**
Surgery	82.2%	337
Chemotherapy	62.9%	258
Radiation	53.7%	220
Medication	38.0%	156
No treatment	2.4%	10
Other	11.7%	48
	answered question	**410**
	skipped question	**0**

13. Are you still receiving treatment (including surgery, radiation, chemotherapy, medication) for your cancer diagnosis?

Answer Options	Response Percent	Response Count
No	57.6%	236
Yes	42.4%	174
	answered question	**410**
	skipped question	**0**

14. What date did you have your last cancer treatment (including radiation, chemotherapy, surgery and medication) for your diagnosis?

Year	Response Percent	Response Count
Earlier than 2006	0.4%	1
2006	4.9%	11
2007	12.4%	28
2008	12.4%	28
2009	22.2%	50
2010	24.4%	55
2011	23.1%	52
	answered question	**225**
	skipped question	**185**

Section 3: Income Supports and Employment Status

15. What was your employment status during each of the following time periods?

Answer Options	At the time of your cancer diagnosis (check one)		During your cancer treatment (check one)		Your current employment status (check one)		Response Count	
Employed full-time by an organization (30 or more hours a week of paid work)	327	80.1%	106	26.0%	172	42.2%	332	81.4%
Employed part-time by an organization (less than 30 hours a week of paid work)	47	11.5%	17	4.2%	49	12.0%	81	19.9%
Self-employed full-time (30 or more hours a week)	26	6.4%	9	2.2%	14	3.4%	31	7.6%
Self-employed part-time (less than 30 hours a week)	18	4.4%	13	3.2%	15	3.7%	29	7.1%
Full-time university or college student	4	1.0%	1	0.2%	4	1.0%	8	2.0%
Not employed	1	0.2%	33	8.1%	16	3.9%	45	11.0%
Homemaker	1	0.2%	3	0.7%	3	0.7%	7	1.7%
On disability benefits	3	0.7%	155	38.0%	66	16.2%	173	42.4%
Retired from paid work	2	0.5%	6	1.5%	25	6.1%	29	7.1%
Other (please specify)							51	12.5%
						answered question	**408**	
						skipped question	**2**	

16. What best describes the level of the position that you held at the time of your diagnosis? (check one)		
Answer Options	**Response Percent**	**Response Count**
Senior Management (e.g., CEO, VP, Director)	9.6%	39
Manager, Supervisor, Leader or Foreman	30.2%	123
No managerial or supervisory responsibility for other employees	51.6%	210
Self-employed	8.6%	35
Not employed at the time of my cancer diagnosis	0.0%	0
	answered question	**407**
	skipped question	**3**

17. What best describes the type of work that you did at the time of your diagnosis? (check one)		
Answer Options	**Response Percent**	**Response Count**
Non-manual work (e.g., office work, desk job)	75.1%	304
Manual work (e.g., heavy lifting, trade, manufacturing)	6.9%	28
A combination of both non-manual and manual work	18.0%	73
	answered question	**405**
	skipped question	**5**

18. Following your diagnosis did your work become ... (check one)		
Answer Options	**Response Percent**	**Response Count**
No change	71.3%	290
Less physical	14.0%	57
More physical	2.0%	8
Other (please specify)	12.8%	52
	answered question	**407**
	skipped question	**3**

19. Approximately how many people were employed at the company where you worked at the time of your cancer diagnosis? (check one)

Answer Options	Response Percent	Response Count
Self-employed	6.2%	25
Less than 5	3.7%	15
5 to 10	7.1%	29
11 to 20	8.1%	33
21 to 50	15.0%	61
51 to 100	8.4%	34
101 to 500	14.5%	59
Over 500	33.5%	136
Don't know/Not sure	3.4%	14
	answered question	**406**
	skipped question	**4**

20. What were your personal sources of income (not household) during each of the following time periods?

Answer Options	At the time of your cancer diagnosis		During your treatment		Your current personal sources of income		Response Count	
Wages and salaries (including vacation and sick days)	347	84.8%	157	38.4%	218	53.3%	360	88.0%
Income from self-employment	53	13.0%	27	6.6%	40	9.8%	60	14.7%
Dividends and interest (e.g., on bonds, savings)	29	7.1%	26	6.4%	32	7.8%	36	8.8%
Employment insurance (EI)	13	3.2%	87	21.3%	10	2.4%	100	24.4%
Private disability insurance	4	1.0%	25	6.1%	7	1.7%	32	7.8%
Short-term disability through work insurance	9	2.2%	120	29.3%	16	3.9%	129	31.5%
Long-term disability through work insurance	8	2.0%	115	28.1%	58	14.2%	141	34.5%
Worker's compensation	2	0.5%	1	0.2%	2	0.5%	4	1.0%
Benefits from Canada or Quebec Pension Plan	20	4.9%	36	8.8%	50	12.2%	59	14.4%
Job-related retirement pensions, superannuation and annuities	17	4.2%	15	3.7%	32	7.8%	34	8.3%
RRSP/RRIF (Registered Retirement Savings Plan/Registered Retirement Income Fund)	9	2.2%	18	4.4%	21	5.1%	36	8.8%
Old Age Security and Guaranteed Income Supplement	11	2.7%	11	2.7%	22	5.4%	23	5.6%
Provincial or municipal social assistance or welfare	3	0.7%	6	1.5%	7	1.7%	9	2.2%
Support from partner/spouse/family/friends	29	7.1%	67	16.4%	52	12.7%	81	19.8%
Personal savings	35	8.6%	86	21.0%	53	13.0%	112	27.4%
Child tax benefit	18	4.4%	25	6.1%	22	5.4%	29	7.1%
Child support	7	1.7%	8	2.0%	9	2.2%	11	2.7%
Alimony	3	0.7%	3	0.7%	5	1.2%	7	1.7%
Other (please specify – stocks, RRSPs, commissions, refinancing, loans, private health insurance)							29	7.1%
						Answered question	**409**	
						Skipped question	**1**	

21. What is the best estimate of your personal income (not household income) from all sources, before taxes and deductions, in the 12 months before your cancer diagnosis? (check one)		
Answer Options	**Response Percent**	**Response Count**
Less than $5,000	1.3%	5
$5,000 to $10,000	1.8%	7
$10,001 to $15,000	1.3%	5
$15,001 to $20,000	1.0%	4
$20,001 to $30,000	7.4%	29
$30,001 to $40,000	12.0%	47
$40,001 to $50,000	11.7%	46
$50,001 to $60,000	11.0%	43
$60,001 to $70,000	10.7%	42
$70,001 to $80,000	9.4%	37
$80,001 to $90,000	6.6%	26
$90,001 to $100,000	5.1%	20
$100,001 to $150,000	8.7%	34
Over $150,000	5.9%	23
Don’t remember/Not sure	0.0%	0
Prefer not to answer	6.1%	24
	answered question	**392**
	skipped question	**18**

