Exploring the Needs of Cancer Survivors When Returning to or Staying in the Workforce

By

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Rehabilitation Sciences Institute

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Abstract

Cancer survivors have strong personal desires to resume work to feel productive and meet financial needs. However, they may be faced with physical and psychological challenges. This research aims to: examine cancer survivors’ perspectives on supports needed when returning to work; investigate sex and gender differences when returning to work; and explore demographic and employment factors that may influence this process. An exploratory qualitative design was used. The study had two phases: focus groups and one-on-one semi-structured interviews. Inductive thematic analysis was used to analyze the data. The total sample includes 15 participants, 87% female and 13% male. Key themes include: changing perspectives on self and work; managing work and social systems; determining disclosure and accommodation; and the importance of supports for return to work and daily life. This study informs cancer rehabilitation research by developing an understanding of the supports needed to help cancer survivors return to work successfully.
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Chapter 1: Introduction

Purpose of Study

In 2017, the Canadian Cancer Society released a report stating that about 1 in 2 Canadians are expected to be diagnosed with cancer in their lifetime (Canadian Cancer Society, 2017). Furthermore, it predicts that nearly 55% of all new cases of cancer will occur in people aged 20-69 years (Canadian Cancer Society, 2017). Given that working age is normally defined as 15 to 64 (Organisation for Economic Co-operation and Development [OECD], 2017), most Canadians who are diagnosed with cancer are likely to be interested in returning to or staying at work as a way to establish normality, social relationships, and enhance quality of life (Peteet, 2000; Steiner, Cavender, Main, & Bradley, 2004). In fact, a literature review by Spelten, Sprangers, and Verbeek (2002) found that, on average, 62% of cancer survivors are able to stay at work or return to work after treatment. Another cohort study found that this number increases to 85% after 4 years, confirming that many cancer survivors are able to remain or stay at work after treatment (Short, Vasey, & Tunceli, 2005).

Cancer impacts not only individuals, but also stakeholders throughout the healthcare system and in the workplace (Maunsell, Brisson, Dubois, Lauzier, & Fraser, 1999; Schultz, Beck, Stava, & Sellin, 2002). Cancer survivors are faced with many physical (e.g. fatigue), cognitive (e.g. “brain fog”), and psychological (e.g. depressive symptoms) barriers that can make returning to work or staying at work difficult (Mehnert, 2011). The severity of the cancer type and stage, as well as comorbidities such as depression and anxiety, can also make it challenging for cancer survivors to successfully return to work (Nitkin, Parkinson, & Schultz, 2011; Spelten et al., 2002). Supporting cancer survivors on this journey has societal benefits due to increased economic and
work productivity (Duijts, Dalton, Lundh, Horsboel, & Johansen, 2016). Healthcare providers and workplace personnel are increasingly being called on to attend to work-related issues such as survivors’ abilities and limitations as they impact work, through maintaining ongoing communication (Cancer and Work Team, 2017). Moreover, environmental factors such as ongoing support at work and from healthcare providers have been shown to be associated with successful return to work (Mehnert, 2011). Despite this, information on how to provide these supports throughout the return to work process and what they specifically entail, is lacking (Stergiou-Kita et al., 2014).

To date the literature on cancer and work has had a narrow focus on young, white American and European breast cancer survivors. There is also a need to develop a deeper understanding of the perspectives of cancer survivors regarding how personal and occupational factors can impact their need for workplace accommodations and supports (Stergiou-Kita et al., 2014). Qualitative research has the unique potential to address this concern since it is used for collecting data on people’s values, feelings, and motivations (Berkwits & Inui, 1998). Therefore, conducting an exploratory qualitative study on a diverse population of Canadian cancer survivors to understand their needs when returning to or staying in the workforce is called for.

The purpose of this study was to explore the needs of cancer survivors when returning to or staying in the workforce, with a focus on examining their perspectives on supports, investigating sex and gender differences, and exploring personal and employment factors that influence the return to work process. This study used an exploratory qualitative research design to elucidate the lived experiences of cancer survivors and discover what factors are most important to successful return to work. An inductive thematic analysis as described by Braun & Clarke (2006) was used to understand the return to work needs of cancer survivors through identifying key themes in the
cancer survivors’ narratives. This study informs cancer and work rehabilitation research by developing an understanding of the supports and strategies that should be implemented to help cancer survivors return to work successfully and improve their overall quality of life.

Theoretical Frameworks

The use of the social ecological theory was carried forward throughout the study to shape the design and analyses. This includes how the objectives, interview guides, and data interpretations were formed.

Social Ecological Theory

Social ecological theory is based on the interrelations between environmental conditions and human wellbeing (Stokols, 1996). It goes beyond previous versions of human ecology, which focused solely on biological and geographical contexts, to also include the influence of an individual’s social environment (Binder, 1972). These physical, social, and cultural considerations have the potential to uniquely impact an individual’s physical health and emotional wellbeing (Stokols, 1992). Loisel’s ecological model of work disability, which is also a type of case management model of return to work, is particularly relevant for this study because of its focus on the dynamic interactions between the individual and stakeholders in the workplace, healthcare and insurance systems (Loisel et al., 2001; I. Z. Schultz, Stowell, Feuerstein, & Gatchel, 2007). A better understanding of these relationships for cancer survivors has the potential to improve health promotion and work outcomes. In fact, the Center for Disease Control and Prevention has adapted the social ecological model of health promotion and conceptualized the individual, interpersonal, organizational, community, and policy level influences on cancer into their Colorectal Cancer
Control Program (Centers for Disease Control and Prevention, 2013). Furthermore, the American National Action Plan for Cancer Survivorship has illustrated how collaboration between and within these levels in the social ecological model is paramount to improving survivor outcomes (Moore, Buchanan, Fairley, & Lee Smith, 2015). The dynamic interactions within this framework are used throughout this study to inform how cancer survivors navigate personal and environmental factors to return to or stay in the workforce, thereby improving their employment outcomes and quality of life.

**Researcher Reflexivity**

Qualitative researchers attend to the issue of reflexivity by reporting any personal beliefs or biases that may shape their explorations early on in the research process (Creswell & Miller, 2000). This reflection allows for a better understanding of the researcher’s position as readers make their way through the study (Creswell & Miller, 2000). In this section, I will reflect on how my personal background and motivators, as well as societal forces, have the potential to influence my interpretations and interactions.

Throughout my academic career, I have developed a passion for affecting positive change through research, particularly in the field of rehabilitation. My journey as a researcher began as a student conducting sport-related head injury prevention research. This experience inspired me to probe deeper, by working with a team to evaluate guidelines for youth returning to activity and school post-concussion, as well as investigating post-concussive sleep disturbances in youth. I developed a passion for advocating for individuals with invisible disabilities through my research in order to help breakdown the stigma associated with these conditions, and to empower these individuals to overcome any barriers preventing them from leading fulfilling lives. My prior
experiences and my desire to help others through research led me to pursue my graduate studies in the rehabilitation sciences. Specifically, I wished to play a part in enabling people with invisible disabilities to lead productive lives, with employment as a focus. Luckily, the opportunity to achieve this goal manifested itself in the form of this graduate thesis project. It is important for me to acknowledge that this was my first time conducting research with cancer survivors, as well as leading a qualitative research study. To address this, I reflected on both the similarities and differences between cancer and head injuries as invisible disabilities and supplemented my knowledge through familiarizing myself with the cancer and work literature. I also took courses on qualitative research methodologies and worked with my team to make sure I felt confident in my ability to run the focus groups, one-on-one interviews, and data analysis for this study. This exploration has allowed me to assist persons with invisible disabilities and advance rehabilitation sciences research. I hope that this project makes a meaningful difference in the lives of cancer survivors and their ability to return to work or stay at work in a satisfying manner.

Further, social factors such as stigma had the potential to impact my experiences when conducting this study. As a society, we have the tendency to discriminate against individuals with disabilities and assume that they are not as competent as everyone else. When we hear that someone has cancer, we are inclined to focus on the diagnosis, and not on the individual’s unique needs and desires. These attitudes can negatively impact the self-perception of cancer survivors and make open communication when disclosing intimate details about their experiences challenging. I also recognize that having not experienced cancer myself, this makes it difficult for me to truly empathize and appreciate the lived experiences of these individuals, and it could make survivors even more uncomfortable. Being cognizant about this, through employing active listening skills and self-reflection, has helped me to reduce the impact this might have on my work
by fully immersing myself in their narratives and creating a safe environment for my study participants.

I admit that prior to my experiences working closely with individuals with disabilities, I was not immune to these negative societal outlooks. In particular, having limited experience with cancer, my views were largely shaped by the world around me. As a result, I viewed cancer as a scary and debilitating disease that causes immeasurable suffering. While this may be true for some, this perspective can impose a bias on my ability to assess the true competency and desires of individual cancer survivors returning to work. However, in recent years I have had the privilege of working with individuals with disabilities in a variety of capacities, including as a Special Olympics Coach and Community Living Volunteer. These opportunities have drastically altered my perspectives on disabilities, including cancer, to realize that every individual has their own unique lived experience of their disability, and deserves respect and dignity to be empowered to reach their full potential. Now, I consider myself a facilitator to effect positive change for individuals with disabilities, and I have a strong desire to influence systemic and societal changes to reduce the discrimination and stigma they face. I believe this current outlook has the potential to impact my study results as it will motivate me to delve into each individual’s story and gather a comprehensive narrative on the needs of cancer survivors returning to work. Conversely, it is possible that my existing views may affect my interpretation of these narratives if I am too optimistic or naïve about how difficult this journey is for cancer survivors and how resistant stakeholders might be to change their views on disabilities. To address these potential biases in my interactions and interpretations, I have made sure to maintain reflective notes after every interview and focus group and to be aware of the potential power dynamics between myself, the researcher, and the vulnerable study participants.
Overall, my personal background and desire to help enhance the lives of individuals with disabilities has been a significant motivator for this study. My role as a graduate student has provided me the unique and humbling opportunity to learn more about the experiences of cancer survivors as I listened to their needs when returning to or staying in the workforce. Throughout this study, I will continue to maintain my role as a researcher by being mindful of my position in the research and ensuring study rigour and quality of data.
Chapter 2: Literature Review

Cancer and Work

The number of individuals surviving cancer in Canada has increased, with 63% surviving at least five years following diagnosis (Canadian Cancer Society, 2015). This progress is a result of advancements in screening, diagnostic, and treatment techniques (Canadian Cancer Society’s Advisory Committee on Cancer Statistics, 2013; de Boer et al., 2008). Studies report that survivors have a strong personal motivation to re-engage in paid employment in order to fulfill financial needs, enhance psychosocial well-being, and provide a sense of normality (A. G. E. M. de Boer et al., 2008; Kennedy, Haslam, Munir, & Pryce, 2007; Rasmussen & Elverdam, 2008; E. Spelten et al., 2003). For most people, including cancer survivors, work contributes to self-identity, financial security, social relationships, and health (Wells et al., 2013). However, epidemiological studies report that cancer survivors are 1.4 times more likely to be unemployed than individuals without health concerns (A. G. E. M. de Boer et al., 2008). The implications of cancer on individuals’ ability to integrate or reintegrate into work is becoming increasingly evident, and there is growing interest in developing interventions and strategies to improve work outcomes and quality of life (Aziz, 2007).

Cancer is classified as a complicated collection of diseases involving abnormal cell growth (Canadian Cancer Society, 2018b; Nitkin et al., 2011). For many cancer survivors returning to work, their diagnosis can present physical, cognitive, and psychological challenges. These challenges are often related to the side effects of common cancer treatments such as surgery, radiation, and especially chemotherapy (Taskila & Lindbohm, 2007). Physical treatment and cancer-related complaints and symptoms like fatigue and physical demands at work can pose a
barrier to cancer survivors who wish to return to work (de Boer et al., 2008). In fact, treatment and cancer-related fatigue is the most prevalent symptom among cancer survivors and it is also associated with higher levels of disability, which can negatively impact a survivor’s ability to meet demands at work (Jones et al., 2016). A literature review conducted by Spelten, Sprangers, and Verbeek (2002) to determine factors that influence the return to work of cancer survivors found that work which requires a significant amount of physical effort is negatively associated with a cancer survivor’s ability to return to work. Many cancer survivors also experience challenges due to cognitive impairments, such as “chemo-fog” (Mehnert, 2011; Raffa, 2011). A cross-sectional study investigating neuropsychological functioning and cancer survivors’ ability to work concluded that the average ability to work was significantly lower in cancer survivors with cognitive impairments compared to those without any (Nieuwenhuijsen, de Boer, Spelten, Sprangers, & Verbeek, 2009). Additionally, many cancer survivors experience psychological symptoms such as anxiety, stress, and depression which can hinder their ability to return to work (Chow, Loh, & Su, 2015). These psychological symptoms have been shown to increase the time until return to work, according to a cross-sectional study which used questionnaires to examine the factors related to return to work for breast cancer survivors in Northern France (Fantoni et al., 2010).

Many personal factors, like gender, age, and level of education, can also impact return to work for cancer survivors. A systematic review on employment and work-related issues in cancer survivors conducted by Mehnert (2011) found that being male was significantly associated with a greater chance of return to work. A large retrospective cohort study on employment pathways of adult cancer survivors further supports this finding. It concludes that females experience statistically significantly higher total rates of cancer-related disability compared with males (Short
et al., 2005), therefore potentially making it more difficult to return to work. Further, the aforementioned systematic review by Mehnert (2011) also found that younger age was associated with a significantly greater likelihood of returning to work. Specifically, the abovementioned study by Short and colleagues (2005) found that cancer survivors who were 45-52 years old were more likely to suffer from cancer-related disabilities than younger survivors. Level of education also has the potential to influence a cancer survivor’s ability to return to work. Both a retrospective study on employment in cancer survivors (Chan et al., 2008), and a systematic review (Mehnert, 2011) found those with higher levels of education were more likely to experience positive employment outcomes. Further, depending on the type and stage of cancer that an individual is diagnosed with, their experience returning to work can vary. For instance, a prospective study on correlates of return to work in breast cancer survivors found that advanced tumor stage negatively impacted survivors’ return to work (Bouknight, Bradley, & Luo, 2006). Similar associations between disease stage and return to work have also been found in lung, cervical, pancreatic, and prostate cancer, among others (Greenwald et al., 1989). More generally, studies show that breast, prostate, and testicular cancer survivors may have relatively higher rates of returning to work (Bradley, Neumark, Luo, Bednarek, & Schenk, 2005; Dunbrack, 2009), whereas individuals with lung cancer, head and neck cancer, leukemia, and multiple myeloma have poorer return to work outcomes due to the severity of their disease and treatment (Feuerstein, Luff, Harrington, & Olsen, 2007; Short et al., 2005; Spelten et al., 2002).

Environmental factors throughout the return to work journey such as supports and services in the workplace and healthcare system can also have a considerable influence on cancer survivors returning to or staying at work. For instance, the previously mentioned literature review by Spelten, Sprangers, and Verbeek (2002) found that a non-supportive work environment was negatively
associated with return to work in cancer survivors. A Norwegian qualitative study examining breast cancer survivors’ views of factors that influence return to work suggested this lack of support from colleagues, employers, and human resources personnel could be because individuals in the work environment do not know how to deal with cancer and its effects (Tamminga, de Boer, Verbeek, & Frings-Dresen, 2012). Survivors felt that their workplace overestimated their ability to work and they had difficulty discussing their cancer (Tamminga et al., 2012). Providing cancer survivors a safe environment, a positive attitude, and appropriate work accommodations can facilitate their return to work journey (Lindbohm & Viikari-Juntura, 2010; Tamminga et al., 2012). Support from healthcare professionals, including professional guidance and information on navigating the work environment, has been found to facilitate return to work for cancer survivors (Tamminga et al., 2012).

Healthcare providers are also a significant source of support for cancer survivors due to their ability to advocate for sick leave benefits and workplace accommodations (Stergiou-Kita et al., 2014). Ideally, there should be ongoing communication between the workplace and healthcare providers to appropriately manage these environmental factors along the return to work journey (Cancer and Work Team, 2017; Franche et al., 2005). This includes addressing any new or ongoing challenges for the survivor, and making sure that all parties are aware of the survivor’s functional abilities and limitations (Cancer and Work Team, 2017).