22. In the 12 months following your cancer diagnosis did your personal income ...? (check one)		
Answer Options	**Response Percent**	**Response Count**
Increase	6.4%	26
Stay the same	31.4%	128
Decrease	60.0%	244
Don’t remember/Not sure	2.2%	9
	answered question	**407**
	skipped question	**3**

23. What is the best estimate of your personal income in the 12 months following your cancer diagnosis? (check one)

Answer Options	Response Percent	Response Count
Less than $5,000	6.3%	17
$5,000 to $10,000	5.1%	14
$10,001 to $15,000	5.9%	16
$15,001 to $20,000	7.4%	20
$20,001 to $30,000	14.0%	38
$30,001 to $40,000	15.1%	41
$40,001 to $50,000	13.2%	36
$50,001 to $60,000	10.3%	28
$60,001 to $70,000	1.8%	5
$70,001 to $80,000	4.4%	12
$80,001 to $90,000	3.3%	9
$90,001 to $100,000	2.6%	7
$100,001 to $150,000	2.2%	6
Over $150,000	2.6%	7
Don’t remember/Not sure	1.8%	5
Prefer not to answer	4.0%	11
	answered question	**272**
	skipped question	**138**

24. Did you have any other health conditions (i.e. other than those related to your cancer diagnosis and treatment) that influenced your work status and/or income at each of the following time periods?

Answer Options	No		Yes		Response Count	
... at the time of your cancer diagnosis	372	91.4%	30	7.4%	402	98.8%
... during your cancer treatment	327	80.3%	71	17.4%	398	97.8%
... currently	304	74.7%	93	22.9%	397	97.5%
If you answered yes to any of the above, please briefly describe these other health conditions and the time period in which they influenced your work experiences.					103	25.3%
				answered question	**407**	
				skipped question	**3**	

25. What was the total amount of time you were away from work following your cancer diagnosis? (check all that apply)

Answer Options	Response Percent	Response Count
<1 week	2.9%	12
1 - 3 weeks	6.1%	25
4 - 8 weeks	10.5%	43
9 – 12 weeks	6.8%	28
13 - 16 weeks	5.9%	24
17 - 20 weeks	6.1%	25
21 - 24 weeks	7.1%	29
More than 24 weeks	39.4%	161
I did not miss any work during treatment	2.0%	8
I retired after I was diagnosed	2.0%	8
I quit my job after I was diagnosed	2.7%	11
I was dismissed from my job after I was diagnosed	2.0%	8
Don’t know/not sure	1.0%	4
I have not yet returned to work. Please specify the amount of time you have been away from work to date.	16.4%	67
	answered question	**409**
	skipped question	**1**

26. What influenced the amount of time that you did or did not take off from work following your cancer diagnosis? Open ended (summary in body of report)

27. What was your return to work schedule like? (check all that apply)

Answer Options	Response Percent	Response Count
I gradually returned to work in terms of the numbers of hours worked or the number of days worked per week	40.6%	166
I immediately went back to work full-time	18.3%	75
I have not yet returned to work in any capacity	15.9%	65
I had flexible scheduling of hours worked each day or the location of work (e.g., work from home)	12.2%	50
I never stopped working during treatment	8.1%	33
I immediately returned to work on a part-time basis	6.6%	27
I retired after I was diagnosed	2.7%	11
I was dismissed from my job after I was diagnosed	2.0%	8
I quit after I was diagnosed	1.5%	6
Other (please specify)	11.7%	48
	answered question	**409**
	skipped question	**1**

28. Which of the following best describes the type of employment you had following your cancer diagnosis or treatment? (check one)

Answer Options	Response Percent	Response Count
Old job with previous employer	64.2%	219
Self-employment	8.5%	29
Different job with previous employer	6.7%	23
Different job with different employer	5.0%	17
I have not yet returned to work	3.5%	12
Similar to old job, but with different employer	2.9%	10
I retired after I was diagnosed	2.1%	7
Other (please specify)	7.0%	24
	answered question	**341**
	skipped question	**69**

Section 4: Concerns, Issues and Challenges Experienced with Return to Work

29. Which of the following cancer or health-related problems resulted in work-related issues, concerns or challenges following your diagnosis or treatment? (check all that apply)

Answer Options	Response Percent	Response Count
Fatigue	73.5%	297
Reduced energy	69.3%	280
Reduced physical ability	47.8%	193
Personal stress	47.3%	191
Reduced cognitive ability to manage work demands (e.g., poor memory, concentration)	45.3%	183
Sleep problems	45.0%	182
Anxiety	43.3%	175
Job-related stress	39.4%	159
Pain	37.1%	150
Body image and appearance	28.0%	113
Depression	25.2%	102
Concern about infection	21.5%	87
Nausea	15.8%	64
Bowel or urinary incontinence	15.1%	61
Loss of appetite	12.4%	50
Shortness of breath	10.1%	41
Lymphedema	9.9%	40
I have not experienced any cancer or health-related problems that influenced my work	6.4%	26
Other (please specify) e.g., numbness, hot flashes	11.6%	47
	answered question	**404**
	skipped question	**6**

30. Please indicate the ways in which your cancer diagnosis or treatment has affected your work (check all that apply)		
Answer Options	**Response Percent**	**Response Count**
My work provided me with a sense of normalcy	43.7%	176
I have changed the priority that work has in my life	40.0%	161
I had coworkers support me at work because of my cancer diagnosis	39.2%	158
I am unable to work in the same way I did before my cancer diagnosis	27.0%	109
I am concerned about not being able to work if I were to become ill again	26.3%	106
Ongoing cancer-related or treatment-related symptoms interfere with my work	18.4%	74
I am unable to work full-time now	16.1%	65
I have earned increased respect at work	14.1%	57
I have stayed in my job because I do not want to lose my health insurance	13.2%	53
The quality of my work has decreased	11.9%	48
I no longer wish to work	10.7%	43
My supervisor and/or employer have not been very supportive	10.7%	43
I worry about being forced to retire or quit work before I am ready	10.7%	43
I have experienced a decrease in pay	9.7%	39
I chose to make a career change	8.2%	33
I have stayed in my job because I do not want to lose my life insurance	7.9%	32
My job was reorganized (e.g., job responsibilities changed)	7.4%	30
I was not able to return to my same job because of medical concerns or reduced physical ability	7.2%	29
I am unable to work at all now	7.2%	29
My coworkers have not been very supportive	7.2%	29
My employer did not make reasonable changes or accommodations in my job to help me	6.0%	24
The terms of my employment were changed	5.5%	22
I have experienced employment discrimination	5.0%	20
I chose to return to a job at a lower level (e.g., fewer responsibilities, less pay)	5.0%	20
I was passed over for a promotion	4.7%	19
My job was terminated	4.5%	18
I have felt that I did not get a job because of my cancer diagnosis	4.2%	17
I left a job that I did not like	3.0%	12
I had to take on a second job because of debt due to cancer	1.7%	7
My employer demoted me	0.7%	3
None of the above	5.5%	22
Other (please specify)	20.6%	83
	answered question	**403**
	skipped question	**7**

31. Which of the following workplace accommodations or supports did you require following your cancer diagnosis or treatment and for each of these please indicate whether you received the accommodation/support?

Answer Options	I required this accommodation or support		I received this accommodation or support		Response Count	
Support from supervisor and/or employer	166	51.7%	162	50.5%	212	66.0%
Paid time off for medical appointments	155	48.3%	137	42.7%	180	56.1%
Support from coworkers	148	46.1%	171	53.3%	205	63.9%
Flexible scheduling of work hours	144	44.9%	135	42.1%	169	52.6%
Gradual increase in work schedule	131	40.8%	120	37.4%	150	46.7%
Gradual increase in workload	106	33.0%	95	29.6%	126	39.3%
Reduced or part-time hours	97	30.2%	83	25.9%	113	35.2%
Return to work meeting with supervisor/employer	91	28.3%	92	28.7%	121	37.7%
Ability to work from home	84	26.2%	71	22.1%	102	31.8%
Additional breaks or rest periods	66	20.6%	41	12.8%	77	24.0%
Unpaid time off	65	20.2%	60	18.7%	83	25.9%
Modified work tasks	61	19.0%	56	17.4%	78	24.3%
Reduced physical tasks	55	17.1%	39	12.1%	66	20.6%
Redesign or adjustment to workspace	27	8.4%	15	4.7%	31	9.7%
Assistive devices	16	5.0%	9	2.8%	17	5.3%
Retraining to perform different work	14	4.4%	5	1.6%	17	5.3%
Other (please specify)					72	22.4%
				answered question	**321**	
				skipped question	**89**	

Section 5: Return to Work Resources and Recommendations

32. Thinking about your work experiences following your cancer diagnosis or treatment, what changes, if any, did you choose to make? Open ended (summary in body of report)

33. Thinking about your work experiences following your cancer diagnosis or treatment, what changes, if any, were beyond your control? Open ended (summary in body of report)

34. What was your main work-related issue, concern or challenge that you have experienced following your cancer diagnosis or treatment? Open ended (summary in body of report)

35. Please indicate which of the following were sources of work-related information, resources and/or support for you following your cancer diagnosis (check all that apply)

Answer Options	**Response Percent**	**Response Count**
Family physician	36.5%	140
Cancer support group	34.9%	134
Oncologist	33.9%	130
Immediate work supervisor	26.0%	100
Online information	25.0%	96
Psychological counsellor	21.4%	82
Nurse	19.8%	76
Human resource representative	18.0%	69
Cancer survivorship program	16.9%	65
Return to work program	15.9%	61
Insurance representative	15.6%	60
Employee Assistance Program	14.3%	55
Disability management representative	13.0%	50
Social worker	10.9%	42
Union representative	9.4%	36
Vocational rehabilitation counsellor (e.g., through an insurance company, hospital or disability-related resource)	6.0%	23
Back at work program	5.7%	22
Occupational therapist	5.2%	20
Legal services	2.3%	9
Vocational counsellor (e.g., through Service Canada)	0.5%	2
No one provided me with any work-related information, resource and/or support	20.8%	80
Other (please specify)	14.8%	57
	answered question	**384**
	skipped question	**26**

36. If you participated in a return to work and/or survivorship program(s) please specify the program you participated in. Open ended (summary in body of report)

37. What information or support would have helped you manage your work-related concerns and return to work experience following your cancer diagnosis? (check all that apply)		
Answer Options	**Response Percent**	**Response Count**
What the impact of my cancer and treatment might have on my work	44.2%	160
Guidance on how much time I should have planned to take off from work	43.9%	159
Managing the pressure to meet work demands	39.5%	143
Knowing what my employment rights are	36.5%	132
Information on sources of income support	35.4%	128
How to manage my symptoms	31.8%	115
How to talk with my coworkers about my cancer diagnosis and treatment	30.7%	111
How to talk with my employer about my cancer diagnosis and treatment	28.7%	104
Access to income support (e.g., long-term disability)	28.2%	102
How to negotiate workplace accommodations with my employer	22.4%	81
What workplace accommodations could be made	22.1%	80
None of the above	18.2%	66
Other (please specify)	12.1%	44
	answered question	**362**
	skipped question	**48**

38. What did you find to be the most helpful to you in managing work-related issues following your cancer diagnosis (e.g., resource, program, person, source of information)? Open ended (summary in body of report)

39. What would you recommend is needed (e.g., information, service, program) to facilitate a positive return to work experience for other individuals who have been diagnosed with cancer? Open ended (summary in body of report)

40. If you have additional comments about your work-related experiences associated with your cancer diagnosis, please write them below. Open ended (summary in body of report)

- 123 respondents provided the following information to describe their work/cancer experience (see Table 25).

Table 25. Q40: If you have additional comments about your work-related experiences associated with your cancer diagnosis, please write them below

Additional Comments	Description
Work Environment	• employer was very supportive/unsupportive • wanted to RTW/kept self going, feeling normal, work was a distraction • used up savings because they were self-employed • changing fields or position because of disability from cancer/lost skills • friends offered work to update skills • discrimination so lesser job/no job • needed more flexibility from employer • how to navigate RTW for those with metastatic illness • need information on how to apply for EI • need information on rights with health insurance/labour laws • need information to employees/employers on what to expect from/how to help individuals returning after cancer • gradual work return is difficult – end up doing more work in less time
Peers	• have RTW support group with peers who get it • want to give back to similar others
Personal	• felt less desirable to employer • need time off work to heal • needs to pace self more • information on how to deal with side effects
Income Support	• need more financial assistance to afford to leave work for treatment • loss of income/pension because of delay in workplace accommodations • insurance pressuring to return too quickly/worked out smoothly
Program	• need program to help with job search • existing programs like Wellspring, Cancer Care were supportive
Health Care Professionals	• oncologist should not be too quick to send people back to work • oncologist return to work conversation too vague • need to normalize time off work to recover from cancer • need information from health care professionals about how long it takes to recover

41. Where did you hear about this survey? (check all that apply)

Answer Options	Response Percent	Response Count
... through a community cancer support organization or group	60.1%	230
... through a national cancer association	14.4%	55
... through the hospital/cancer clinic where I received my treatment	7.3%	28
... from a partner/spouse/family member/friend	5.0%	19
Other (please specify)	20.4%	78
	answered question	383
	skipped question	27

Appendix K: Caregiver Detailed Findings

Section 1: Respondent Demographics

1. What is your age? (check one)

Answer Options	Response Percent	Response Count
18 - 24 years	6.7%	4
25 - 34 years	11.7%	7
35 - 44 years	25.0%	15
45 - 54 years	38.3%	23
55 - 64 years	15.0%	9
65 - 74 years	3.3%	2
75 years of age and over	0.0%	0
	answered question	**60**
	skipped question	**0**

2. Are you… (check one)

Answer Options	Response Percent	Response Count
Male	11.9%	7
Female	88.1%	52
	answered question	**59**
	skipped question	**1**