Supportive services for cancer survivors aimed at improving the management of symptoms, rehabilitation, and accommodation of disabilities can improve employment outcomes (Short et al., 2005). However, unique challenges arise for cancer survivors due to emotional stress, persistent fatigue, and ongoing cognitive and psychosocial impairments. These challenges may make open communication with employers and establishing effective accommodations difficult.
(Brown, Owens, & Bradley, 2011; Taskila, de Boer, van Dijk, & Verbeek, 2011). In particular, cancer survivors require a significant amount of support from employers and medical professionals in terms of work-related advice. A 2005 report by the UK group *Cancerbackup*, now merged with *Macmillan Cancer Support*, stated that cancer survivors who did not receive information about dealing with work issues were four times more likely to report that their working lives deteriorated because of their cancer (Morell & Pryce, 2005). This finding is supported by a qualitative exploratory study investigating the experience of returning to work following cancer which states that, “more advice is required from health professionals about returning to work, along with reasonable support and adjustments from employers to ensure that cancer survivors are able to successfully reintegrate back into the workforce” (Kennedy et al., 2007, p.17). There is a need to better understand the perspectives of cancer survivors and their unique needs when returning to work so that such advice and support can be offered effectively.

**Limitations in the Literature**

There is in fact a gap in the cancer research when it comes to exploring the return to work experience for cancer survivors (Kennedy et al., 2007). A meta-synthesis of survivors’ work experiences, consisting of a rigorous systematic search that yielded 39 qualitative studies, concluded that although studies have identified factors associated with positive employment outcomes following cancer, there is a need to increase knowledge regarding survivors’ perspectives on factors and accommodations that promote successful work outcomes (Stergiou-Kita et al., 2014). Specifically, there is a need to better understand the continuous planning and decision-making process regarding return to work. Currently, the literature predominantly focuses on cancer survivors who are early on in their return to work experience and does not usually
consider perspectives on factors relevant to supporting employment once it is obtained (Stergiou-Kita et al., 2014). Moreover, returning to work is a continuous process, starting with an individual’s cancer diagnosis and lasting beyond their initial reintegration into the workforce. For example, upon returning to work, a cancer survivor might have new unique needs, or different perspectives on the fulfillment and meaning of work (Main, Nowels, Cavender, Etschmaier, & Steiner, 2005). Understanding these perspectives can help assess individuals’ work-related goals and improve targeted interventions overtime to meet these needs.

Additionally, there is a need to further examine the impact of workplace accommodations and supports available to cancer survivors as this can improve employment outcomes (Mehnert, 2011). An exploratory qualitative study conducted by Stergiou-Kita and colleagues (2016) to address this recommendation suggests that supports need to be customized to fit the specific demands of the cancer survivor wanting to return to work. However, there is still the need to develop a deeper understanding of how perspectives on work-related roles can impact the need for these workplace accommodations and supports.

Another gap in the literature relates to supports that can be provided from the healthcare sector, that may enable return to work. It is known that ongoing, quality support from healthcare team members and vocational service providers can influence employment outcomes for cancer survivors (Stergiou-Kita et al., 2014). Since cancer is a chronic condition, this continuous consideration of implementing effective strategies, accommodations, and supports is important to achieving success at work (Mehnert, 2011). Despite this, the meta-synthesis found that there is a lack of information regarding what these supports should specifically entail and how this should be provided throughout the cancer recovery and rehabilitation process (Stergiou-Kita et al., 2014).
Another limitation in the literature is the predominant focus on relatively young, white American and European breast cancer survivors (Stergiou-Kita et al., 2014). It is important to incorporate more diverse populations of cancer survivors from different backgrounds, locations, and socioeconomic status to broaden the current understanding of how these intersecting factors may influence employment experiences and outcomes (Stergiou-Kita et al., 2014). Examining these diverse factors in a Canadian context is an important start to fill the gap in existing research. In fact, a recent systematic review and meta-synthesis of 25 qualitative studies on supporting work-related goals after cancer included only 2 Canadian studies, with the rest from Europe (UK, Sweden, Denmark), the USA, and New Zealand (Wells et al., 2013). The review derived many common themes based on survivors’ lived experiences with regards to the importance of work, re-evaluating one’s life following cancer, on-going symptoms affecting work ability, and the significant role that support plays in enabling a positive return to work experience (Banning, 2011; Steiner, Nowels, & Main, 2010; Wells et al., 2013). Further, these two Canadian studies were not recent and focused on specific cancers such as primary bone cancer and breast cancer (Maunsell et al., 1999a; Parsons, Eakin, Bell, Franche, & Davis, 2008). In Canada, there are federal and provincial legislations that govern the establishment of workplace accommodations and the protection of individuals with a disability from discrimination (Ontario Human Rights Commission, 1962; The Ontario Government, 2011). Nevertheless, there is great variability in the work-related supports and accommodations in the system that cancer survivors are eligible to receive or have access to (Stergiou-Kita, Pritlove, Holness, et al., 2016). For instance, some survivors might have access to private disability benefits through their employer and others might receive publicly funded national or provincial disability programs (Stergiou-Kita, Pritlove, Holness, et al., 2016). Understanding the lived experiences of diverse Canadian cancer survivors
using a qualitative study design can help ensure successful return to work for impacted individuals. This perspective will also help improve the availability of resources for Canadians who currently must navigate a return to work system that can differ from those in countries with established literature.

An additional focus that has not been explored in depth is the sex and gender differences in work experiences. This attention is important since men and women seek and receive employment supports in different ways (Doren & Benz, 2001), and invisible disabilities can be interpreted differently for men and women (Banks & Kaschak, 2003). Additionally, examining sex and gender differences in work experiences and post-cancer outcomes can help with the development of individual work strategies (Stergiou-Kita et al., 2014). Overall, conducting research in a diverse group of Canadian cancer survivors is called for in order to comprehend a variety of different survivors’ perspectives and to learn about occupational and environmental factors that support successful return to work (Stergiou-Kita et al., 2014).

**Study Rationale**

The aforementioned systematic review and meta-synthesis of 25 qualitative studies on employment and cancer by Wells et al. (2013) reports that interventions need to be person-centered, acknowledging the employment outcomes that are relevant to the survivor in order to achieve their work-related goals. Stergiou-Kita et al. (2014) support these findings in their qualitative meta-synthesis of 39 studies on survivors’ work experiences, stating that cancer survivors were unhappy with the work-related advice provided to them since it did not always consider their individual situations. This finding is significant considering how individuals’ experience of their treatment and diagnosis, and thus their work-related goals, are unique.
There is an urgent need to develop improved employment strategies and policies for cancer survivors (Macmillan Cancer Support, 2007). Conducting research to understand survivors’ experience, to learn about occupational and environmental factors that support successful return to work, and how these factors influence the need for these targeted supports is called for (Stergiou-Kita et al., 2014). Therefore, the overall research question for this study was: “What are the needs of cancer survivors when returning to or staying in the workforce?” The research objectives were: i) to examine cancer survivors’ perspectives on supports needed when returning to work or staying in the workforce; ii) to investigate sex and gender differences when returning to work or staying in the workforce; and iii) to explore personal and employment factors that influence the return to work process.
Chapter 3: Methods

An exploratory qualitative research design was used to allow an understanding of the lived experiences of cancer survivors when returning to work. Qualitative research is useful when gathering meaningful information on people’s values, feelings, and motivations (Berkwits & Inui, 1998). In this case, qualitative research reflects the perspectives of cancer survivors as they grapple with the challenges of returning to work or staying at work after a cancer diagnosis. These perspectives can uncover the processes that are most important to successful return to work and how factors at multiple levels - including personal, occupational, and environmental - can interact with these processes to impact successful return to work (Stergiou-Kita et al., 2014).

This study had 2 phases: 1) focus groups with an educational component on return to work; and 2) one-on-one semi-structured interviews in-person. This combined approach was used because it has been shown in the literature to enhance the trustworthiness and richness of study results (Lambert & Loiselle, 2008). Specifically, the flexibility of one-on-one semi-structured interviews allows the interviewer or interviewee to direct the conversation towards a more in-depth and broader discovery of information important to the participant (Gill, Stewart, Treasure, & Chadwick, 2008; Guest, Namey, Taylor, Eley, & McKenna, 2017). Focus groups are effective in stimulating discourse on more sensitive themes that might not come up using individual interviews alone, in large part because of the interpersonal setting and group dynamics (Guest et al., 2017).

The order of these two phases varied across participants, depending on participant availability and focus group scheduling. Demographic and personal information was collected at the beginning of the focus group or interview, depending on which phase the participant completed first. A demographic questionnaire (Appendix I) modeled on the Demographic Survey form used
by a Canadian Partnership Against Cancer study (Canadian Partnership Against Cancer, 2012) was used to characterize our sample. The information obtained from the participants included their age (not date of birth), cancer diagnosis including stage and duration, level of education, marital status, and household income, providing a picture of participants’ cancer and current personal situation. Participants who already filled out the demographic form at a focus group did not have to fill it out again. Interviews and focus groups were digitally recorded and transcribed verbatim.

This study was given ethics approval by the university and hospital research ethics boards at which it was conducted.

**Recruitment of Participants**

Inclusion criteria for both Phase 1 (focus group) and Phase II (interviews) were: 1) 18 years of age or older; 2) able to communicate in English; 3) diagnosed with cancer; 4) working part or full time for pay at time of cancer diagnosis; 5) either remained at work during treatment or planning to return to work after treatment. The study participants were recruited using purposive sampling. This strategy means that participants was recruited based on the pre-determined selection criteria above, and because of their lived experience which could provide information to answer this study’s research question and objectives (Patton, 1990; Sandelowski, 1995).

Pamphlets (Appendix II) were made available in clinic rooms throughout one local cancer rehabilitation and survivorship clinic and cancer survivors who noticed the pamphlets and were interested could help themselves to one. Pamphlets were also available at the front desk so that the receptionist could assist with recruitment. If a patient noticed the pamphlet and/or expressed an interest, they helped themselves to one or asked the receptionist. Clinicians also informed patients of the research project if the patient mentioned a challenge they were having with regards to work
in a clinic session. If individuals were interested in participating, they either contacted the student researcher themselves using the information provided on the pamphlet or provided the receptionist or clinician their written consent (Appendix III) to have their contact information (phone number) passed along and be contacted by the researcher. The clinicians and the receptionist were made aware of these options in advance and were given the necessary forms, so they could assist appropriately.

Further, posters (Appendix IV) were put up throughout two local hospitals, specifically, in the clinics frequented by cancer survivors. The posters had the contact information for the student researcher on them. The pamphlets and posters were also made available at two local community-based support centers for cancer survivors. Ethics approval was obtained for all of the above procedures as well as for advertising the study on the cancer rehabilitation and survivorship clinic’s Twitter page in order to reach more potential participants.

All interested participants who met the study criteria and either contacted the study themselves, or gave consent to be contacted, were contacted by phone and invited to participate. At this point, the participants were given further details about the study. If a participant decided to proceed with one or both phases of the study, verbal consent was first given over the phone (Appendix V). Then, on the day of the focus group or interview (depending on which came first), the physical consent sheet (Appendix VI) was reviewed and signed. The study team coordinated participation through scheduling two focus groups at different times and allowing flexible 1-on-1 interviews to accommodate a variety of participants. This included offering the option of phone interviews for participants who were not able to meet at the study location, as well as scheduling interviews in the evening for individuals who could only attend after working hours. If any
participants wanted time to think about being involved in one or both phases of the study, they could contact the study at a later time or ask the study to follow-up with them.

**Data Collection**

Phase 1: Focus groups: The two focus groups that were held each had a discussion component and an educational component on return to work. The discussion part used open-ended questions and probes (see focus group interview guide, Appendix VII) to allow individuals to speak freely about the return to work experience. The second part of this session was an educational component to provide the participants with information about legislation relevant to returning to work, how to prepare for their return to work, and where they can get more information and support. The educational component did not contribute to this research and was included to provide resources on returning to work, as well as an incentive for participants looking to benefit from taking part in this study. It is possible that this component may have impacted participants’ knowledge and discussion points during the one-on-one interviews, and this limitation is discussed further later on. This educational component was designed based on topics that patients visiting the cancer rehabilitation and survivorship clinic thought were particularly relevant to know as a cancer survivor trying to return to work or staying in the workforce. This information was only collected for the educational component using a confidential salient belief questionnaire handed out to 15 patients in the clinic.

The focus groups ran with different participants each time. They were held at the local cancer rehabilitation and survivorship clinic and co-facilitated by one researcher and one clinician. Each session lasted about two hours. The sessions were held at different times to accommodate participants’ schedules.
Phase 2: Interviews: Participants (who either also attended a focus group or not) were invited to the one-on-one interview. These interviews lasted about one hour in total. A semi-structured interview guide (Appendix VIII) was used to allow for an in-depth discussion on return to work needs and an elaboration of topics that arose in the focus group, as well as additional lived experiences.

The questions asked in both Phase 1 (Focus Groups) and Phase 2 (Interviews) were aimed at collecting data on our three objectives: i) cancer survivors’ perspectives on supports needed when returning to work or staying in the workforce; ii) sex and gender differences when returning to work or staying in the workforce; iii) the demographic and employment factors that influence the return to work process. For example, questions included:

1. What has your experience been like when returning to work or staying at work following your cancer diagnosis?
2. What has influenced or supported you to make or not make work changes (sense of normalcy, supportive employer, etc.)?
3. What do you think impacts your needs when returning to work or staying at work the most?

In this exploratory qualitative study, we collected an adequate sample in relation to the study’s research question and objectives (O’Reilly & Parker, 2013; Sandelowski, 1995). Data was collected until the point where new categories and themes stopped emerging, and the research question was sufficiently answered. Although this adequate sample contributes important new knowledge, there was still the possibility of recruiting more diverse participants including men and those with different socio-economic backgrounds, which are limitations discussed later on. For this study, 15 one-on-one interviews were conducted in total.
Data Analysis

All stages of data collection and analysis were supervised and discussed with the study team. The demographic data were analyzed descriptively and used to characterize the study sample. The focus group and interviews were digitally audio-recorded and transcribed verbatim. All of the transcribed data in both the focus group and interviews were analyzed holistically using inductive thematic analysis, as outlined by Braun & Clarke (2006). This data-driven approach ensures that the identified themes are strongly linked to the transcripts themselves. In order to facilitate this analysis, a computer-based qualitative data management software, NVivo, was used to store and organize coded data.

The first step in this analysis involves becoming familiar with the data. This was achieved by listening through all the audio-recordings completely while transcribing them verbatim. Through this process, a holistic understanding of the full set of study data was formed. Next, a subset of transcripts was selected to generate initial codes. Two researchers separately created these initial codes and then came together to develop a comprehensive codebook (Appendix IV). Codes were selected to be included in the codebook if they were initially identified by both researchers and if both agreed that they were applicable to the dataset. Codes were edited and added as necessary throughout the data analysis using the same protocol. This codebook was used to analyze the rest of the transcripts. Initial themes were formed based on careful assessment of the coded transcripts then discussed in order to identify the ones most relevant to the study’s research question and objectives. Finally, these selected themes were defined along with the corresponding subthemes.
In order to better illustrate this process of data analysis, an excerpt from Participant #14F’s interview transcript will be used. When discussing her experiences with work support, Participant #14F said:

But, the interesting thing is, you get the [work] support right at the beginning. You get a ton of support. Then all of a sudden, it’s like…the support kind of starts to ween off, and it’s like, but you know what, I still kind of need that support.

The initial code that was created using this passage was, ‘lack of ongoing support in the workplace.’ This initial code was then grouped with other related ones that emerged in the initial sub-set, such as ‘support from coworkers’, to form the code ‘Work Support’ in our codebook, which was used to code the rest of the transcripts. The broader category into which this code was subsumed was ‘Support from Stakeholders.’ Other codes in this category included, ‘Family and Friend Support’, ‘Insurance Support’, and ‘Healthcare support.’ This category was relevant for addressing our first research objective, to examine cancer survivors’ perspectives on supports needed when returning to work or staying in the workforce. Lastly, the aforementioned codes in this category were then combined with the code ‘Family and Social Life’ from the category ‘Personal Factors’ and grouped together to create the larger theme ‘Importance of Supports for Return to Work and Daily Life’ to better reflect the survivors’ narratives. This process was repeated several times throughout the data analysis to generate the most salient themes and subthemes. For instance, the theme ‘Importance of Holistic Supports for Return to Work’ also includes the subthemes: ‘Supportive Work Environment’, ‘Interacting with Insurance Companies’, ‘Family and Friend Support’, and ‘Experience with Healthcare Provider and Community Supports.’