3. What is the highest level of education you have completed? (check one)

Answer Options	Response Percent	Response Count
Some elementary school	0.0%	0
Elementary school	0.0%	0
Some high school	0.0%	0
Completed high school	10.2%	6
Non-university certificate or diploma (e.g., college, trade, apprenticeship)	10.2%	6
Bachelor's degree	45.8%	27
University degree above bachelor's (e.g., M.A., PhD, medical degree)	28.8%	17
Other (please specify)	5.1%	3
	answered question	**59**
	skipped question	**1**

4. What province or territory do you live in? (check one)

Answer Options	Response Percent	Response Count
Alberta	8.5%	5
British Columbia	1.7%	1
Manitoba	18.6%	11
New Brunswick	5.1%	3
Newfoundland and Labrador	1.7%	1
Northwest Territories	0.0%	0
Nova Scotia	10.2%	6
Nunavut	0.0%	0
Ontario	44.1%	26
Prince Edward Island	1.7%	1
Quebec	6.8%	4
Saskatchewan	1.7%	1
Yukon	0.0%	0
	answered question	**59**
	skipped question	**1**

5. What is the population of the town/city in which you live? (check one)

Answer Options	Response Percent	Response Count
1 to 1,000	1.7%	1
1,001 to 30,000	10.0%	6
30,001 to 100,000	20.0%	12
100,001 to 500,000	20.0%	12
Over 500,000	40.0%	24
Don't know/Not sure	8.3%	5
	answered question	**60**
	skipped question	**0**

6. What is your current marital status? (check one)

Answer Options	Response Percent	Response Count
Married	51.7%	31
Living Common-law	6.7%	4
Widowed	21.7%	13
Separated	3.3%	2
Divorced	3.3%	2
Single, never married	13.3%	8
	answered question	**60**
	skipped question	**0**

7. What is the best estimate of your personal income (not household income) from all sources, before taxes and deductions, in the past 12 months? (check one)

Answer Options	Response Percent	Response Count
Less than $5,000	1.7%	1
$5,000 to $10,000	0.0%	0
$10,001 to $15,000	1.7%	1
$15,001 to $20,000	6.8%	4
$20,001 to $30,000	11.9%	7
$30,001 to $40,000	6.8%	4
$40,001 to $50,000	8.5%	5
$50,001 to $60,000	8.5%	5
$60,001 to $70,000	10.2%	6
$70,001 to $80,000	6.8%	4
$80,001 to $90,000	6.8%	4
$90,001 to $100,000	10.2%	6
$100,001 to $150,000	5.1%	3
Over $150,000	6.8%	4
Prefer not to answer	8.5%	5
	answered question	**59**
	skipped question	**1**

Section 2: Cancer and Caregiving Experience

8. Is the person you provide/provided care for your… (check one)

Answer Options	Response Percent	Response Count
Spouse/partner	51.7%	31
Parent	30.0%	18
Sibling	8.3%	5
Child	3.3%	2
Friend	3.3%	2
Other family member (e.g., aunt, cousin)	1.7%	1
Grandparent	0.0%	0
Other (please specify)	1.7%	1
	answered question	**60**
	skipped question	**0**

9. Was the individual that you provide/provided care for diagnosed with cancer in the past 5 years? (check one)

Answer Options	Response Percent	Response Count
Yes	100.0%	60
No	0.0%	0
	answered question	**60**
	skipped question	**0**

10. What was the date of their cancer diagnosis?

Year	Response Percent	Response Count
Earlier than 2006	5.0%	3
2006	10.0%	6
2007	11.7%	7
2008	18.3%	11
2009	20.0%	12
2010	18.3%	11
2011	16.7%	10
	answered question	60
	skipped question	0

11. What cancer(s) was the individual you provided care for diagnosed with? (check all that apply)

Answer Options	Response Percent	Response Count
Colorectal	35.0%	21
Leukemia	8.3%	5
Lung	8.3%	5
Brain	5.0%	3
Breast	5.0%	3
Kidney	5.0%	3
Prostate	5.0%	3
Head and Neck	3.3%	2
Melanoma	3.3%	2
Non-Hodgkin Lymphoma	3.3%	2
Thyroid	1.7%	1
Bladder	0.0%	0
Other (please specify)	33.3%	20
	answered question	60
	skipped question	0

12. What stage was their cancer when it was diagnosed? (check one)

Answer Options	Response Percent	Response Count
Stage 0	3.3%	2
Stage I	10.0%	6
Stage II	3.3%	2
Stage III	30.0%	18
Stage IV	31.7%	19
Don’t know/Not sure	21.7%	13
	answered question	60
	skipped question	0

13. What type of treatment did they have following this diagnosis? (check all that apply)

Answer Options	Response Percent	Response Count
Chemotherapy	76.7%	46
Surgery	58.3%	35
Medication (e.g., prescribed pain medication, hormonal therapies such as Tamoxifen)	38.3%	23
Radiation	36.7%	22
No treatment	1.7%	1
Other (please specify)	18.3%	11
	answered question	**60**
	skipped question	**0**

14. Are they still receiving treatment (including surgery, radiation, chemotherapy, medication) for this cancer diagnosis?

Answer Options	Response Percent	Response Count
Yes	31.7%	19
No	68.3%	41
	answered question	**60**
	skipped question	**0**

15. What date did they have their last cancer treatment (including radiation, chemotherapy, surgery and medication) for their diagnosis?

Year	Response Percent	Response Count
2006	2.6%	1
2007	7.7%	3
2008	15.4%	6
2009	23.1%	9
2010	23.1%	9
2011	28.2%	11
	answered question	**39**
	skipped question	**21**

16. How many months have/did you provide care for this individual following their cancer diagnosis? (check one)

Answer Options	Response Percent	Response Count
<1 month	1.7%	1
1 to less than 2 months	1.7%	1
2 to less than 4 months	6.7%	4
4 to less than 6 months	15.0%	9
6 months or longer	43.3%	26
I am still providing care, please specify how long you have provided care to date	31.7%	19
	answered question	**60**
	skipped question	**0**

17. During this time, on average how much time do/did you provide care to this individual? (check one)

Answer Options	Response Percent	Response Count
A few hours a month	1.7%	1
A few hours a week	15.0%	9
Less than an hour a day most days	10.0%	6
A few hours a day most days	26.7%	16
A number of hours a day most days	26.7%	16
24 hours/day	8.3%	5
Other (please specify)	11.7%	7
	answered question	**60**
	skipped question	**0**

18. Would you say your caregiving role for the individual who was diagnosed with cancer did/does preoccupy you… (check one)

Answer Options	Response Percent	Response Count
All of the time	47.5%	28
Often	42.4%	25
Sometimes	10.2%	6
Rarely	0.0%	0
	answered question	**59**
	skipped question	**1**