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1 Throughout this thesis, gender is indicated beside a participant’s # as F for female or M for male.
Study Rigour

The recommendations of Mays and Pope (2000) were followed to achieve trustworthiness and auditability in our study, specifically: using at least two researchers throughout the process for coding and conducting the focus groups; taking reflective notes after the focus groups and interviews; and maintaining a decision trail to document the study process. The credibility of the research was upheld through controlling bias using the triangulation of data and of researchers. This means that more than one method of data collection (focus groups and interviews) were used and that several investigators on the study team were involved throughout the process of forming themes based on this data (Golafshani, 2003). Furthermore, the data analysis process included reading completely through the transcripts to get familiar with the data and start recognizing preliminary codes, then jointly coding a subset of transcripts to ensure that different perspectives on the data were considered when developing the coding book. Transferability of the study was also achieved through making sure to collect an adequate sample, as discussed earlier (Sandelowski, 1995).
Chapter 4: Results

Study Sample

The above-mentioned demographic questionnaire was administered to all participants (n=15) in order to characterize our study sample. Participants were asked to indicate their age ranges. 13.3% (n=2) of the participants were between 25-34 years old, 26.7% (n=4) between 35-44 years, 40.0% (n=6) between 45-54 years, and 20.0% (n=3) were between 55-64 years old. There were more females than males in the study, with 87% (n=13) of the participants being female and 13.3% (n=2) male. 46.7% (n=7) of the 15 participants indicated they had a ‘university degree above bachelor’s’, 46.7% (n=7) had completed a bachelor’s degree and one participant had ‘completed high school.’ In terms of marital status, 73.3% (n=11) of participants were married, 20.0% (n=3) were single or never married, and 6.7% (n=1) living common-law. Household income was reported to be $20,000-34,999 for 6.7% (n=1) of participants, $50,000-74,999 for 6.7% (n=1), $75,000-99,999 for 13.3% (n=2), $100,000-149,999 for 20.0% (n=3), $150,000-199,999 for 26.7% (n=4) and $200,000 or more for 6.7% (n=1). Three participants indicated that they did not know their household income or preferred not to disclose it. There was diversity in terms of cancer types, with 26.7% (n=4) diagnosed with breast cancer, 20.0% (n=4) ovarian and/or uterine, 13.3% (n=2) leukemia, 13.3% (n=2) non-Hodgkin’s Lymphoma, 13.3% (n=2) head and neck cancer, 6.7% (n=1) thyroid cancer, and 6.7% (n=1) multiple myeloma. The median time since cancer diagnosis was 21 months, with a range of 12 to 82 months ago. These cancers were diagnosed at a variety of stages, with 20% (n=3) at Stage I, 46.7% (n=7) at Stage II, 13.3% (n=2) at Stage III, and 6.7% (n=1) at Stage IV. Two participants did not know or were not sure of their cancer stage at diagnosis.
At the time of the study, 40% (n=6) of participants were still receiving some treatment for their cancer diagnosis. Overall, 73.3% (n=11) received chemotherapy, 73.3% (n=11) received radiation, 66.7% (n=10) received surgery, and 33.3% (n=5) received medications as treatments throughout their journey. Furthermore, 66.7% (n=10) of participants self-reported on the questionnaire that they were still experiencing cancer or treatment-related symptoms.

Information about participants’ employment status was obtained from the one-on-one interview transcripts. Participants’ occupations were diverse and included office work in human resources and jobs as healthcare professionals like physiotherapists and nurses. At the time of the interviews, 66.7% (n=10) of the participants had not yet returned to work. No participants stayed at work without any time off. In fact, the median time off reported by participants was 1 year, with a range of 2 weeks to 6 years.

Table 1 summarizes these participant demographics and Table 2 includes information on participants’ employment status, including a full list of the job descriptions mentioned above. Also, although it was not part of the demographic survey, it should be noted that several participants in this sample were visible minorities and for some English was not their first language.

**Thematic Analysis**

The thematic analysis conducted on the 15 one-on-one interviews and two focus groups, (with four participants in each focus group and eight participating in total), yielded four themes: changing perspectives on self and work; managing work and social systems; determining disclosure and accommodation; and importance of supports for return to work and daily life. Each theme was further divided into sub-themes to better illustrate specific topics within the data. These
themes and their corresponding sub-themes are mapped out in Figure 1, are summarized in Table 3 with brief descriptions, and will be reported on in this section.

**Changing Perspectives on Self and Work**

The theme ‘changing perspectives on self and work’ includes the following subthemes: ‘perceptions and meanings of work’, ‘personal motivators to return to work’, ‘reflecting on return to work’, and ‘stigma influencing self-perception’.

**Perceptions and Meanings of Work**

Participants shared how they define work and how their outlooks have changed throughout their journey, including the importance they now attribute to work. For many participants, work contributed to their identity, sense of normality, health, and social relationships. Participant #13F talked about work as an integral part of her identity saying, “The main part of all this is identity. Identity. […] It’s like I work for this company and I’m a this and I’m a that. Now, I’m unemployed, I’m on disability.” Not being able to work and thereby losing her sense of identity was difficult for Participant #13F. Moreover, for Participant #9F, her perceptions about work included, “…a few things. Um, part of my identity, wanting to feel normal, wanting to feel productive.” Participant #12F shared a similar perspective when discussing the meaning of work during a focus group, stating that, “…it’s part of the rehabilitation, and it’s [a] part of feeling productive and kind of normal.” When discussing how work is related to her health and social life, Participant #3F agreed that work provided her with values that contribute to her self-identity. She said:
I just do whatever people need to do to be healthy, yeah, so, to exercise, to have a healthy diet, um, to maintain a social life and, I guess work it’s a – it’s part of that, as I said as it gives me values of my self-identity and, um, I guess it helps for the recovery process, too.

Furthermore, participants’ changing perspectives shaped their priorities when returning to work, with many participants attributing less importance to work and now seeking more work-life balance than before. For instance, when asked about how her perspectives about work have changed, Participant #14F shared:

Absolutely it has changed. Um, so, for me work is not a priority. […] My priority is my health, my family, [and] my children. Um, I do plan on going back and I do plan on giving it my best, but it’s definitely not a priority. Not looking to be promoted, I want to go in, do my work, get out and get on with life.

She also described that in order to achieve this work-life balance, she will scale back her hours and make time to exercise, which she believes will also help prevent a cancer reoccurrence. Participant #3F agreed with this outlook and the importance of work-life balance to maintain well-being, stating:

I guess now my priorities would be changed in a way that I don’t really want to give so much time to my work […] because I think stress is one of the factors affecting my illness, too. Yeah, and um, keep the work-life balance as much as I can, and spend as much time as I would like to have for my personal self-care, doing exercise, um social or meditation, yeah, this is what I really want to allocate my time for.

Participant #15F passionately agreed with how important health and well-being are now to her, sharing that:
Life is important. Money isn’t everything. Career is not everything. Your health is the most important thing, because if you don’t have your health, you don’t have anything. Money can’t buy you health, you know? It, it can’t change a cancer diagnosis. It can’t change chemotherapy. It can’t change radiation. It can’t change your fingers going black, your tongue going black, losing all your hair.

Evidently, for Participant #15F, the monetary gains from going back to work cannot outweigh the importance of maintaining her health through work-life balance and making her career less of a priority. Participant #12F was in agreement with this perspective, sharing that, “I think that I learned to be more balanced and I hope that I will be able to convey this message to everyone.” She also further elaborated on this outlook in the focus group, saying that, “It makes me realize that there is life outside of work. […] I forgot myself. My health. My balance with family and everything. […] If they offer me a part-time, I will take it. My priority won’t be the full-time.”

However, not all participants shared this outlook on work. In fact, when asked about her perspectives on work since her diagnosis, Participant #13F said:

I’ve heard people share that they feel different about it and all of this stuff – I don’t! Because to me, I get validation from working, I get, um, relationships from working. All of these things that I get from working has not changed at all.

She was not alone in her opinion, as Participant #10M also said, “No, nothing has changed. Um, I guess I need to work more this time. Because of the financial hit.” Therefore, due to the impact that cancer has had on his financial situation, it is likely that Participant #10M will not reduce his hours to maintain balance like the other participants but will instead be working harder.
Personal Motivators to RTW

Study participants shared how personal factors, such as their desires, personality, age, and family or financial situations can motivate them to return to work. As mentioned in the previous sub-theme, one’s need to maintain one’s identity and sense of normality are also motivators. These characteristics are not only ways of defining work but can also impact a cancer survivors’ desire to return to work. Participant #6 shared:

I think the sort of Type A in me just wanted to get back to full-time to say that I was back to full-time and just be done. I was um, [was] gradually feeling better by that point too and had felt like I identified so much with being a nurse and being off you lose a bit of that identity. Um, so the drive to be back was um, really strong.

For Participant #6, the way she attributed her identity to her work was a very strong motivator for her to return to work after cancer. Her self-reported ‘Type A’ personality pushed her to want to return to work. These personality traits also motivated other participants to return to work, including Participant #9F, who said “I’ve always been like, you know, Type A. I love to work. If I’m not working, then it’s not good and I was like really itching to get back to work as soon as possible.” Moreover, for Participant #8F, her determined personality not only drove her to return to work, but also to advocate for other cancer survivors who are trying to return. While discussing the difficulties she experienced from employers when trying to return to work, she said:

I refuse to give up. And it’s…knowing all too well…that the stress could push me over. And yet…I have a desire, and a burning principle that…I will count the cost no matter what it is. And I will advocate for future cancer patients.

Her personality and passion for her work are enough to push her to return to her job no matter what it takes, and to help others throughout the process.
Additionally, participants shared that age was also a personal factor that played a role in their return to work. Participant #7M said, “I’m getting older, and the older you are, the hard – the harder it is to get hired by anybody. Yeah, so, but I’m going to give it a try.” He realized that because of his age, he has to try to return to work as soon as possible, in order to have the best chance of getting a job. For Participant #8F, she expressed, “I need this! You know? I’m too young!” Again, her age played a role in how important it was for her to return to work. For others, age played a role in not only motivating them to return to work, but also the kind of work they would be returning to. Participant #13F said, “I’m at an age where I want regular work” and therefore would likely be motivated to return to a more stable, full-time job.

Unique family and financial situations were reported to play a role in encouraging cancer survivors to return to work. For instance, having children to take care of was a significant motivating factor for the female participants in this study. When Participant #2F discussed her experience she shared that, “It turned out okay because of the motivating factors and the distractions – I think the distraction and motivation are big compared to say if I didn’t have a kid, it’d be, I think, it’d be very different.” Moreover, as mentioned in the previous sub-theme, money was an important part of returning to work for Participant #10M. In fact, when asked at the end of his interview if there was anything else he wanted to share he said, “So one of the factors that influence people to go back to work I guess like me is the financial thing.” Therefore, he acknowledges that his financial situation is a motivator for him, as well as other cancer survivors, to go back to work to meet their needs. It can be noted though that this is not always the case. When Participant #1F was asked about her financial situation as a motivator to return to work, she said, “we didn’t have any worries” and this was not a major consideration for her. Similarly,
Participant #12F said, “Yeah, there are many things that I need to be careful about and the budget gets affected, but there is not the imminent pressure that I have to go back.”

Reflecting on RTW: Feeling ready

Throughout the return to work process, cancer survivors inevitably found themselves reflecting on their readiness to return and what a successful return to work would look like to them. This contemplation also included realizing how psychosocial symptoms, such as feeling anxious or stressed, impacted returning to work. Primarily, participants discussed what it meant to “feel ready” to return to work, and how difficult it was to ever feel completely ready to go back. For Participant #2F, she said, “I think emotionally, I’m like mentally, I’m ready to go back to work already. And physically too, actually, yeah.” Evidently, feeling ready to return involves many different elements. Other cancer survivors have a harder time assessing their readiness. For instance, Participant #13F disclosed:

So, in all honesty, the desire to go back to work is 100%. The ability to go back to work, I don’t know, it’s not for me to judge, because they say you will never feel like you should – like you are able to go back to work.

Despite this, participants stated they know it is important not to return before they are ready. Participant #10M stated, “I feel like um… I’m losing a lot by not getting back to work. […] But, also, I want to make sure I’m ready.” They realize that if they return to work too soon, it is possible that this can set them up for failure. Participant #12F agreed – “I think that many, many people go back to work when they are not ready and that just makes them fail.” Furthermore, Participant #15F wondered:
What’s the purpose of going to work when you’re not ready and all you’re going to do is leave? […] When I’m ready to go back to work, I need to hit the ground running full speed ahead. Just like how I used to. And I’m not there yet.

According to participants in this study, successful return to work can be supported by understanding their perspectives on what an ideal return to work looks like. From Participant #13F’s perspective, “I want to work, I really do want to work, but only when I’m able to. Because I don’t want to go back and forth, back and forth, back and forth.” Although she mentioned earlier that she felt unable to judge her own work readiness, she realized that a successful return to work would be one where she was able to feel ready not just to go back, but to stay back. For others, a successful return involved knowing how much time off they needed, even though this was sometimes difficult to approximate. When talking about her experience, Participant #3F considered:

I guess I also faced the dilemmas here like you know, the longer that you might be away, the harder that you might be able to get back to work. But, at the same time, I have to ask myself whether I’m physically or psychologically ready to return to work.

It is clear that taking the time to be ready to return is important, although participants shared that sometimes they are caught in a situation where they do not want to be taking too much time off work either. Some sought help from healthcare providers who understood their unique goals and facilitated their ability to return to work successfully. For example, Participant #14F stated:

Through occupational therapy they’re just helping me with strategies to deal with stress and fatigue and managing my time better. So, I’m hoping that I can get this all in place so when I do go back to work, I’m ready for a successful return.
As Participant #14F shared, psychosocial symptoms such as anxiety and stress can impact their ability to return to work. She said:

With the brain fog comes the stress and anxiety because it’s like oh my gosh, I want to do my job, I want to do it well, and I want to perform to the level I performed before – will I be able to?

In her case, managing these emotions helped her feel ready for a positive return to work. She even mentioned later that, “the anxiety and fear has gotten a bit better just because I think that I’m better equipped now.” She is not alone in feeling these symptoms. For Participant #11F, “Fighting with cancer, it also includes lots of emotional stress.” Participant #15F noticed that this is an issue that extends to other cancer survivors, too. She stated that, “A lot of individuals that I have talked to […] they’re all in the same boat. A lot of them are scared and not ready to go back, but they have to.” Participant #3F proposed that these emotions throughout the process of returning to work might be caused by the “uncertainties and unknowns that increased [her] anxiety.” For Participant #5F, she attributed her feelings to her changing level of productivity, “My performance was fine, but like I wasn’t, you know […] I just wasn’t as productive. Like, everything is just sort of not as…you know? You’re stressed out.” These feelings of inadequacy at work causing distress were shared by Participant #15F – “For me with stress and the anxiety and knowing that I can’t do it […] it’s a road block.” Thus, reflecting on returning to work entails thinking about these psychosocial issues and how they impact feelings and ability to return to work.

*Stigma Influencing Self-Perception*

In addition to participants’ changing perspectives on work, they also reported a shift in how they perceive themselves. They explained that this change can be attributed to the burden that they
feel, and how stigma influences their self-esteem. Study participants voiced that they felt like a problem to the people around them because of their cancer. Participant #13F felt like a burden on society and social structures as a whole. “You’re like a parasite on the system or whatever. Even though you paid into it.” She felt like she was treated unfairly, and she stated, “Now I don’t want to share about the cancer because I don’t want the stigma or the whatever since I’m job hunting.” Participant #12F echoed these sentiments, as she said, “Sometimes I feel the stigma, like, you know, I’m not working…so what does that mean, that I’m not a valuable member of the society, or what?” Other study participants shared that they felt like a burden to specific individuals in their lives, including their coworkers and family members. When discussing her interactions with coworkers, Participant #14F mentioned that she did not share her feelings with them because, “I’m not feeling 100% today – nobody wants to hear that.” Participant #6F felt similarly when talking about her spouse. She said, “I didn’t want to feel responsible for somebody else’s life being disrupted because mine was.” Conversely, Participant #9F acknowledged, “I think there’s a lot of stigma with this cancer that I really didn’t want people to know about what I’d been through.” In this case, she was more concerned about the stigma she would face from coworkers, and perhaps not as much the burden she might have potentially imposed on them. Nonetheless, it is clear that the stigma associated with cancer can impact an individual’s self-perception and like they are being a burden to those around them.

These changing self-perceptions that developed through the cancer journey can influence an individual’s self-esteem and negatively impact their confidence, and therefore their ability to return to work. Participant #7M said, “In my case, will I be able to do the job? When am I going to feel well enough? I have the stamina…[but] you lose a lot of self-confidence.” When Participant #12F was talking about her symptoms, she said, “So, emotionally there is also […] the depression
at the beginning. The self-esteem. [...] The feeling of inadequacy, like you don’t belong.” This has taken a great toll on her ability to maintain a positive outlook of herself during the process of returning to work. Participant #13F was in agreement. She shared:

My self-esteem was extremely low prior to this, but cancer and work and all of that [...] now it’s gotten even lower. Because, you feel you are getting older, now you have this black mark against you because of cancer.

She also talked about the impact on her return to work, as she said:

My personal factors would be my self-esteem. I don’t want to comb my hair, I don’t want to get dressed up. [...] I know I have to do all of that, but the desire to do all of that is not there. [...] It has impacted my life 100%.

This experience not only impacts her ability to return to work, but also to go about her everyday life.

Participants in this study reported that hair loss as a result of cancer treatment has the ability to add to this low self-esteem and stigma that cancer survivors may feel. For many, the experience of losing their hair had negative implications for their self-perception. This hair loss was especially difficult for Participant #4F. She said, “Before I have long hair and then after that I lost my hair. I don’t know people, maybe think or not think, but in my mind – yeah, [I’m] self-conscious.” She also later added that, “it emotionally impacts me. If you [have] hair then nobody knows what happened, if you have no hair then everybody knows. Then you feel more down.” The visibility of the hair loss was an indicator to the people around her of her diagnosis, and she felt that she was subjected to cancer-related stigma as a result. Participant #9F agreed that this visibility made her uncomfortable, and despite trying to hide it with a hat, it still influenced her self-perception. She shared, “Since I went back to work during chemo, I did not have hair. I wore a hat to work and so
it was pretty obvious to everybody what had happened.” Participant #15F was also deeply impacted by this experience, when talking about how money cannot buy health, she passionately said, “It can’t change a cancer diagnosis. It can’t change chemotherapy. […] Losing all your hair.”

On the other hand, the men in this study did not experience such devastation from chemotherapy-related hair loss. One of the male participants, Participant #7M, recognized this and suggested:

We guys can get away with our billiard ball head and then make a joke about it. But, for…my wife has beautiful hair, I can’t imagine a woman, you know, even though I have been through so much stuff, I feel fortunate.

It is clear to him that he was fortunate to not have to undergo the same stigma that women do in these situations. Participant #4F affirmed these beauty standards when she said, “I am a pretty woman and I had long hair and [now] I am different.” Evidently, she felt as though her hair was a part of her identity and that it was needed to feel good about herself. Now, her outward appearance has changed, and she is struggling with this reality.

Managing Work and Social Systems

The theme ‘managing work and social systems’ refers to participants’ experiences with the resources they were provided, with navigating the system as a whole, and with managing communication amongst stakeholders along their journey. These ideas were organized into three sub-themes: quality and accessibility of resources; navigating the systems; and communication within the system.

**Quality and Accessibility of Resources**
Participants felt it was important to have access to resources that meet their unique needs when returning to work. Some study participants felt that they had access to enough individualized resources for a successful return to work. For example, Participant #5F felt, there were more than enough resources to address her concerns, stating, “to be honest there were more resources that I just haven’t felt I really needed.” Participant #2F revealed that her long-term disability pension was able to provide her with all the resources she needed with regard to finances and health benefits, in particular.

Many of the participants in this study mentioned that community-based support centers for cancer survivors played a big role in offering resources that met their needs. For example, Participant #3F talked about how the “[Community Resource] has been great” and how nice it was to get out of the house and see other cancer survivors. Participant #12F mirrored these sentiments about the usefulness of the return to work program that was offered by saying, “This was the first step and made me think about how to go back and what to think about that.” There are also other programs that are offered by these centers. Participant #15F discussed how:

They have a financial program. They have some exercise program. […] They have meditation programs. They had some career training stuff. […] The workshops they have to help you get ready. […] They talk about legal issues, return to work issues, employment law, long-term disability. So, they attack all those key things.

This breadth of workshops and programs specific to cancer survivors and their needs have proved to be very helpful for our participants who accessed these services when returning to work.

Unfortunately, some participants also had difficulties accessing these supports. For Participant #1F, she said, “I tried to get help from [Community Support], but you know they don’t have certain schedules for their back to work courses […] so the timelines didn’t work for me.”
Despite these scheduling conflicts, she felt that she was “well supported in the hospital” which made up for it.

Personal factors, such as being a woman and having children, can also impact the resources needed to return to work successfully. Participant #14F was able to feel like her needs were met in this regard. She described a special program that offered the support of nannies to mothers who were cancer survivors and commented that “The best resource that we got was the nanny, that was phenomenal.” Although, she pointed out that, “It’s only available to women,” she expressed that she feels that men who have had cancer also need this resource, and that it is unfortunate that there are not enough nannies to expand this service to them, too. Participant #14F also had a good experience with the resources that her healthcare professionals and insurance provided. She said that, “They actually assess you individually and they came up with an exercise program to address my specific needs.” She was provided with educational resources to address her symptoms – “they talked about brain fog, fatigue, and how to deal with those.” She acknowledged that she has been lucky to have all these personalized resources available to her.

However, not everyone is offered enough resources to meet their needs when returning to work. Some participants were frustrated by the lack of training resources to improve their job-specific skills for when they return to work. When asked what was missing from the resources he was provided, Participant #10F said that “The learning upgrade is not on these programs. […] That’s the thing that I think I need.” Other participants would have appreciated more information about their legal rights when returning to work. This is particularly important for people like Participant #11F who is worried about how she can stand up for herself if her company tries to prevent her from returning to work. She said, “I don’t know what my legal rights are – how can I
fight back? [...] Some help about legal issues would be great.” These concerns and more were echoed by Participant #12F when asked about what resources she would have wanted. She stated:

Definitely law. How to plan to return to work. I think that most of the information was how to deal with physical illness or physical discomforts, rather than [...] how to communicate your needs, how to advocate for accommodations. What are your rights. How to program a gradual return to work. How to negotiate.

According to this participant, these additional resources would have helped to improve her ability to return to work. Similarly, Participant #6F would have appreciated it if the resources she was provided were more individualized. She found that, “It was more just like the same thing [...] like it was really basic general info about returning to work after you’ve been off for a while.” She, as well as other participants, believe that cancer survivors have more specialized needs that need to be addressed to facilitate returning to work.

Study participants observed that sometimes resources were simply inaccessible to them and required a significant amount of work for them to access. For example, Participant #12F shared, “It’s very hard for us cancer survivors dealing with what we are dealing [with] and on top of that try to find our own way and our resources. [...] So that should not happen.” Participant #3F also said, “There are a lot of programs and services outside, you just have to do the research.” Similarly, Participant #7M stated, “Well, no one has given me any resources, but I am fairly proficient with researching things on the net.” They indicated that cancer survivors are expected to search for resources on their own, despite the hardships they are likely already enduring. This point is reinforced by Participant #8F who said, “The resources I pretty well sought out myself.” Delving deeper into this issue, Participant #13F talked about her experience as she said, “I have been very, very proactive. I have found a lot of resources for myself. [...] The resources are there,
but not enough. There are still a lot of gaps in the resources that we need.” She suggested that, for instance, “A lot of people are in a lot of pain and they don’t know that there’s a pain doctor, or a pain clinic.”

Some study participants offered solutions to these problems of limited accessibility of resources. Participant #14F’s solution to the problem of “a slew of great programs out there that you can definitely benefit from. […] I find that sometimes it’s hard to find them” was, “a one sheet thing. If you are looking for this kind of help, this is what – where you go or what you do. So, if you’re looking for financial support, this is who you call.” She also discussed how it is important to be given this “right at the beginning of your journey.” Participant #9F had the same thoughts, saying “I was already in the thick of it by the time the resources would have been helpful.” Although resources early on can potentially have a positive impact, Participant #12F shared at a focus group that, “one of the gaps that I see is that there are resources […] [for] back to work when you are already in [the workplace], but not the transition.” Furthermore, other opinions included Participant #10M desiring a “step by step process when I need it” and Participant #3F wishing “all these [healthcare] professionals would know more about these resources.” Understanding these perspectives can help with making recommendations to create a better process for cancer survivors in the future.

Navigating the System

Navigating back into the workforce was seen to be a difficult process, but not every study participant had a bad experience navigating back into work. Some participants experienced systemic barriers, some needed professional help, and others had few troubles at all. Participants who had prior knowledge of the health and insurance systems, typically through their experience
as healthcare professionals, had an easier time when returning to work. For instance, as a nurse, Participant #6F knew that there was a nursing hotline available for her to call if she needed any help along her journey. When asked how this experience would have gone without her pre-existing knowledge, she said:

    Overwhelming, for sure. […] Sometimes I wonder how people do it, like people that English isn’t their first language, or people that don’t have like a ride to get to the hospital like that are having to stress about driving.

    Another healthcare professional, Participant #5F, said that “the system, you know, it’s just, even if you know it, it’s just so stressful.” Evidently, they are aware that the navigation process is difficult and that they are in a unique position to overcome some of the challenges within it. Other participants were also able to have an easier time returning to work despite not having this specific insight that healthcare professionals do. For Participant #1F, she expressed that her gradual return to work where, “I think every two weeks or three weeks we changed the schedule. That [was] very helpful.” Easing into the process helped her handle it better as a whole. Also, Participant #11F said, “I think it wasn’t difficult because […] the employer picks the insurance company to manage the disability, so they informed me from the beginning that I have to communicate with them. […] So, it was very clear.” Receiving well-defined assistance from employers and insurance personnel was similarly responsible for positively impacting the navigation process.

    Nonetheless, many study participants did have a negative experience while managing their way back into the workforce. Simply put, Participant #7M described his experience as “very, very, very confusing” and Participant #5F compared it to, “death by a thousand papercuts.” For some, these hardships were influenced by having to lead their own return to work plan, which was stressful and uncomfortable for Participant #6F. She said, “I then really started to guide my own
return which was weird too because I really thought somebody would be phasing me back up to full.” Moreover, for Participant #15F, she stated:

The whole thing was trouble. I didn’t even know what I was doing. […] There was so much…phones, emails to send […] so many people. I couldn’t understand anything, it was just so much. That’s why I needed the help, because I couldn’t figure out all these forms.

When asked about her own problems handling paperwork, Participant #4F called it a “big barrier.” These difficulties navigating the system were reported to be related to various other challenges faced when going back to work. Administrative barriers, such as dealing with confusing paperwork, were the last thing that participants wanted to be responsible for when already undergoing such a difficult journey, as evident in the example above. Physical barriers also were experienced when navigating back into work – Participant #9F stated, “I think for me the biggest barrier was after surgery. I wasn’t supposed to lift for 6 weeks […] [and] because I have a physically demanding job, my employer did not want to permit me back to work.” When accommodations in the workplace are not present, it can be more difficult for cancer survivors to navigate returning to work. For example, Participant #8F was also experiencing pushback from her employers while navigating back to work. Frustratingly, she shared, “Then it was barrier, after barrier, after barrier – no we can’t accommodate, no we can’t accommodate. And months, months on end [I] keep pushing to try to get back to something. […] It’s not been easy.” Specifically, one of the many barriers she faced to successfully navigating back into work was that her employers did not want to financially support her return. She acknowledged, “I know this is part of the barrier as well…somebody’s got to pay for [my job]. […] [And] I know she doesn’t want to pay.” When asked about her experience going back into the workforce, Participant #15F said, “I think navigating is [difficult] because I don’t know the social things that are going on in the work
environment.” For her, this barrier of not being up-to-date with the social events at work made it more difficult to reintegrate into her job and navigate the process to do so. These psychosocial and emotional barriers were experienced by participants who underwent the return to work process, and they found that these obstacles as a whole impeded their progress.

Participants clearly identified a need for professional help to get over these challenges in navigating systemic issues and getting back to work successfully. Specifically, Participant #12F said that:

That’s a gap – navigation is terrible. We know how hard it is to navigate the health system, now imagine navigating the insurance system when we are not familiar with that. It’s terrible. There is no way – we need a navigator.

Participant #3F echoed this when discussing how no one helped her navigate the system and stakeholders relevant to her return to work – “I wish there could be someone, maybe perhaps the GP [general practitioner] can do this…that provides like a comprehensive picture like okay, look at your needs, this is what you have.” During a focus group, Participant #7M also advocated for this kind of systemic support. He said, “there [should be] a company that specializes in helping people who have been through cancer” to navigate the system. It is clear that this is an idea shared by many cancer survivors that has the ability to ease their process of navigating back into the system.

**Communication within the System**

Participants emphasized that an important part of navigating into the workforce is communicating with stakeholders throughout the system, including colleagues and employers at
work, insurance providers, and healthcare providers. Often, intercommunication between these stakeholders can help with navigating this process.

The majority of the stakeholder communication that was required by participants was at work. Despite talking about feeling stigma at work, some participants still felt comfortable discussing their experiences openly with their coworkers in order to ease the transition back into work. Participant #6F said, “I just was really up front about what I was going to go through. […] I didn’t want it to be awkward when I went back.” A similar strategy was employed by Participant #1F – “I actually kept it public to the team, so everybody knew that. […] So, when I came back they just welcomed me back.” Participant #14F talked about attending work events to stay in contact with coworkers. She said, “I do try to keep in touch. Otherwise, it becomes really awkward if you’re gone for like a year and then all of a sudden you’re going back.” She also felt comfortable when talking to her manager. She shared:

If I wanted to have a conversation with [my boss] now saying, what does work look like when I go back? She would be open to having that conversation with me. […] So, that gives me comfort and that’s reassuring.

Participant #15F was able to feel comfortable communicating at work. She stated, “Some people said […] you don’t have to say anything. But I was comfortable because I wanted to show strength that I’m not afraid no matter what happens, I’m going to be able to communicate.” Participants felt that this open communication helped study participants get back to work. When discussing her mentors in the workplace, Participant #5F said, “[I have] really meaningful relationships with mentors because they’ve helped me sort this out and I think only because I’ve been like completely open about it.”
However, communication with managers and leadership at work was not as straightforward for other participants. Participant #2F said she still “has to figure that out” to make sure that she will “have a bit of information when [she has] that conversation [on gradually returning to work] with the workplace.” In her case, she wants to be more prepared before communicating with her work. Others simply had little communication with their workplace at all. For Participant #4F, this was particularly distressing and confusing. She disclosed, “They are not saying anything for more than one year. They are quiet, they don’t [send] any email, they don’t [call] any phone.” Participant #8F agreed, saying “[with] my leadership, there was always strained communication. They didn’t communicate on hardly anything.”

Moreover, a lot of the time, participants were actually forced to only communicate with insurance and were not allowed to have contact with their workplace, which they would have preferred. This included Participant #10M, who said, “So, I’m only speaking with my insurance. […] With regards to return to work, I haven’t spoken with my previous company.” Participants speculated that this is because of a lack of understanding of legal and insurance issues on the employers’ part. For instance, Participant #11F elaborated, “They’re afraid to say something and legally being in a bad position so they always ask, um, advise me to communicate with them through insurance.” This was difficult for her because it left her with a lot of uncertainty about her ability to return to work and whether she was communicating appropriately. Frustratingly, she felt that, “I’m so open and […] I don’t know if there should be a certain frame in my communication.” Participant #12F had a comparable experience as she said there was a,

Lack of communication with the insurance and with the employer because I don’t feel confident or comfortable talking with them. I don’t know how they will interpret the information. So, it is hard, and this is not just me. This is a constant that I see, I’ve seen
through my whole journey – talking with people in different stages in the process, that the stress and the not knowing what and how to communicate with the insurance and the employers, it’s so high. And that’s ridiculous. Because it’s not helping anybody.