19. During which of the following time periods did you provide care for this individual? (check all that apply)		
Answer Options	**Response Percent**	**Response Count**
At the time of their cancer diagnosis	75.0%	45
During their cancer treatment	83.3%	50
During palliative care	41.7%	25
Other (please specify)	16.7%	10
	answered question	**60**
	skipped question	**0**

20. Are you still actively providing care for this individual?		
Answer Options	**Response Percent**	**Response Count**
Yes	35.6%	21
No	64.4%	38
	answered question	**59**
	skipped question	**1**

21. Do/did you live in the same residence with the individual for whom you are/were providing care?		
Answer Options	**Response Percent**	**Response Count**
Yes	70.0%	42
No	30.0%	18
	answered question	**60**
	skipped question	**0**

22. What types of care do/did you provide? (check all that apply)		
Answer Options	**Response Percent**	**Response Count**
Emotional support	98.3%	59
Home management (e.g., cooking, cleaning, running errands, laundry, bill paying)	93.3%	56
Transportation to and from medical appointments	83.3%	50
Support with activities of daily living (e.g., bathing, dressing, toileting, feeding)	55.0%	33
Skilled care (e.g., injections, inserting feeding tube)	23.3%	14
Other (please specify)	25.0%	15
	answered question	**60**
	skipped question	**0**

Section 3: Income Supports and Employment Status

23. Which of the following best describes your employment status during each of the following time periods?

Answer Options	At the time the individual to whom you are/were providing care was diagnosed with cancer		During the individual's cancer treatment		Your current employment status		Response Count	
Employed full-time by an organization (30 or more hours a week of paid work)	46	76.7%	39	65.0%	38	63.3%	49	81.7%
Employed part-time by an organization (less than 30 hours a week of paid work)	9	15.0%	12	20.0%	10	16.7%	15	25.0%
Self-employed full-time (30 or more hours a week)	3	5.0%	1	1.7%	1	1.7%	3	5.0%
Self-employed part-time (less than 30 hours a week)	1	1.7%	2	3.3%	2	3.3%	3	5.0%
Full-time university or college student	1	1.7%	1	1.7%	1	1.7%	2	3.3%
Not employed	0	0.0%	3	5.0%	2	3.3%	5	8.3%
Homemaker	0	0.0%	1	1.7%	0	0.0%	1	1.7%
On disability benefits	0	0.0%	3	5.0%	3	5.0%	5	8.3%
Retired from paid work	0	0.0%	0	0.0%	2	3.3%	2	3.3%
						answered question	60	
						skipped question	0	

24. Which of the following best describes the level of the position that you held at the time you began providing care for the individual diagnosed with cancer? (check one)

Answer Options	Response Percent	Response Count
Senior Management (e.g., CEO, VP, Director)	6.7%	4
Manager, Supervisor, Leader or Foreman	30.0%	18
No managerial or supervisory responsibility for other employees	56.7%	34
Self-employed	5.0%	3
Not employed at the time I began providing care for the individual	1.7%	1
	answered question	60
	skipped question	0

25. Approximately how many people were employed at the company where you worked at the time the individual to whom you are/were providing care was diagnosed with cancer? (check one)		
Answer Options	**Response Percent**	**Response Count**
Self-employed	5.2%	3
Less than 5	10.3%	6
5 to 10	5.2%	3
11 to 20	8.6%	5
21 to 50	19.0%	11
51 to 100	8.6%	5
101 to 500	10.3%	6
Over 500	29.3%	17
Don’t know/Not sure	3.4%	2
	answered question	**58**
	skipped question	**2**

26. What were <u>your</u> personal sources of income (<u>not</u> household) during each of the following time periods?								
Answer Options	**At the time the individual to whom you are/were pro-viding care was diagnosed with cancer (check all that apply)**		**During the individual’s cancer treat-ment (check all that apply)**		**Your current personal sources of income (check all that apply)**		**Response Count**	
Wages and salaries (including vacation and sick days)	52	89.7%	45	77.6%	42	72.4%	56	96.6%
Income from self-employment	7	12.1%	6	10.3%	6	10.3%	9	15.5%
Dividends and interest (e.g., on bonds, savings)	5	8.6%	6	10.3%	5	8.6%	7	12.1%
Employment insurance (EI)	1	1.7%	5	8.6%	0	0.0%	5	8.6%
Private disability insurance	1	1.7%	2	3.4%	0	0.0%	2	3.4%
Short-term disability through work insurance	1	1.7%	3	5.2%	2	3.4%	5	8.6%
Long-term disability through work insurance	1	1.7%	3	5.2%	1	1.7%	4	6.9%
Worker’s compensation	1	1.7%	1	1.7%	2	3.4%	2	3.4%
Benefits from Canada or Quebec Pension Plan	1	1.7%	1	1.7%	5	8.6%	5	8.6%
Job-related retirement pensions, superannuation and annuities	1	1.7%	1	1.7%	3	5.2%	3	5.2%
RRSP/RRIF (Registered Retirement Savings Plan/Registered Retirement Income Fund)	2	3.4%	2	3.4%	2	3.4%	3	5.2%
Old Age Security and Guaranteed Income Supplement	1	1.7%	1	1.7%	1	1.7%	1	1.7%
Provincial or municipal social assistance or welfare	0	0.0%	0	0.0%	0	0.0%	0	0.0%
Support from partner/spouse/family/friends	1	1.7%	7	12.1%	7	12.1%	10	17.2%
Personal savings	5	8.6%	12	20.7%	9	15.5%	13	22.4%
Child tax benefit	7	12.1%	8	13.8%	6	10.3%	9	15.5%
Child support	1	1.7%	1	1.7%	1	1.7%	1	1.7%
Alimony	0	0.0%	0	0.0%	0	0.0%	0	0.0%
Other (please specify)							6	10.3%
						answered question	**58**	
						skipped question	**2**	

27. What is the best estimate of your personal income (not household income) from all sources, before taxes and deductions, in the 12 months before you began providing care? (check one)

Answer Options	Response Percent	Response Count
Less than $5,000	1.8%	1
$5,000 to $10,000	5.3%	3
$10,001 to $15,000	1.8%	1
$15,001 to $20,000	3.5%	2
$20,001 to $30,000	8.8%	5
$30,001 to $40,000	7.0%	4
$40,001 to $50,000	14.0%	8
$50,001 to $60,000	7.0%	4
$60,001 to $70,000	5.3%	3
$70,001 to $80,000	7.0%	4
$80,001 to $90,000	10.5%	6
$90,001 to $100,000	8.8%	5
$100,001 to $150,000	3.5%	2
Over $150,000	7.0%	4
Don’t remember/Not sure	0.0%	0
Prefer not to answer	8.8%	5
	answered question	**57**
	skipped question	**3**

28. In the 12 months after you began providing care did your personal income… (check one)

Answer Options	Response Percent	Response Count
Increase	6.8%	4
Stay the same	47.5%	28
Decrease	42.4%	25
Don’t remember/Not sure	3.4%	2
	answered question	**59**
	skipped question	**1**