She explained further as she said:

[I was] sending them my updates and how I am doing because I think that that’s the way of really paving the road for a good return to work. […] The person dealing with disability informed me not to be in touch with them. That they don’t need any updates and that they will know about my case through the insurance company.

This was very surprising to her, because she knew about how important it was “to educate organizations to be supportive and be in touch with the person that is out of work. That will reduce the stress, it will make the person or the employee welcome when the time comes.”

Another stakeholder group requiring that participants had to communicate with when returning to work was healthcare professionals. The experiences that participants had with this group varied. Many participants thought that healthcare professionals were good at communicating with them. Participant #1F said that, “any question that I asked, [the physician] gave me an answer. […] He didn’t talk much but everything he told me, he gave me the clear information and gave me the confidence.” Importantly, healthcare professionals were perceived to be more effective at helping participants return to work when they underwent interprofessional communication. Participant #14F pointed this out when she talked about a new portal that physicians were using to share information amongst themselves and with patients. She said that, “It’s hard to retain all that information. So, it’s great that you have this portal and you can go back and you can revisit it.”

On the other hand, Participant #13F felt like there was a lack of communication and that this was a big problem. She said, “They are so compartmentalized. I go in for A, B, C and I may
be asking my surgical oncologist and he’ll say ask your family doctor. […] I think a conversation is valid, and they don’t do that.” She even “suffered unnecessarily back of a lack of communication within the system” when her physicians did not appropriately direct her to a pain clinic.

Participant #11F, whose return to work was delayed because of a lack of communication between her employers and insurance providers. She said, “I called them on Friday because I haven’t heard anything from them. […] She said they are not ready because insurance didn’t send them the documents they were supposed to send.” Relatedly, this absence of communication created a “terrible” experience for Participant #12F which “created a lot of anxiety and stress, and the last thing that a patient – a person surviving cancer needs.” Fortunately, some participants were able to benefit from effective communication amongst stakeholders. For Participant #7M, when talking about getting on track to return to work, he said, “everybody keeps [talking] with everybody. Which I find fabulous.” Participant #14F’s healthcare professionals and insurance company had “these conference calls every couple of weeks and then they gave me an update on the call.” Getting her involved in this communication was an excellent and useful way to keep everyone on board with her progress returning to work.

Determining Disclosure and Accommodation

‘Determining disclosure and accommodation’ describes how cancer survivors managed to handle the stigma they faced disclosing their diagnosis and symptoms, and how this was related to their ability to receive appropriate accommodations at work. This theme was illustrated using the sub-theme ‘requesting symptom-related accommodations’ to provide a more focused perspective.

Requesting Symptom-related Accommodations
Study participants benefited from being able to request accommodations at work that helped to alleviate the symptoms they were experiencing. This process involved dealing with the dilemma of whether or not to disclose their diagnosis to receive the help that they needed to return to work successfully.

Requesting accommodations to reduce the impact of symptoms when returning to work was seen to be important. For instance, almost all of the study participants discussed how a gradual return to work would be beneficial for dealing with symptoms of fatigue. When talking about a graduated return, Participant #12F shared, “My concern is how I’m going to manage my fatigue. That’s a biggie.” Participant #1F said, “The biggest impact is the energy level. […] And you just couldn’t work long hours no more.” Similarly, Participant #4F was given “light work, and after some time […] [her] regular job” and Participant #2F expressed in the focus group, “I think that for me it’s like energy is kind of low a little bit. So, when I go back to work, I’m hoping to get a graduated [return].” Further, to Participant #15F, “a gradual return is the best option”, but she also believed that “working from home is going to help”, along with “taking breaks during the business day, […] getting up, walking, going to get some fresh air, taking the pressure off of whatever, the pressure points are in my body. […] Just taking a mental break.” Depending on the nature of the job and unique experiences, there were a variety of other kinds of accommodations that study participants found useful. For example, Participant #3F experienced pain in her back and stated that, “sometimes I find I cannot sit for a long time […] I hope I can have that kind of flexibility that I can take a break […] so I won’t sit for two hours.” Given Participant #5F’s cancer-related neck swelling, she mentioned:

I took call accommodations which I hadn’t taken before, which basically means I didn’t do overnight shifts for a couple of months. […] You’re sleeping like two hours in 24 hours on
like a very crappy mattress. And if you happen to have like a ton of neck swelling, it’s like not super comfortable.

For Participant #9F, her parking spot was a block away from her work, so she said, “I asked for a closer parking spot […] I am glad that I did it because […] even if I could sleep in just 10 more minutes, it’s totally worth it.” Other accommodations were much more specific to certain cancer-related side effects and symptoms, like how Participant #14F said she wanted, “a fan because I get hot” and how Participant #7M “cannot work in places with too much dust or too much mould” since he might risk a lung infection. Additionally, Participant #11F’s symptoms required her to request, “an air humidifier in my office […] and 15 minutes in the morning and afternoon for exercises – I have mouth and neck exercises I have to do all my life.” Participant #6F had a similar experience as she shared:

So, I had like an oral cancer, so I had no saliva and I always have to have a drink or gum and I have to go brush my teeth or have to do like a lot of things throughout my day.

She later added:

My dry mouth is a big problem because I talk to patients all the time. […] I’m always chewing gum which is like clearly like unprofessional, but I told my manager like I have to chew gum at work – and then I have a water bottle and then a spray and then my mouth care.

Fortunately, she was able to be provided these accommodations and breaks that she needed to make sure that she was able to take care of herself and her symptoms at work.

There were a few other participants who also did not have a problem with requesting accommodations or did not anticipate that it would be a problem when they did. Participant #14F
said, “I don’t foresee there being any issue at all” and Participant #2F discussed how, “I’m sure they’ll accommodate whatever […] I’m like 100% sure, I’m not even worried about it at all.”

Unfortunately, not everyone had such a straightforward experience with requesting accommodations to meet their return to work needs. Many faced challenges with stigma that influenced disclosure and ultimately if they would receive any work modifications. Participant #15F said:

I was advised not to bring it up. […] And if you are looking for a new job, don’t bring it up if you get the job. Because most people don’t want to hire someone who’s sick. Or who even survived.

When Participant #10M discussed why he initially did not want to accept a gradual return to work, he said, “It’s the concern that I don’t want to be labeled as different.” This stigma, particularly directed at the invisibility of the illness, impacted accommodations. Participant #12F shared, “From what I see and what I’ve heard is most of the physical accommodations are obvious. […] You can sell them better than the disability that you don’t see.” Furthermore, this particularly frustrated Participant #11F and impacted her thoughts about disclosure. She expressed:

When you say fatigue, people think that you are lazy, right, you know? But it’s a different type of fatigue, right? You sleep but you still wake up tired. Just they don’t know it – that’s why they cannot understand it. […] But it’s hard to you know, wait there, you know, disclosure or not to disclose thing also but if you know, when I say I have fatigue, they think that you know maybe they believe me maybe they are not.

She elaborated on these feelings later when she added, “If you disclose it, they are not going to hire you. I am sure they are not going to hire you. If you don’t disclose, it’s, you know, I
would feel uncomfortable.” Not only would she feel uncomfortable, but she would also likely not receive the accommodations that she would require to meet her needs and improve her wellbeing.

Specifically, Participants #8F and #13F had a really difficult time trying to navigate disclosure and accommodations. Participant #8F said, “I disclosed to them that I have cancer. […] Could have shot myself in the foot by disclosing, you know?” This is because, even having gone through the difficult process of disclosure, she stated that they said, “these are your restrictions, there’s too many restrictions, we can’t accommodate.” This left her feeling frustrated and she shared:

I fully disclosed my medical to my own leadership. I didn’t have to, but I thought in so doing, maybe, maybe they’ll make a change and somehow be nice? No. Absolutely not. […] You know what it’s like to fight depression? To fight the stigma of having a mental illness associated because you’ve got cancer that has no cure? […] I need to have a purpose to get up and go to work in the morning.

Being able to receive the accommodations she needs to be able to go to work would mean a lot to Participant #8F, but unfortunately disclosing her needs seems to have worked against her and has led to stigma and discrimination.

As mentioned, Participant #13F has been deliberating whether or not to disclose her cancer diagnosis as she prepares to find a new job. She considered:

How do I tell my employer, you know, I suffer from brain fog, and it may or may never go away? Am I going to be the next candidate for the next promotion? Do you see what I’m saying? So, even if I get the job, can I keep it?
She also realized that, “There are so many road blocks to not disclosing, and once you disclose, you stigmatize yourself.” This led her to further contemplate her situation and whether or not disclosure would be worth it for her. She said:

Now I don’t want to share about the cancer because I don’t want the stigma or the whatever since I’m job hunting. […] So, I don’t know if I should, because I want special accommodation, because I need special accommodation, because of whatever. Would it benefit me to do that or not? […] But with me, starting out with a new employer, or even my same employer in a different capacity […] should I disclose, or should I not disclose? What’s the benefit of it?

Overall, accommodations can help manage symptoms at work when they are provided. However, knowing when to disclose to receive these accommodations can be difficult for cancer survivors who are not readily offered these supports.

**Importance of Supports for RTW and Daily Life**

The theme ‘importance of supports for RTW and daily life’ consists of the various types of support that participants received, or would have wanted to receive, throughout their journey to help them return to work and improve their wellbeing. This theme included four sub-themes: ‘supportive work environment’, ‘interacting with insurance companies’, ‘family and friend support’, and ‘experience with healthcare providers and community supports.’

**Supportive Work Environment**

In general, to study participants, a supportive work environment consisted of ongoing, emotional support and understanding from employers and coworkers. Some study participants
were fortunate to have experienced support from their workplace throughout their return. For example, Participant #14F said, “it was comforting because people who reach out – hey, how’s it going, how are you feeling – so I felt like I was getting that support.” She was even given updates while she was away that created “a very comfortable work environment, it was supportive.” A confidential and respectful environment helped participants feel supported at work. Participant #1F shared, “My coworkers are very good, they are very supportive, and they keep all my information confidential.” Despite Participant #9F’s one boss invading her privacy, she still felt supported by the boss at her other job because, “she’s really, really careful about asking appropriate questions. [Also] she brought me food to my house like after my surgery […] so she’s been like really, really supportive.” She also acknowledged that feeling understood and accepted by her colleagues at work was important for her to feel supported. She shared, “I do think my workplace was helpful. […] And they were supportive, and they didn’t make me feel like I couldn’t do my job. Everyone just kind of treated me like normal. Which, it was appreciated.” Participant #12F shared this perspective when talking about feeling comfortable at her workplace because, “They were absolutely supportive, and they understood right away.” For Participant #2F, this understanding at work allowed her to be supported and not be rushed back. She stated:

They’re actually giving me more time off than I thought I would get. So, that’s kind of nice, because usually you’d think they would rush you back […] but my work is just like no, make sure you feel better […] so it’s really been great.

Another positive aspect of understanding at work is the ability to share duties amongst staff. Participant #5F elaborated on this when she said:

I work largely with other trainees and it’s very supportive […] especially when you leave, I mean I felt bad, you leave workload and we managed to figure out other people’s vacation
schedules so that the workload wasn’t outrageous and things like that and people were really understanding.

Emotional support was also a key factor in feeling supported returning to work. This was especially evident if the individuals providing support had any lived experience with cancer themselves. When talking about the emotional support she was provided at work, Participant #3F said, “Some of them have the cancer experience themselves, some of them have loved ones that went through the same thing. So, I find I’m more closer to those people with similar experiences.” In Participant #5F’s situation, this emotional support came from mentors in her workplace. She said, “some of the mentors provided kind of informal emotional support” and that “the biggest thing has been supportive mentors.” This is because they are people “who understand the work environment and who can say like, you know, A or B is reasonable.”

When these positive aspects of support at work and others were not present, participants felt their absence. Participant #9F who was offered some support at work thought that, “it would have been nice if my work team had been a little more supporting” of her ability to go back to work. Similarly, Participant #3F said, “I wish I would have more [support] from my coworkers” and Participant #4F thought, “some of the employers only think about the work paper and whatever kind of work and what kind of rule or regulation they just want to go through and that’s why sometimes [it’s a] hard thing.” She feels she would have benefited from being provided more attention on her and not on administrative duties. Participant #15F experienced a lack of support because, “the employer pushes you to go back to work too fast” and she was “missing that relationship with your colleagues, those are great relationships to have.” Some participants had specific concerns, such as Participant #12F who said, “Another challenge that I see is the lack of support for retraining…it’s either what you were doing or nothing.” She discussed that employers
need “to reduce that fear and to give the support that hey, you are going to be kind of welcome when you’re ready.”

Participant #13F felt like her colleagues were not accepting of her limitations and this led to a lack of encouragement to bring her back. She discussed in the focus group, “So, for support from my company, not one, because they basically washed their hands because I’m no longer really an employee – I’m just one letter away from bye.” Participant #8F also experienced this gap in support due to her employers not accepting her limitations. She expressed:

It would have been viewed as a performance concern, that I couldn’t do it, as opposed to, okay we want to support you, you have a medical condition […] I said I need support. I need somebody to cover my back. And the leadership just wasn’t interested in listening.

For her, this negative experience also included a lack of trust because:

The breaches of privacy were incredibly painful because it was…I’m going to share with the people that I know that are going to be there to support me – I don’t want the world knowing about my affairs. […] I’m a thorn in your flesh now that I can’t give you the output that I gave you for 8 and a half years.

This situation was very difficult for Participant #8F since “there was great capacity and potential to return to something else as long as I’d have the supports in place” and because “there were no signs of caring, there were no signs of compassion, there was no I’m sorry, there was nothing! Nothing!”

Additionally, Participant #6F also had a difficult time with the lack of workplace supports available to her when she was returning to work. In particular, there was a lack of understanding and acknowledgement of her situation amongst leadership at her work. She said in the focus group:
I just wanted somebody to say, hey how’s it going? And I was missing that point throughout, well, to this day no one has asked me how I’m doing. It’s just weird. It would have given me again the opportunity to say I need something, X, Y, Z. Um, versus putting it on me to ask for it. […] So, just having somebody say how are you coping, how does it feel to be back, how are you doing? Would have been a good opener into having a conversation about what I needed without having me to bring it up, but yeah.

She also said, “My peers were really amazing at like checking in and making sure I was okay and how am I doing, but my management, not a word. Like which actually blew me away.”

Ultimately, one of the most significant gaps for Participant #6F and additional study participants was the lack of ongoing work support. She frustratingly explained:

So, I felt very well supported while I was off. And very encouraged to go back, but then when I got back it was almost like, she’s back, and don’t mention a thing and she’ll be back to her normal duties. […] Nobody was supporting me to say how are you doing, does it feel okay? […] So, I found that to be interesting because I would have expected that would continue on while I was back.

Participant #14F had a similar experience, as she stated:

The interesting thing is, you get the support right at the beginning. You get a ton of support. Then all of a sudden, it’s like…the support kind of starts to ween off, and it’s like, but you know what, I still kind of need that support.

Moreover, Participants #9F and #11F also felt that this lack of continuing support throughout their journey negatively impacted their return to work. Participant #9F shared:
I was like kind of disappointed because like no one sent me a card and no one like checked on me and only like one person in the whole department like sent me an email to say like thinking about you.

And Participant #11F said, “Few people reached me through my personal email asking how I am doing sort of thing, you know? […] Nothing from my supervisors. I only received a, you know, get well soon card after six months.” The provision of ongoing emotional support at work had a significant influence on a participants’ journey.

*Interacting with Insurance Companies*

In addition to support from employers and coworkers, cancer survivors may have received supports from insurance companies through their interactions going back to work. This elaborates on the aforementioned experiences that study participants had communicating with insurance companies, to focus on more direct interactions and support. For some, insurance companies were present and helpful, yet others dealt with pressure and stigma due to the lack of support.