29. What is the best estimate of your personal income (not household income) from all sources, before taxes and deductions, in the 12 months after you began providing care? (check one)		
Answer Options	**Response Percent**	**Response Count**
Less than $5,000	10.3%	3
$5,000 to $10,000	3.4%	1
$10,001 to $15,000	6.9%	2
$15,001 to $20,000	17.2%	5
$20,001 to $30,000	13.8%	4
$30,001 to $40,000	3.4%	1
$40,001 to $50,000	3.4%	1
$50,001 to $60,000	10.3%	3
$60,001 to $70,000	6.9%	2
$70,001 to $80,000	13.8%	4
$80,001 to $90,000	0.0%	0
$90,001 to $100,000	0.0%	0
$100,001 to $150,000	0.0%	0
Over $150,000	3.4%	1
Don’t remember/Not sure	0.0%	0
Prefer not to answer	6.9%	2
	answered question	29
	skipped question	31

30. What was the total amount of time you were away from work to provide care? (check all that apply)		
Answer Options	**Response Percent**	**Response Count**
<1 week	15.3%	9
1 - 3 weeks	13.6%	8
4 - 8 weeks	20.3%	12
9 - 12 weeks	13.6%	8
13 - 16 weeks	8.5%	5
17 - 20 weeks	1.7%	1
21 - 24 weeks	3.4%	2
More than 24 weeks	10.2%	6
I did not miss any work during the time I provided care	5.1%	3
I retired from my job to provide care	1.7%	1
I quit my job to provide care	3.4%	2
I was dismissed from my job because of my caregiving responsibilities	0.0%	0
Don’t know/not sure	5.1%	3
I have not yet returned to work. Please specify the amount of time you have been away from work to date.	5.1%	3
	answered question	59
	skipped question	1

31. What influenced the amount of time that you did or did not take off from work following the cancer diagnosis (e.g., finances, work responsibilities, personal issues, other)? Open ended (summary in body of report)

32. Have/did you make any of the following adjustments or changes to your paid employment as a result of your caregiving responsibilities?

Answer Options	Often		Sometimes		Rarely/Never		Response Count	
Refused work	7	11.9%	9	15.3%	19	32.2%	35	59.3%
Refused new responsibilities	9	15.3%	17	28.8%	11	18.6%	37	62.7%
Reduced hours	20	33.9%	18	30.5%	6	10.2%	44	74.6%
Changed work schedule/times	24	40.7%	12	20.3%	8	13.6%	44	74.6%
Used vacation time or sick days for care responsibilities	25	42.4%	16	27.1%	8	13.6%	49	83.1%
Other (please specify)							7	11.9%
						answered question	59	
						skipped question	1	

Section 4: Work-Related Concerns, Issues and Challenges Experienced

Q33. What workplace accommodations did you need that you did not get to help you provide care for the individual diagnosed with cancer (e.g., reduced hours, short or long periods of time away from work)? Open ended (summary in body of report)

34. How often has/is your work been affected by your caring role in the following ways?

Answer Options	Often		Sometimes		Rarely/Never		Response Count	
Absences	25	42.4%	23	39.0%	7	11.9%	55	93.2%
Interruptions	20	33.9%	19	32.2%	8	13.6%	47	79.7%
Arriving to work later than usual	14	23.7%	16	27.1%	16	27.1%	46	78.0%
Having to leave earlier than usual	16	27.1%	24	40.7%	9	15.3%	49	83.1%
Lack of concentration	35	59.3%	18	30.5%	4	6.8%	57	96.6%
Less productivity than usual	29	49.2%	17	28.8%	6	10.2%	52	88.1%
Other (please specify)							7	11.9%
						answered question	59	
						skipped question	1	

35. What was your main work-related issue, concern or challenge that you have experienced as a result of providing care for the individual with cancer? Open ended (summary in body of report)

Section 5: Return to Work Resources and Recommendations

36. Please indicate which of the following provided you, or the individual you were providing care for, with any work-related information, resources and/or support? (check all that apply)

Answer Options	**Response Percent**	**Response Count**
Oncologist	27.6%	16
Family physician	27.6%	16
Immediate work supervisor	25.9%	15
Online information	24.1%	14
Social worker	20.7%	12
Nurse	15.5%	9
Cancer support group	15.5%	9
Human resource representative	13.8%	8
Psychological counsellor	12.1%	7
Employee Assistance Program	6.9%	4
Insurance representative	3.4%	2
Disability management representative	3.4%	2
Cancer survivorship program	3.4%	2
Back at work program	1.7%	1
Vocational rehabilitation counsellor (e.g., through an insurance company, hospital or disability-related resource)	0.0%	0
Vocational counsellor (e.g., through Service Canada)	0.0%	0
Occupational therapist	0.0%	0
Legal services	0.0%	0
Union representative	0.0%	0
Return to work program	0.0%	0
No one provided me with any work-related information, resource and/or support	34.5%	20
Other (please specify)	17.2%	10
	answered question	**58**
	skipped question	**2**

37. If you or the individual you were caring for participate in a return to work and/or survivorship program please specify the program you participated in. Open ended (summary in body of report)

38. What information or support would have helped you manage your work-related concerns while providing care for the individual with cancer? (check all that apply)

Answer Options	Response Percent	Response Count
How to manage caregiving and work demands	58.2%	32
What my employment rights were/are	52.7%	29
Information on potential sources of income support	49.1%	27
What the impact of providing care might be on my work	47.3%	26
How to talk with my employer about my caregiving role	45.5%	25
What workplace accommodations could be made	43.6%	24
Guidance on how much time I would likely need to provide care	41.8%	23
How to negotiate workplace accommodations with my employer	41.8%	23
How to talk with my coworkers about my caregiving role	40.0%	22
None of the above	10.9%	6
Other (please specify)		5
	answered question	**55**
	skipped question	**5**

39. What did you find to be the **most** helpful to you in managing work-related issues during your caregiving experience (e.g., resource, program, person, source of information)? Open ended (summary in body of report)

40. What would you recommend is needed (e.g., information, service, program) to reduce work-related issues for caregivers of individuals who have been diagnosed with cancer? Open ended (summary in body of report)

41. If you have additional comments about your work-related experiences associated with caregiving, please write them here. Open ended (summary in body of report)

- The last question in the survey invited caregiver respondents to offer any additional comments. Caregivers (n = 12 responded to this question) described the stress of trying to both do their jobs and provide care, needing financial help to make it work, and wanting flexibility from the employer.

42. Where did you hear about this survey? (check all that apply)

Answer Options	Response Percent	Response Count
Through a community cancer support organization or group	47.4%	27
Through the hospital/cancer clinic where I received my treatment	7.0%	4
Through a national cancer association	14.0%	8
From a partner/spouse/family member/friend	12.3%	7
Other (please specify)	21.1%	12
	answered question	**57**
	skipped question	**3**

Appendix L: Focus Groups

Recruitment Flyer

Return to Work Concerns Faced by People Dealing with Cancer

Are you interested in participating in a research study on return of work concerns, issues and challenges?