Firstly, several participants had a positive experience when interacting with insurance companies. Participant #1F was glad that “insurance covered [the medication] so they just provide everything that would probably make me feel better and recover faster” and Participant #10M said, “So far so good with everything. Yeah, insurance, all good.” For Participant #6F, these positive interactions were shaped by ongoing check-ins, encouragement, and understanding from insurance personnel. She explained:

I had a really, really awesome insurance person. […] She was very supportive like she would because you would think that kind of role would be very like inquisitive and like, can you go back to work? Like, she just felt really bad for me and she was just like, how
are you? Like she started every conversation about like how I was doing before we talked about what she needed to be calling for and even with like paperwork she was like don’t stress about it.

Similarly, Participant #14F received good support from her insurance company because they were accommodating and communicative. She talked about how, “With the insurance companies, typically what I like to do is I like to schedule things. So, we’ll just exchange emails and come up with a time that works. […] So, it’s been very easy.” However, she did experience some pressure from them to return to work. She shared:

Because I kind of feel that the insurance company – and this is horrible to say – it’s all about money and getting you back to work early. Although they say […] we want to make sure that you’re equipped to go back to work, and I want to believe that, but I just feel like it’s a little bit rushed.

Fortunately, the insurance company listened to her concerns and she said, “I feel a bit better now because they have agreed with the November timeframe to return to work. I have some more time, I can relax, I can […] get myself ready to go back to work.”

On the other hand, many study participants did not receive the same encouraging support when interacting with insurance companies. For instance, there were several who were pressured to go back to work like Participant #14F was, yet their insurance companies were not supportive like hers. Participant #15F said, “My experience has been the insurance company pushes you to go back to work too fast. […] They’re very aggressive […] They have to stop forcing people, it’s not good” and Participant #3F shared, “Yeah the insurance company definitely wants me to start getting back to work soon […] I felt rushed in terms of the push.” Additionally, when she worked for one day while on leave, Participant #9F got a lot of pressure from her insurance company to
go back to work immediately. She explained, “I had to be like really careful after that point with what I was doing because […] the insurance companies are really like annoying.” Although, it should be noted that she does attribute her outlook on her pre-existing negative experiences with insurance companies through her job as a physiotherapist. She admitted:

I think because I came in with this bias of like – I’ve had so many conflicts with insurance companies through my private clients in the past, that I came in like really defensive. […] It was by far the most unpleasant part of this whole experience. […] I feel sick just like talking about it, and I, I know part of that is because of my past experiences.

Participant #12F had a similarly unpleasant experience, which ended in a law suit. She said:

I was forced to go for a return to work program with the insurance company when I was not ready and that was a failure. And a failure for them, failure for me, failure for everybody – that ended in a lawsuit. And that doesn’t help anybody. It’s just ridiculous and it’s just because a lack of understanding and empathy and compassion or adjudicators in the insurance company that don’t understand the unique issues that a patient or a person suffering with cancer has.

This was very frustrating for her, particularly because she felt that for them, “It doesn’t matter. At the end it is money. The survivors cost this much money to the organization and the insurance. The fastest that the survivor goes back to work, the less money.” She also felt like the insurance company was not trying to understand her unique needs because she explained how:

I was blamed when I was talking with the insurance because in their perspective I was too busy doing things rather than being at home waiting to be better. And for me it was like,
are you crazy? I’m going out to do exercise, to build again my body and my mind to be able to return to work and you’re putting that against me?

This lack of targeted support was also experienced by other study participants. Participant #15F said that, “They give whatever cancer you have, they have like, there’s an average […] they have all these benchmarks. Some people are over, under and some of that information is misleading, but the insurance company that’s what they go for.” Comparably, Participant #13F mentioned that, “The [insurance] carrier is not rehabilitating me for my job, they’re rehabilitating me for any job” and that they provided her with “nothing, other than when [the insurance person] felt I was really ill, she would call, contact me, once a month.”

Furthermore, lack of trust from insurance companies was a challenge for cancer survivors. Participant #7M thought that, “the biggest business in many insurance companies is when they don’t pay you. […] If they find an excuse not to pay you, they won’t pay you.” This included not having cancer-related symptoms believed. Participant #11F explained that:

Now I’m having some issues with insurance because as long as I had the cancer and ulcers and that sort of physical stuff they were very understanding, you know? They were very good. But now, I have cancer-related fatigue and it is sort of a grey zone. I feel like they are not believing it.

As a recommendation on how to improve interactions with insurance and cancer survivors returning to work, Participant #12F proposed:

What I would love to have […] from the insurance […] hopefully [is] a clear support and guidance, tools, conferences, interviews, one-on-ones, explanations – things that make us understand their way of assisting and how can they support us and what can we do.
Family and Friend Support

Outside of the work environment and insurance companies, family and friend support played a significant role in helping participants improve their wellbeing to feel ready to return to work. This could include emotional supports, the role of family and social life, and help within the home.

Overall, study participants benefited from the emotional supports they were provided from their family and friends. This included acts of kindness like when Participant #1F’s “son’s friend’s parent […] gave us a lot of help. She just went to the hospital sometimes to bring food […] so that helped me a lot.” It also included supportive families, like Participant #9F’s, as she said:

I couldn’t have done it without them, I don’t know how people do this living in a different city from their family, like, I just can’t even begin to wrap my head around that. So, being in a supportive environment, having people taking care of me was really crucial to my healing and my rehab. […] I felt like I was ready to go back to work.

More specifically, spouses played an important role, as Participant #8F shared, “my husband has been very supportive” and Participant #10M said, “my spouse has been great.” Participant #7M even explained that, “I think the biggest help has been my wife. She has been a blessing to me.” And, when asked about how she impacted his return to work, he said, “I don’t think I would have the willingness to live if it wasn’t for her.” He acknowledged how this experience has been difficult for her as well, but he is extremely grateful for the support she has provided. Moreover, Participant #11F’s “primary support came from my family. My husband […] he’s been very supportive from the beginning and he never imposed me to […] he never told me that I should go back or not.” For Participant #2F, this “emotional support I get from my family […] helped because like the fact that I do have the support at home and stuff does make me be
like, okay, I can go to work.” Participant #6F also noticed that she was better able to cope with the hardships she faced going back to work “because I had great support and great friends” and this made it “much easier if you have people cheering you on. Like it didn’t make it physically any easier, but it made it definitely mentally easier.” Furthermore, this experience has made Participant #6F, “more aware of people’s struggles and the importance of having friends and help.” She also benefited particularly from the help of her spouse, as she said that it was:

100% positive […] we’re a great team, he’s been there for every appointment, he’s slept on the floor at the hospital for ten days. […] It’s been good, he knew exactly like who I was and how to navigate that with me.

Additionally, Participant #14F shared how she had a “supportive spouse” and a “supportive network of friends and family […] [that were] very helpful to kind of navigating and getting ready to go back to work.” She even said that her husband, “always supported me like whenever you’re ready [to go to work], don’t feel like you need to go.”

Participant #14F did point out that she specifically appreciated the support of friends who had the lived experience of going through cancer. She shared:

I was very fortunate, I have a friend who went through breast cancer, so she would call me every once in a while, and she got it. […] We went through that journey together and we would help and support each other emotionally.

Discussing this later, she added guiltily, “I know that other people have good intentions and stuff but it’s like, you don’t get it.” Participant #3F felt similarly as she shared, “I find talking to people with similar experiences is very helpful.”

Study participants appreciated the support they received from family and friends when they were treated normally and encouraged to pursue their return to work goals. Participant #5F said:
It’s a bit counter-intuitive, but I think actually just trying to be kind of normal – like I think I would have responded badly if people in my life, especially people really close to me, had been like, oh let me do everything for you.

Likewise, Participant #9F shared, “I mean my friends I think really kind of just treated me like everything was normal the whole time, so that was really helpful.” She later added:

My friends have been supportive, and I felt like they really treated me going back to work as like a very matter of fact thing. Like oh, of course you’re going back to work! Whereas like other maybe people might, might say like oh you’re crazy, why are you going back to work? But my friends like know how important my work is, and they just, it was like really like obvious to them that I was going to be going back and we just normalized that process I think.

Participant #12F pointed out that to her, family support was ongoing, whereas support from friends tended to fade over time. She explained that:

[Family] are the ones that are there forever. […] At the beginning, everyone is kind of supportive and then the interest is fading because everybody gets busy and again it’s like, well, probably she has been in the journey for so long so, she may be fine? […] And that’s interesting because this is a chronic thing.

There were other gaps in family and friend support that were pointed out by several study participants. In particular, many cancer survivors wished for more emotional support. For example, Participant #3F acknowledged that her husband provided her support but that she wished, “he could give me more like talking but I think he’s a guy and he won’t talk much about feelings and emotions.” Similarly, Participant #14F stated, “At times I felt like I wasn’t getting the support that I needed”, but despite that she still said, “my husband was like my rock, like he did everything,
and I relied on him for everything.” Participant #4F also wanted more support, as she said, “I want more family to look after me and more care [for] me, because I [am] thinking I don’t know how long I am. […] I just need everybody to say to me a good thing, not like bad.”

Another gap in the support offered by friends and family was a lack of understanding of participants’ perspectives and limitations. Participant #13F thought, “I don’t think they realize that I’m still not well and that’s the part that is hard…for, not only me, but for them, too.” This gap left Participant #11F feeling pressured to go back to work as she shared, “They are neutral [on] the whole, but I feel that they are looking for me to go back to work because it means for them that I’m completely okay.” On the other hand, this lack of understanding potentially made it difficult for Participant #1F’s husband to support her as she said, “he didn’t want me to go back to work anymore”, despite her desire to return.

As mentioned earlier, these supports are related to family and social life. For Participant #13F, she said, “My family life has been non-existent because I can’t really do very much. Thank God my sister has been in my life to help my senior parents and now her family is here so that’s a blessing.” Her sister was able to provide her with support to get better, despite her inability to be involved with her family life at the time. Further, Participant #15F’s “big, multi-generational family” shared her diagnosis with each other and with friends, and this impacted the amount of support she received because:

They wanted people to see me, they wanted me to get the help and stuff like that […] a lot of people would call and just ask me how I’m doing, and you know, encourage me to go to church and encourage me – so that was um positive, a lot of people would come and visit.
Also, Participant #5F noticed how her social life was impacted by this support. She talked about how she tried to organize a dinner for her friends before her treatments, but “then I would just be like, oh, nobody really wants to do that.” This led her friends to eventually encourage her to fulfill her desire of getting together and providing her that emotional support, “which was really great.”

Participants included in family support help with household chores and responsibilities, while illustrating the impact of gender roles. Since many of the study participants were women, they used to be tasked with typical household roles. However, these responsibilities tended to be altered throughout their cancer journey and return to work. For example, Participant #1F said, “My husband, he supports me so much because when I went back to work, I didn’t do anything at home. So, my only job is to work. […] Yeah, my husband did just change a lot.” Similarly, Participant #12F said, “Still, there are many house chores that I cannot do. So, he has to do chores that I was doing myself.” Participant #14F also shared how this helped to “release a lot of the stress because [if] I don’t feel like I need to cook dinner, or I need to do the laundry.” These roles were also impacted by whether or not the participants had children. Participant #14F said that, “If I didn’t have the kids and I just wanted to lay on the couch and do nothing, I could. But with them, I wanted to create a home environment that they were used to.” This involved making sure that the aforementioned chores still got completed, and how she worked with her partner to accomplish this. Moreover, Participant #2F, who also has children, explained that her husband, “had to probably take care of the baby a bit more than usual” which “definitely helped.” However, this role reversal was not permanent, and she is “still the primary caregiver.”

Additionally, some female participants also had their roles change back or not change at all, for various reasons. For instance, Participant #3F said that, “the role hasn’t changed much”
although she did “shift all my household chores to my sons.” Participant #6F simply felt more normal when fulfilling her chores because “I had a purpose in my day” and therefore “didn’t really allow for a ton of role changes.”

From a men’s perspective, Participant #10M felt that his role of “being the breadwinner […] changed” and that he “can’t do some stuff at home because of [his] condition.” Thus, he sought the support of his family along his journey. This is important to note because men tend to feel a lot of pressure to be the provider in their family, and this switch in roles potentially had a significant impact on him.

Experience with Healthcare Providers and Community Supports

Lastly, experiences with healthcare professionals and related community supports were reported to have an impact on going back to work. This includes addressing return to work needs, understanding the individual’s perspective, and supporting their goals. Many of the study participants had an overall good experience interacting with a wide variety of healthcare professionals. When asked about his experience, Participant #7M said, “I would say very good.” Participant #6F echoed this and said, “I adore my team, I have had nothing but exceptional care. […] My surgeon is insanely amazing, my oncologist is great, the speech therapist, the dietician, the radiation technicians, I loved them.” Further, Participant #5F shared, “the main treating doctor was super supportive and helpful.”

In particular, advice from healthcare professionals on returning to work was appreciated. Participant #6F, who was eager to get back to work, stated, “The oncologist’s opinion that I wasn’t ready was valuable because I needed to hear it from her.” Otherwise, she might have gone back before she was able to do so successfully. Also, Participant #7M shared the advice his physician
gave him, which was “very simple, you know your limitations.” This wisdom allowed him to reflect on his ability to return to work appropriately. Participant #12’s advice came from “several doctors because [of] the nature of the illness” who gave “very supportive, clear […] great advice.” When she experienced setbacks on her journey, her psychiatrist helped her “to deal with that and really to be more realistic about conditions.” For instance, when her surgeon told her she might never go back to work, and that it will be a long journey, she said, “at the beginning it was hard to hear that, but then when I was going through all this I realized how wise he was.” For other participants, advice was provided in the form of specific recommendations. Participant #11F said that her “occupational therapist suggested 12 weeks of gradual return to work” because of her fatigue level. Her healthcare team also suggested that she goes “back to work as soon as possible but not before [being] completely ready.”

Some study participants were not given any advice on returning to work from healthcare providers. Participant #14F thinks this is because “I really haven’t asked my surgeon or my oncologist about advice to return to work” since “I don’t really feel that that’s they’re realm of expertise.” She would rather “go through the survivorship clinic and talk to somebody who does this day in and day out and leave it up to them.” On the other hand, participants such as Participant #13F have desperately asked for guidance on returning to work but have not been provided any. She explained that despite her overall experience being satisfactory:

Not one of them offered me [return to work advice]. I’ve asked, and I’ve asked, and I’ve asked, and I’ve asked. Zero. […] My family doctor – she won’t mention it. I’ve asked, I’ve gone to see internists, I’ve gone to see oncologists, I’ve gone to see – they don’t talk about it. Not one of them said I think you’re capable of going back to work […] or not one of
them said I don’t think you’re capable of going back to work. They don’t discuss work, period.

She would have appreciated being given recommendations and insight into what to expect returning to work, while making sure that her perspective was in agreement with the doctor’s opinion.

In order to achieve this, Participant #13F and many others hoped that their healthcare professionals would understand their individual needs and support their wishes. For instance, Participant #6F was glad that her physician “knew that my goal was to be able to be articulate going back. So, when we worked together that was our common goal.” This is important because, as Participant #3F explained, “They need to have a more holistic approach. Not just looking at physical aspects, whether your surgery scars are fine, whether your radiation is done. It’s also looking at other perspectives, like the cognitive, mental, emotional or social.” Participant #14F sought somebody “who deals with cancer patients, because I think it is very unique.” This was especially important to her because of an instance where her physician said, “you don’t strike me as the depressed type” which made her feel like she was not truly understood and could not be adequately supported by him. Similarly, Participant #11F had a good experience that left her “very happy, because they didn’t just treat the cancer, they also provided all the services – occupational therapy, psychosocial oncology – it was an amazing thing to have.” These supports that were provided to address her unique needs were helpful when putting together her return to work plan. Moreover, Participant #8F found that “most doctors […] have no idea about anything in support” but her “hematologist has been very supportive [because] he’s identified and mentioned that I’ve had a lot of employment stress issues.” To her, having her situation understood by her hematologist
allowed her to feel more supported when going back to work than she did with other physicians.