WHY: The Canadian Partnership Against Cancer (CPAC) is currently conducting a study that looks at the concerns, issues and challenges that people diagnosed with cancer experience when they return to work during or after treatment. The feedback we receive from participants will help inform future programs, services and resources.

WHAT: We will be conducting a focus group discussion that will ask questions about your return to work experiences both during and after treatment and about any concerns, issues and challenges you experienced.

HOW LONG: The focus group discussion will be held on [insert date and time] and will take 1.5 hours of your time

WHO: If you are:

- 18 years of age and older AND
- Have had a cancer diagnosis in the past 5 years AND
- Were working at the time of your diagnosis

…then we would like to hear about your work-related experiences.

To assist with your expenses each participant will be provided with a **$50 gift card**.

If you are interested in participating please register for the group before [insert date] by contacting [insert local contact information].

Informed Consent: Focus Group (Teleconference)

Understanding the Return to Work Experiences of Cancer Survivors

You are being asked to participate in a research study. Before you give your consent to be a volunteer, it is important that you read the following information and ask as many questions as necessary to be sure you understand what you will be asked to do.

Investigators:

Judy Gould, PhD, funded by the Canadian Partnership Against Cancer
Fred Ashbury, PhD, funded by the Canadian Partnership Against Cancer
Cathy Cameron, MHSc, funded by the Canadian Partnership Against Cancer
Manon Labrecque, MA, funded by the Canadian Partnership Against Cancer

Purpose of the Study: The investigators want to learn more about the return to work experiences for individuals who have experienced a cancer diagnosis and treatment. The investigators wish to conduct focus groups and teleconferences with up to 50 people who have been diagnosed in the last 5 years.

Description of the Study: After you have had an opportunity to review and discuss this research consent form with the teleconference group facilitator and if you feel comfortable providing your consent then we would ask you to sign at the end of this document. If you consent to participate in the teleconference we will be asking you questions like what kind of return to work arrangement did you have with the employer and/or insurance company, how you experienced the return to work transition, gaps in resources, and any recommendations you might have for helpful resources. At the end of the teleconference we will ask you to complete a short demographic survey which will inquire about your age, family status, date of diagnosis, education and two questions about your work. The teleconference recording, the short form about your demographics and all responses are strictly confidential.

Risks or Discomforts: Because of the personal nature of the questions asked, you may find yourself recalling unpleasant memories while responding to the teleconference group questions. This may be a source of discomfort to you. If you begin to feel uncomfortable, you may feel free not to answer questions, either temporarily or permanently. You are not obliged to answer questions about things you do not wish to talk about.

Benefits of the Study: It could be that recalling return to work experiences elicits pleasant memories. However, the investigators cannot guarantee that you will experience any benefit. It is possible that the results of this study will spur the creation and development of programs and resources to help people living with cancer return to work, although again, the researchers cannot guarantee this outcome.

Confidentiality: In all instances, your teleconference group recording, transcription, and short demographic survey are strictly confidential. Your audio-recording and transcription will be identified by number, not by name. The corresponding list of numbers and names will be kept in a secure, separate location. The audio-recording and transcription will be kept in a secure location and will only be used for the purposes of the research described above. After the completion of the research project, the recording and transcripts will be stored for seven years and then will be destroyed. In the resulting publication, no identifying characteristics and no names will be used. The findings of this study (without your identifying details) will be relayed to the sponsor of this research: the Canadian Partnership Against Cancer. All work will be completed only by the investigators named above. You have the right to check your study records and request changes if the information is not correct. By signing this information and consent form, you consent to the collection, access, use and disclosure of your information as described above. While every effort will be made to protect the privacy of your information, absolute confidentiality cannot be guaranteed. This does not limit the duty of the researchers and others to protect your privacy.

Incentives to Participate: There will be a $50.00 gift-card for all teleconference group participants which will be mailed to you immediately following the teleconference.

Voluntary Nature of Participation: Participation in this study is voluntary. Your choice of whether or not to participate will not influence your future relations with the Canadian Partnership Against Cancer or with any individuals involved with the research. If you decide to participate, you are free to withdraw your consent and to stop your participation at any time without penalty or loss of benefits to which you are allowed. At any point in the study, you may refuse to answer any particular question or stop participation altogether.

Questions about the Study: If you have any questions about the research, please ask. If you have questions later about the research, you may contact one of the researchers (Judy Gould at judygould@rogers.com). Please contact the Director, Human Research Protection Program, IRB Services, who is not affiliated with the research or the research team, if you

- have questions about your role and rights as a research participant
- wish to obtain more information about research in general
- have concerns, complaints or general questions about the research, or
- wish to provide input about the research study

You can do so in the following ways:

- In writing: 300-372 Hollandview Trail, Aurora, ON L4G 0A5
- By phone: 1-866-449-8591
- By email: subjectinquiries@irbservices.com

Agreement: This teleconference is taking place over the phone and so we would ask that if you consent to participate that you indicate your agreement verbally which will be audiorecorded. We then ask that you sign below and either scan and email or mail in your signed consent form (we will provide the addresses to you at the time of the teleconference). Please also mail to us your completed short demographic survey. Your signature below indicates that you have read the information in this agreement and have had a chance to ask any questions you have about the study. Your signature also indicates that you agree to be in the study and have been told that you can change your mind and withdraw your consent to participate at any time. You have been given a copy of this agreement. You have been told that by signing this consent agreement you are not giving up any of your legal rights.

Name of Participant (please print)

Signature of Participant Date

Signature of Investigator Date

Demographic Survey:
Return to Work Focus Group for Individuals with Cancer

1. What is your age (check one)?

   ☐ 18-24 years

   ☐ 25-34 years

   ☐ 35-44 years

   ☐ 45-54 years

   ☐ 55-64 years

   ☐ 65-74 years

   ☐ 75 years of age and over

2. Are you (check one)?

   ☐ Male

   ☐ Female

3. What is the highest level of education you have completed (check one)?

   ☐ Some elementary school

   ☐ Completed elementary school

   ☐ Some high school

   ☐ Completed high school

   ☐ Non-university certificate or diploma (e.g., college, trade, apprenticeship)

   ☐ Bachelor's degree

   ☐ University degree above bachelor's (e.g., M.A., Ph.D., medical degree)

   ☐ Other (please specify) ______________________

4. What province or territory do you live in? ______________________

5. What is the population of the town/city that you live in (check one)?

   ☐ 1 to 1,000

   ☐ 1,001 to 30,000

   ☐ 30,001 to 100,000

   ☐ 100,001 to 500,000

   ☐ over 500,000

   ☐ Don't know/Not sure

6. What is the current marital status (check one)?

   - ☐ Married
   - ☐ Living common-law
   - ☐ Widowed
   - ☐ Separated
   - ☐ Divorced
   - ☐ Single/never married