Yet another example is Participant #9F, who said:

Before I started chemo, and like one of [the doctors] was really supportive, and like, oh yeah, like do a few rounds of chemo but you should definitely return to work, it’ll be really good for like your sort of spiritual whatever. And some of the other doctors were like, no, you shouldn’t return to work. And, I just, I found that really like off-putting, that they were trying to keep me from something that was really important to me and I mean, I know that if anyone said to these doctors like, stop doing your job they would be like, absolutely not! So, I found that really like, kind of like a double standard.

It was frustrating for Participant #9F to feel like her desire to return to work was not understood by all of the healthcare professionals responsible for providing her support. She elaborated that:

I thought that was really not realistic of them and it wasn’t very holistic of them. […] I found that very discouraging, their attitudes toward me returning to work. And I know part of it was because my job is so physically demanding, but I also thought it, it lacked certain respect for my ability to self-assess myself and say that I’m capable of doing this. Then I had like one doctor who was more of someone we consulted with who did encourage me to go to work and I thought that was really, like it’s a good doctor.

For Participant #9F and others, it was important for doctors to support their desires and provide them with holistic care to better understand these perspectives. Participant #12F thinks that this could be addressed by having,
A deep conversation with the patient, because many times the healthcare providers don’t know exactly what the job description or the tasks is. And just to say that the patient looks good, it doesn’t mean that they are ready to go back to work.

There are other gaps in the support provided by healthcare providers that study participants have identified. This includes limited time with healthcare professionals, the lack of ongoing support, and the need for more education. Participant #4F explained how “[Physicians are] helpful, they want to help [in] their own way […] but they have no time.” Further, in terms of ongoing support, Participant #12F suggested that:

I will say that support from the healthcare providers […] at the beginning they are there because I think their goal is just to fix you, or to save you, so they want to be involved. And then the interest just fades. […] And I see that as an opportunity really if you guys want to do something meaningful for the patients. Think about that gap.

This idea was also influenced by an experience she had with an occupational therapist that did not want to help her with returning to work until she had a set date, and thus she felt that the ongoing support here was lacking.

She also talked about how:

The lack of education for the healthcare providers guiding patients to go back to work is huge. And it plays a big issue, because if my oncologist in a report says that she will recommend [that I] go back to work, and the insurance get that, or the employer gets that and I’m not ready, it will just ruin the whole thing. So, that is what I say, I don’t feel supported.

Participants emphasized that professionals must take the time to provide ongoing, targeted return to work advice that meets cancer survivors’ unique needs.
Finally, it should be noted that the aforementioned community-based centers within the healthcare system for cancer survivors were also a valuable support for study participants. Participant #3F said, “I find it very supportive and we have – I joined the breast cancer support group – we still meet on a regular basis. So, I find talking to people with similar experiences is very helpful.” For her, these supports were significant because of the opportunity to be in a supportive environment where the participants and healthcare providers were able to meet her needs – particularly through return to work workshops that taught her “the importance of a gradual return to work […] and remind ourselves that we have the strength and resilience to [get] through [this].” These group sessions also provided her with direct insight from other members about their “process of returning to work and now they went back to work and we met, and they talk about the experience.” Participant #12F agreed as she shared, “we are so blessed, at least here in [City Name] to have many organizations that provide support to cancer survivors […] because we can go there and be educated and have the support that we need.” Moreover, Participant #8F said that these community-based centers were a “tremendous support […] that kept me out of falling into depression.” Similarly, Participant #15F passionately spoke about her experience with these centers and the various programs that they offered to improve her health and return to work. She also said how they helped her “find a new support group [and] find a new set of friends” who “encouraged each other on our journey.” However, she did disclose that, “it’s also very hard when you’re in a group that, the friends that you meet…they die.” Dealing with this was difficult, especially since she initially had a hard time encouraging herself to access these supports since she said, “I was scared, and I wasn’t ready yet.” Despite this, she has benefited greatly and believes “it’s so important to recovery […] to know people are going through similar things, similar challenges, it’s just, it’s therapeutic, it really is.”
Overall, participants reported that their experience with healthcare providers and related community-based supports had a significant impact on their return to work. They suggested that these supports should be provided throughout their journey and should do their best to appreciate the unique desires of each cancer survivor.
Chapter 5: Discussion

The purpose of this study was to investigate the needs of cancer survivors when returning to or staying in the workforce. Specifically, it focused on examining cancer survivors’ perspectives on supports, sex and gender differences, as well as personal and employment factors that influence the return to work process. The study used an exploratory qualitative research design, including inductive thematic analysis as described by Braun and Clarke (2006), in order to understand the return to work needs of cancer survivors.

The central findings of this study are reflected in the four identified themes: changing perspectives on self and work; managing work and social systems; determining disclosure and accommodation; and the importance of supports for return to work and daily life. Together, these themes and their subthemes suggest that cancer survivors may need: time and opportunity to come to terms with changing work capacity, work identity and centrality of work; help dealing with the dilemma of disclosure and determining workplace accommodations; professional assistance navigating the system to streamline access to resources and ensure effective communication across different sectors; and ongoing, targeted support from many different stakeholders to meet their unique needs with a focus on peer-support. These key findings and their respective recommendations will be discussed in this chapter, highlighting interesting findings. Sex and gender differences are integrated throughout the discussion and include how changing perspectives on identity due to appearance, having children, and gender roles influenced cancer survivors’ ability to return to work.

Cancer survivors in this study revealed that they need the time and opportunity to come to terms with changing work capacity, work identity and centrality of work after experiencing cancer.
Adequately reflecting on and considering these changing perspectives can prepare cancer survivors for a more successful return to work. Study participants explicitly discussed the need for time to re-evaluate work-life balance post-cancer diagnosis. Experiencing cancer inspired a re-evaluation of what aspects of life were most important to participants. Changing perspectives shaped their priorities when returning to work, specifically by seeking reduced hours to make more time for activities, such as self-care and spending time with family and friends, which improved well-being. A qualitative study on breast cancer survivors’ views on the return to work process also found that survivors experienced cancer as a significant life event that inspired them to make social and family life a higher priority than before their diagnosis (Tamminga et al., 2012). Another qualitative study by Main and colleagues (2005) looking at return to work in a diverse group of American cancer survivors supported these results. These authors found that experiencing cancer changed participants’ outlooks on the significance of work in their lives. In particular, these findings included the participants’ interests in focusing on a more balanced approach by decreasing hours and pacing themselves, findings which also emerged in this study.

Given the significant life events and the many physical, emotional, and psychological impacts, participants agreed that it is difficult to feel completely ready to return to work after cancer. Thus, study participants expressed the need for help determining their capacity to return to work. A qualitative study exploring work readiness in cancer survivors also found that these domains are important determinants, and that the complexity of cancer is what makes it difficult to accurately determine work readiness (Stergiou-Kita, Pritlove, Holness, et al., 2016). Feeling uncertain about one’s ability to return to work is not unique to cancer survivors, as injured workers have also discussed how their perceived inability to perform negatively impacts their expectations when returning to work (A. M. Stewart, Polak, Young, & Schultz, 2012). Participants in our study
explained that a successful return to work meant not going back until they felt as ready as possible, in order to ensure they stay back. They needed to find the right balance between taking the time they needed, and not staying off for too long, to return to work successfully. The general return to work literature for injured workers and those with invisible disabilities, such as traumatic brain injuries, is in agreement that returning to work too early can increase the chances of an unsuccessful return to work (MacEachen, Ferrier, Kosny, & Chambers, 2007; Mansfield et al., 2015). On the other hand, the aforementioned study on work readiness by Stergiou-Kita and colleagues (2016) reported that returning to work too late can jeopardize a survivor’s employment and financial stability. Therefore, cancer survivors need help with accurately determining their capacity to return to work to better prepare and plan for a timely and successful transition.

Participants also discussed how cancer-related feelings of anxiety and stress made them question their competence and level of productivity, and hence their reflection on their readiness and capacity to go back to work. A systematic review on physical and psychosocial problems in cancer survivors beyond return to work provides evidence that psychosocial problems, such as anxiety and depression, in cancer survivors do in fact negatively impact work ability because of reduced productivity and quality of work (Duijts et al., 2014). However, a cross-sectional study by Pryce and colleagues (2007) points out that further research is required to develop a more in-depth understanding of how psychosocial factors can predict return to work in cancer survivors.

Another significant finding is that cancer survivors need the opportunity to come to terms with their changing notions of work identity. For instance, participants discussed work identity, particularly with regards to feeling like a burden to those around them, including to their friends and the workplace as a whole. Some study participants expressed that they specifically did not want to bother their friends and co-workers with their cancer-related problems, so they kept their
emotions from them. Similarly, a qualitative study by Mak, Chaidaroon, Fan, and Thalib (2014) found that cancer survivors viewed themselves as a burden to others, leading them to downplay their illness to their loved ones or co-workers. Interestingly though, a scoping review on stigma and work provides some evidence that opening up to family members can actually help survivors overcome these feelings of being a burden (Stergiou-Kita, Qie, Ki Yau, & Lindsay, 2017). The implications of this finding are that cancer survivors could benefit from assistance to feel more comfortable at work by discussing their feelings with loved ones. Similar strategies could also be employed in the workplace. Education should be provided to survivors, family members, and employers to help them overcome these barriers together.

Further to the issue of changing work identity and feeling like a burden, study participants also shifted their self-perceptions and experienced wavering self-esteem when returning to work. Experiencing lowered self-esteem is a common consequence of cancer and cancer treatment (Curbow, Somerfield, Legro, & Sonnega, 1990). A qualitative study on breast cancer survivors found that this lack of confidence can indeed act as a barrier to return to work (Tamminga et al., 2012). Additionally, female participants were particularly impacted by the visibility of their cancer-related hair loss. A prospective, longitudinal study by Münstedt et al. (1997) found that 46.6% of participants reported hair loss to be the most traumatic side effect of therapy, and 73.3% said they were not as self-confident as they were beforehand. Similarly, in the current study, participants and females in particular expressed losing their hair made returning back into society and work even more distressing as they had to cope with their new identity and lowered self-esteem. Nonetheless, another study where participants also mention the impact of hair loss suggests that issues with self-esteem can be improved by overcoming these barriers and returning to work (Nachreiner et al., 2007). Cancer survivors need the opportunity to come to terms with
this new identity when returning to work. The Canadian Cancer Society (2018) suggests that it is useful for cancer survivors to remind themselves that changes like hair loss are only temporary, and that it takes time to work through and grieve the loss of their “old bodies.” They also suggest that cancer survivors should discuss these feelings openly with trusted individuals to cope with this changing notion of identity and improve self-esteem.

This study also sheds light on the need for more research on motivational factors that may influence return to work. Although some personal motivators to return to work such as maintaining a sense of normalcy and fulfilling the individual’s meaning of work have been supported in the literature (Islam et al., 2014; Mehnert, 2011), there are others that have not been studied. Demographic and family related factors may play a role; for instance, age was a factor that motivated participants in this current study to return to work. Some discussed how they felt that being older made it more difficult to return to work, and because of that they were motivated to return sooner. Others talked about how they were too young to stop working already, and therefore wanted to go back to work. Although there appears to be a lack of information on age specifically as a motivator to return to work in cancer survivors, studies on breast cancer survivors have found that older age is associated with a lower likelihood of return to work (Bouknight et al., 2006; Drolet et al., 2005). Exploring these feelings and how they impact return to work is called for.

In this study, only female participants discussed how having children was a motivating factor to go back to work, mainly because of the need to provide for them. Although this may also be true for men, it was not mentioned by participants. In contrast, a randomized trial found that there was no significant association between having children, less than 18 years of age, and returning to work in breast cancer survivors (Johnsson et al., 2007). More research is needed to understand the role of family and children in influencing decisions regarding return to work.
Greater knowledge on how personal factors influence return to work can help develop a better understanding of how to meet the holistic needs of cancer survivors and how these factors and perspectives act as influencers to return to work.

It was also expressed by study participants that they need help determining workplace accommodations and dealing with the dilemma of disclosure. The need for workplace accommodations to address unique needs and symptoms was given importance in this study. Participants who did not receive accommodations in the workplace had a more difficult time trying to stay at work. Correspondingly, a cross-sectional study on cancer survivorship and work concluded that workplace adjustments can improve cancer survivors’ ability to navigate the world of work (Pryce et al., 2007). Study participants explained how they were able to manage their cancer-related symptoms at work by requesting specific accommodations. For example, some participants benefited from scheduling breaks to alleviate symptoms, and others had more particular needs like a fan for hot flashes or a humidifier for a dry mouth. In fact, the most common request was for a gradual return or reduced hours to deal with the prevalence of cancer-related fatigue. This result is seen in other studies where the majority of survivors also requested less working hours in order to manage their symptoms (Taskila et al., 2011). Being provided these accommodations to reduce the impact of symptoms when returning to work positively impacted participants’ journeys. Likewise, it has been previously shown that accommodations to reduce working hours and limit physically demanding tasks supports cancer survivors to accomplish their work-related goals (Pryce et al., 2007; Taskila & Lindbohm, 2007). It is important that cancer survivors are able to request these accommodations, because without them symptoms such as fatigue and depression can get significantly worse (Duijts et al., 2014; Taskila et al., 2011). Therefore, this current study recommends that appropriate measures are taken to ensure cancer
survivors are provided an accommodating work environment that meets their unique needs. These accommodations could be achieved by helping cancer survivors recognize the adjustments they need and educating the workplace on how to supply them.

The process of deciding whether or not to disclose their illness in order to receive accommodations to facilitate return to work was a challenge many study participants had to deal with first and expressed needing help with. This dilemma existed because of the potential stigma that may result from disclosing their diagnosis in the workplace. Specifically, participants wanted to be viewed as “normal”, since they were scared their symptoms, especially invisible ones like fatigue, would not be believed and that disclosure would prevent job promotions. This result is supported by a systematic review and meta-synthesis of qualitative studies that concluded cancer survivors may be hesitant to disclose their illness so as to protect their job and pre-cancer identity (Wells et al., 2013). Similarly, cancer survivors in a qualitative study by Stergiou-Kita and colleagues (2016) reported being concerned about how seeking accommodations could be a problem, and could make them appear different from others, including their own pre-cancer self. Another qualitative study on breast cancer survivors returning to work also found that although participants required work adjustments, they were worried about being labeled as a cancer patient (Kennedy et al., 2007). These feelings of shame and inadequacy associated with cancer-related stigma influenced survivors to downplay their symptoms and not request accommodations in order to seem more capable at their job (Grunfeld, Drudge-Coates, Rixon, Eaton, & Cooper, 2013). Further, disclosing cancer can make survivors and co-workers feel uncomfortable, as cancer is still a difficult topic to discuss at work (Tamminga et al., 2012). In general, there were participants in this study who both did and did not decide to disclose their diagnosis. This decision depended on the individual’s personality, values, and comfort at work. Previous studies have shown similar
results (Kennedy et al., 2007), while others have had all participants disclose their illness despite the barriers present (Tamminga et al., 2012). Reaching informed decisions about disclosure is important for return to work and can affect the provision of accommodations and ultimate work success (Stergiou-Kita, Pritlove, & Kirsh, 2016; Stergiou-Kita et al., 2017).

To meet this need, it is recommended that: education should be provided to the workplace on addressing misperceptions regarding cancer and work ability, to enhance awareness of stigma in order to reduce its impact and to create a more comfortable work environment; and advocacy efforts at work should be encouraged to empower cancer survivors with the information they need to fulfill their employee rights to accommodations (Stergiou-Kita et al., 2017). These measures are important as a literature review on employers’ attitude towards people with disabilities found that, although employers reported positive attitudes towards these individuals, their hiring decisions, worker performance reviews, and provision of accommodations were negatively impacted (Burke et al., 2013). Engaging cancer survivors in the development of policies to protect their rights is beneficial to enhance understanding of their needs when requesting accommodations (Stergiou-Kita, Pritlove, & Kirsh, 2016). For cancer survivors who choose not to reveal their cancer diagnosis, there should be an accessible option for them to receive symptom-related accommodations without the need to provide unnecessary personal information.