7. What was the date of your cancer diagnosis? Month ______ Year ________

8. What cancer(s) were you diagnosed with (check all that apply)?

   - ☐ Bladder
   - ☐ Brain
   - ☐ Breast
   - ☐ Colorectal
   - ☐ Head and Neck
   - ☐ Kidney
   - ☐ Leukemia
   - ☐ Lung
   - ☐ Melanoma
   - ☐ Non-Hodgkin's Lymphoma
   - ☐ Prostate
   - ☐ Thyroid
   - ☐ Other (please specify) ___________________________

9. What stage was your cancer when it was diagnosed (check one)?

   - ☐ Stage I
   - ☐ Stage II
   - ☐ Stage III
   - ☐ Stage IV
   - ☐ Don't know/Not sure

10. What type of treatment did you have following your diagnosis (check all that apply)?

☐ Surgery

☐ Radiation

☐ Chemotherapy

☐ Medication
(e.g., prescribed pain medication, hormonal therapies such as Tamoxifen)

☐ No treatment

☐ Other (please specify) ___________________________

11. Are you still receiving treatment for your cancer diagnosis?

☐ Yes

☐ No

12. What best described the level of position you held at the time of diagnosis (check one)?

☐ Senior Management (CEO, VP, Director)

☐ Manager, Supervisor, Leader or Foreman/woman

☐ No managerial or supervisory responsibility for other employees

☐ Self-employed

☐ Not employed at the time of my cancer diagnosis

13. Which of the following best describes the type of employment you had following your cancer diagnosis or treatment (check one)?

☐ Old job with previous employer

☐ Different job with previous employer

☐ Similar to old job but with different employer

☐ Different job with different employer

☐ Self-employment

☐ I have not yet returned to work

☐ I retired after I was diagnosed

☐ Other (please specify) ______________________________

Focus Group Protocol: Individuals with Cancer (Teleconference Version)

Facilitators: ______________________________

Date: ______________________________

Various participant locations: ______________________________

Total # of Participants: ______________________________

Gender breakdown of participants: ______________________________

General characteristics of participants (type of cancers, employed/ self-employed etc.): ______________________________

Introductory Script

The Canadian Partnership Against Cancer (CPAC) is currently conducting a study to explore the challenges that people diagnosed with cancer experience with respect to their work and the impact of the diagnosis on their capacity to work or return to work. The feedback we receive from participants will help inform future programs, services and resources. The investigators wish to conduct focus groups and teleconferences with up to 50 people who have been diagnosed in the last five years.

You have all had the opportunity to review the consent form that was sent to you in an email when you demonstrated interest in participating in this teleconference. If you consent to participate, the teleconference will commence, will be about 1.5 hours in length, and will be audio-recorded and later transcribed. During the teleconference we will be asking you questions like what kind of return to work arrangement you had with the employer and/or insurance company, how you experienced the return to work transition, gaps in resources and any recommendations you might have for helpful resources. At the end of the teleconference we will ask you to complete a short demographic survey, which we emailed to you along with the consent form. On that form we inquire about your age, family status, date of diagnosis, education and two questions about your work. The teleconference recording, the short form about your demographics and all responses are strictly confidential. If you feel comfortable providing your consent, then we would ask you to verbally do so now so that we can audio-record your consent. Also sign at the end of the consent form document and email a scanned copy to judygould@rogers.com or mail the consent form to (provides address). Thank you for participating. In appreciation of your participation we will mail to your address a $50 gift card.

Questions/Probes

1. What was your work experience following your cancer diagnosis (e.g., leaving work for treatment or working through treatment)? What was it like coping with work and cancer when you were first diagnosed? What did you do regarding work while you had cancer treatment?
2. If you left work, how long were you off? What kind of arrangement did you make when it came time to return to work (gradual return, flexible, no arrangement regarding reduced workload to begin)? If you did not leave work, what arrangements did you make with your employer regarding workplace accommodation during treatment?
3. How have you experienced the transition to return to work? What happened with the arrangements that were made? What made the transition difficult (e.g., people, resources)? What helped make that transition easier (e.g., people, resources)?
4. How were you practically and emotionally supported by your employer? If you had to leave work and had to liaise with an insurance company, how were you practically and emotionally supported by the insurance company?
5. How is what you are now doing with respect to work the same as what you did before your cancer diagnosis (e.g., working or not, type of job, part-time/full-time, etc.)? What has influenced or supported you in keeping these aspects of your work the same (e.g., work as sense of normalcy, supportive employer, was working PT before and can still work PT hours, self-employed, etc.)?
6. How is what you are now doing with respect to work different compared to what you did before your cancer diagnosis (e.g., working or not, type of job, part-time/full-time, etc.)? What has influenced or resulted in this change (e.g., unable to work in same way, symptoms interfere with work, priorities have shifted, etc.)?
7. What were the gaps between what you had and what you needed to make a successful transition to work or to successfully manage work following diagnosis?
8. What resources did you access for support related to work or financial issues? What resources would have been helpful? If you had to prioritize which resources would have been helpful, what would come first?

Following the call, please complete the short demographic survey and either email a scanned copy to judygould@rogers.com or mail it to (provides address).

Thank you once again.

Appendix M: Characteristics of Focus Group Participants

Category	Subcategory	Results
Age	25-34	3
	35-44	6
	45-54	4
	55-64	2
Gender	Male	7
	Female	9
Education	High School Diploma	2
	Bachelor's Degree	7
	Non University Certificate	6
	University Certificates	1
Province	Quebec	9
	British Columbia	2
	Manitoba	5
Population	1001 to 30000	3
	30001 to 100000	1
	100001 to 500000	4
	More than 500000	6
	Don't know	2
Marital Status	Married	8
	Common-law	1
	Separated	1
	Divorced	4
	Single/Never married	2
Date of diagnosis	05/2011	1
	01/2011	1
	09/2010	1
	08/2010	1
	06/2010	1
	03/2010	1
	09/2009	1
	02/2009	1
	12/2007	1
	11/2007	1
	10/2007	1
	07/2007	1
	06/2007	1
	10/2007	1
	10/2006	1
	09/2006	1

Type of Cancer	Bladder	2
	Breast	2
	Colorectal	3
	Head and neck and Other: Pharynx	1
	Lung	1
	GI	1
	Testicular	1
	Sarcoma-ankle	1
	Leukemia and/or Lymphoma	2
	Ovarian or Germ Cell Ovarian	2
Stage	I	3
	II	4
	III	5
	IV	1
	Don't know	3
Type of Treatment	Surgery	12
	Radiation	5
	Chemotherapy	13
	Medication	5
	Other – hernia repair 3 times	1
Still in Treatment?	Yes (one taking Tamoxifen)	3
	No (one will be on and off chemo)	13
Type of Work at Diagnosis	VP	1
	Supervisor/Manager	5
	No managarial responsibility	8
	Self-Employed	2
Type of Work after diagnosis	Same work for same employer	10
	Different work for same employer	1
	Different work for different employer	3
	Other (self-employed to employee of previous client)	1
	Forced to retire due to treatment-related hernia	1

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