Another key finding is the need for professional assistance navigating the system, and streamlining access to resources, as well as ensuring effective communication across different sectors. Many participants struggled with this navigation. According to them, there were too many stakeholders and administrative processes that they had to coordinate on their own, which was overwhelming given they were also faced with dealing with their cancer diagnosis. Despite this need for help, many study participants had the difficult task of guiding their return to work
independently. Many studies have also found that cancer survivors are left to navigate and negotiate return to work issues on their own, mainly due to a lack of resources to assist them with the process and a void of informed guidance (Morrison & Thomas, 2014; Nitkin et al., 2011; Wells et al., 2013). It has been suggested that this navigational help could include assistance with knowing when to return to work and at what pace (Morrison & Thomas, 2014). Cancer survivors in other studies have also expressed that they require assistance navigating back to work – specifically to better understand how their health issues, workplace supports, and accommodations can help manage their transition (Munir, Kalawsky, Wallis, & Donaldson-Feilder, 2013; Tiedtke, Donceel, et al., 2012; Tiedtke, de Rijk, Donceel, Christiaens, & de Casterlé, 2012). In particular, this study and others suggest the increased use of occupational or vocational therapists to take on this navigational role, with an added focus on accessing resources and facilitating communication, as described below, since they are well positioned to address these gaps and understand individual survivors’ needs (Morrison & Thomas, 2014).

Professional guidance can address the need for more targeted and accessible return to work resources. Participants discussed the need for resources that meet their unique desires returning to work and called for increased accessibility when seeking these resources. Since all cancer patients will require some kind of resources, it is important to meet these varied, unique needs and realize that some individuals will need more input and specialized services than others (Fitch, 2000). A photovoice study by Morrison and Thomas (2014) suggests that individualized resources need to be targeted to ensure success. Conversely, despite this call for personalized resources, an Australian qualitative study pointed out that targeted care plans are untested and can be difficult and expensive to implement (Jefford et al., 2008) and suggest the use of more generic resources for common issues. However, this current study found a need for resources to be delivered to meet
individual needs. For instance, having children was a personal factor specific to female participants that impacted the resources they needed. A doctoral thesis by Rothberg (2014) on the journey of female cancer survivors supported that nannies are a valuable personalized resource for facilitating balance when returning to work. A comprehensive, accessible and individualized approach using professional guidance can reduce the current difficulties that cancer survivors have with a lack of available, specialized resources going back to work.

Study participants explained how there is also a need for more information on return to work resources, as it was difficult for them to find certain resources, such as information on their rights as employees returning to work. An Australian qualitative study also found that survivors needed more information on where to access resources (Jefford et al., 2008). This finding is further supported by a European qualitative study where participants said that limited resources on the impacts of cancer and treatment on work ability were an obstacle to return to work (Bains, Yarker, Amir, Wynn, & Munir, 2012). There is a need for more informative resources to educate and empower cancer survivors to return to work (Lydon & Hughes, 2012). Study participants suggested some solutions to this issue, such as widespread dissemination of a comprehensive checklist of targeted resources that would cover all aspects of the transition into the workforce, from diagnosis to return to work. Moreover, these resources should be multidisciplinary, consisting of psychological, physical, vocational, occupational and legislative interventions to facilitate a complete and successful return to work (de Boer, Frings-Dresen, & Feuerstein, 2016). These holistic resources are starting to become available for Canadian cancer survivors, and they even provide information on legal issues which participants identified to be lacking (Cancer and Work Team, 2018a). Although some studies have found that it is critical to provide information specifically post-treatment (Jefford et al., 2008), study participants wished resources would be
provided throughout the entire cancer journey and as early as possible upon cancer diagnosis. The use of professional guidance after diagnosis plays a significant role here to facilitate the return to work process. They can help with accessing resources and with providing more information using a comprehensive list on resources to meet unique needs. This delivery can ensure timely access to resources that can improve return to work outcomes.

In this study, there were a number of participants who were healthcare practitioners, and their return to work was facilitated by prior knowledge and experience navigating health and work systems for patients. Others studies have not reported these individuals in their sample or did not specifically analyze this difference (Kennedy et al., 2007; Stergiou-Kita, Pritlove, Holness, et al., 2016). This finding illuminates how improving information on return to work resources and knowledge of the return to work system may enable returning to work successfully. Knowing more about what specific information gives these individuals with prior experiences an advantage, may lead to incorporating that information into the professional guidance cancer survivors should receive to navigate the system and return to work.

An additional need discussed by participants, which can also be addressed through professional guidance, is for increased intercommunication amongst system stakeholders and themselves. For cancer survivors, clearly communicating their needs to stakeholders is vital to support successful return to work (Munir et al., 2013). These stakeholders, as identified by study participants, include co-workers, employers, insurance providers, and healthcare providers. For example, some participants felt that communicating openly with their coworkers and managers eased their transition back into work. Effective communication with employers and colleagues helped with guiding the return to work process and successfully reintegrating back into work after cancer (Wells et al., 2013; Yarker, Munir, Bains, Kalawsky, & Haslam, 2010). For some, the
communication process was not so simple since their managers were unresponsive. Likewise, a qualitative study on the role of communication in return to work for cancer survivors found that almost half of their participants did not have any contact with their managers while they were away (Yarker et al., 2010). This absence left them feeling let down and concerned about the support they would receive upon their return. This uncertainty is anxiety-provoking and difficult to experience and was shared by the participants in this study. This finding substantiates the recommendation that stakeholders in the workplace should be educated on how to improve communication with cancer survivors to better understand their needs and enable a successful return to work.

Many participants in this study were required to only communicate with their insurance providers, and not with their employers. This restriction frustrated them, and they speculated that it was imposed by their companies since their employers either did not know how to communicate effectively with them, or they were worried about the potential legal consequences of doing so. Interestingly, this finding seems to be unique as other studies have only mentioned the importance of communication from both employers and insurance and did not discuss these issues (Tiedtke, de Rijk, et al., 2012). This current study suggests the need to conduct more research on this forced communication with insurance companies, specifically in a Canadian context, to better understand the feelings of confusion and frustration that cancer survivors face when they are not allowed to communicate to the extent that they want to. It is important to consider how these restrictions in the system can impact their need for increased communication, and the guidance of professionals, such as occupational or vocational therapists may be effective as a liaison to achieve successful return to work.

Participants also discussed how a lack of communication between stakeholders significantly reduced their ability to navigate the return to work process. This point further
substantiates the call for coordination and assistance from professional services with navigating communication when returning to work. For instance, one participant felt that her journey was hindered by a lack of effective interdisciplinary communication within the system, specifically amongst healthcare professionals. The absence of communication between professionals has been identified as a problem for cancer survivors returning to work, due to the professionals’ own uncertainty (Bains et al., 2012; Stergiou-Kita, Pritlove, Holness, et al., 2016). Much research shows that improving communication between stakeholders can fill an important gap and support successful return to work (Larsson & Gard, 2003; Stergiou-Kita, Pritlove, Holness, et al., 2016; Yarker et al., 2010). Generally, participants in this study expressed that being a part of this intercommunication helped keep everyone on board with their return to work progress, and even helped survivors communicate more confidently. A qualitative study on work readiness confirms this result, suggesting that direct intercommunication provides stakeholders with the most up to date knowledge regarding specific job details and supports (Stergiou-Kita, Pritlove, Holness, et al., 2016). The authors suggest that this understanding facilitates a successful transition back to work for cancer survivors. Therefore, in accordance with what is suggested by Tiedtke and colleagues (2009), in order to reduce concerns regarding return to work and to improve the process, employers, healthcare and insurance providers should increase and improve the consistency of communication between themselves and with cancer survivors. This communication should be framed in a way that is in agreement with the individual’s specific work context for optimal results (Stergiou-Kita, Pritlove, Holness, et al., 2016). This current study upholds these recommendations, and suggests that overall, in order to meet cancer survivors’ needs when navigating back to work, the implementation of above-mentioned professional services could be most effective. This suggestion is significant because this professional assistance can help provide a streamlined and
targeted navigational approach to accessing resources and effective intercommunication – both of which are needs that participants identified they require when managing their return to work.

Participants in this study called on the various influential stakeholders in their lives to provide the support they needed: healthcare providers, workplace personnel, insurance companies, and family and friends. Additionally, peer support from individuals with a first-hand experience of cancer was reported to be particularly helpful across all of these environments, especially at community-based centres. This point will be discussed at the end of the discussion on these findings.

Study participants discussed how they found receiving advice on returning to work specifically from health care practitioners to be beneficial. This finding is related to the previous recommendation for professional guidance, particularly from occupational or vocational therapists, to ease navigation and support successful return to work. This advice on return to work builds on the navigational help with accessing resources and facilitating communication provided by these professionals to also provide individualized help to cancer survivors putting together a plan to return to work. For instance, the Cancer and Work Team (2018b) suggests that other members on a medical team such as family doctors and psychiatrists can assess, treat, and address specific issues and mental health challenges regarding patients’ ability to work. A qualitative study on return to work after cancer also found that participants were positively impacted by obtaining personalized work advice, and wanted to receive even more (Kennedy et al., 2007). Healthcare providers need to respect a survivor’s perspective and specific job-related abilities in order to better evaluate work readiness and improve work outcomes (Stergiou-Kita, Pritlove, Holness, et al., 2016). Otherwise, general recommendations to return after treatment and having to make decisions independently may end up negatively impacting cancer survivors and their return to work.
(Kennedy et al., 2007; Stergiou-Kita, Pritlove, Holness, et al., 2016). To achieve these specific needs, participants in this current study suggest that healthcare providers educate themselves and set aside enough time to have meaningful, ongoing conversations with survivors. A systematic review by Wells and colleagues (2013) also encourages these conversations as they shed a light on survivors’ values of work and their work-related demands. Thus, this strategy can help leverage the role of support from healthcare providers to improve the return to work process and is recommended. Unfortunately, there were several participants who were denied or not provided this advice and were left feeling unprepared to return to work. They also felt that their desire to return to work was not being acknowledged appropriately. The existing literature suggests that a reason for this widespread gap is that healthcare providers are not equipped with the knowledge to handle individualized work-related issues (Bains et al., 2012; Kennedy et al., 2007; Main et al., 2005; Maunsell et al., 1999). Therefore, this current study suggests that it is critically important to train healthcare providers treating cancer survivors with the information they need to be equipped to provide specific work-related advice, such as when to return and what treatments to seek, or at least appropriately direct cancer survivors to established professional services that can fulfill this need. Again, this includes engaging in conversations with cancer survivors to better understand and meet specific needs.

In general, throughout this chapter, there is evidence on how a supportive work environment facilitated participants’ ability to return to work. In light of this finding, it is important to ensure ongoing, emotional support and understanding from employers and co-workers to cancer survivors in the workplace. This finding is affirmed by several studies that also concluded support in the workplace is a key factor for cancer survivors to return to work and stay at work (Islam et al., 2014; Kearney Mahar, Brintzenhofeszoc, & Shields, 2008; Mackenzie, 2014; Wells et al.,
Study participants acknowledged that feeling understood and accepted at work eased their transition. This appreciation for their needs and limitations helped with distributing duties, feeling more comfortable at work, and receiving aforementioned accommodations like enough time off work. Similarly, a qualitative study on breast cancer survivors returning to work reported that survivors had a difficult time explaining their needs and asking for help at work if their limitations were not accepted by colleagues (Tamminga et al., 2012). This acceptance is an essential part of establishing a supportive work environment and should be encouraged. Further, study participants expressed that emotional support at work, such as ongoing check-ins and displaying empathy, was particularly helpful for easing them back into a comfortable and encouraging work environment. This finding is significant since emotional support at work can improve well-being and the overall return to work experience (Bloom, Stewart, Johnston, Banks, & Fobair, 2001; Nachreiner et al., 2007; Taskila et al., 2006). It is suggested that emotional support should be offered ongoingly to adapt to cancer survivors’ changing needs at work (Underwood et al., 2015).

In this study, the majority of work support came from co-workers, with participants having a harder time dealing with the management at work. In fact, for some, there was a significant lack of understanding and acknowledgement of their situation from employers. This neglect was difficult for cancer survivors to deal with as they tried to meet their needs and return to work. This observation is upheld by Taskila and colleagues (2006) who found that cancer survivors received the most work support from their co-workers. The literature also confirms that when employers do not appreciate cancer survivors’ limitations this can lead to unrealistic expectations of survivors and an overestimation of their work abilities, which can further hinder a successful return (Tamminga et al., 2012). Therefore, it is particularly important that employers in the work
environment take the initiative to be well-equipped at welcoming back cancer survivors in an understanding and accepting way.

Participants emphasized that support at work must be ongoing in order to be especially impactful. Many study participants only received support at the beginning of their return and noted that this faded overtime. Not being checked-in on in the workplace made them feel as though their diagnosis and experiences were being ignored. This lack of follow-up at the workplace has been shown to include diminished empathy and support, which can make returning to work difficult for cancer survivors (Yarker et al., 2010). It is recommended that individuals in the workplace should seek to support cancer survivors from the beginning of their journey and well after they have returned to work for optimal employment outcomes. This suggestion even has the potential to benefit employers as well, as cancer survivors will be able to be more productive in a supportive work environment.

To ensure this work support, cancer survivors need help to combat existing workplace discrimination. Study participants felt that they faced discrimination in the workforce, particularly while job hunting. The qualitative study by Mak and colleagues (2014) also confirmed the presence of hiring discrimination related to a history of cancer. These results are significant as experiencing workplace discrimination, including hiring discrimination can negatively impact employment opportunities for cancer survivors (Stergiou-Kita et al., 2017). The provision of interactive educational tools and mandatory workshops on anti-discrimination to employers and stakeholders within the workplace are recommended, in addition to educating cancer survivors to prepare to deal with negative attitudes they may confront when returning to work. Not only do cancer survivors need support in the workplace to facilitate a successful return to work, but there needs to be a reduction in the discrimination survivors face in order for them to be more comfortable.
Therefore, antidiscrimination policies to recognize and reduce discrimination should be put into place. This suggestion includes having employers and cancer survivors become familiar with relevant anti-discrimination legislation (Stergiou-Kita, Pritlove, & Kirsh, 2016; Stergiou-Kita et al., 2017).

Study participants discussed how a lot of the same aspects of a supportive work environment, like ongoing check-ins, encouragement, and understanding, were also helpful when received from insurance companies. These strategies allowed participants to better negotiate time off work and to make appropriate arrangements for a gradual return to meet their needs. Despite the aforementioned gap in research on Canadian cancer survivors interacting with insurance companies, there is evidence that support from insurance companies can be very helpful (Tiedtke et al., 2009). Therefore, when study participants did not have positive interactions with insurance companies, their return to work suffered. Some participants discussed how their needs were not understood, leading to discrimination and pressure to return to work before they were ready. For example, they felt that their invisible disabilities, such as cancer-related fatigue, were not believed. They also felt that insurance companies should be rehabilitating them for their specific job, and that the companies cared more about money than understanding their needs. There is limited literature pertaining to the role of insurance in a Canadian context, where universal healthcare and insurance is independent of employment status, for instance (Maunsell et al., 2004). However, a Canadian study by Stewart and colleagues (2001) does provide some insight into the role of breast cancer survivors interacting with insurance when returning to work. The authors found that 20% of their sample identified insurance problems, and that issues with disclosure and discrimination impacted these difficulties, similar to the experiences of survivors in this study (D. E. Stewart et al., 2001). These findings substantiate the need for further research into the support insurance
companies offer to Canadian cancer survivors when returning to work. Nonetheless, it is clear from this study that cancer survivors need this support to be targeted and respectful of their experiences and circumstances to facilitate return to work. This study recommends that insurance companies improve their interactions with cancer survivors by taking the time to clearly understand their individual needs and desires, and how to assist and support them going back to work. This proposal goes beyond the current main discussion points on length of sick leave (Maunsell et al., 1999b) to include a more holistic appreciation of survivors’ unique circumstances.

Cancer survivors also need support from family and friends to improve their wellbeing and support them to feel ready to return to work. This source of support includes ongoing, emotional supports and an understanding of cancer survivors’ circumstances. Interestingly, this support also impacts family life. Participants benefited from the emotional support that their family and friends provided. Some even suggested that they would have appreciated more support from these individuals, despite acknowledging that this might be difficult on them. Previous research affirms these sentiments, reporting that family and friends are a main source of support for cancer survivors, and that survivors often worry about the consequences this may have on loved ones (Main et al., 2005; Taskila et al., 2006). Further, participants stated that although this support is not work-specific, it is particularly helpful for improving their health and encouraging them to go back to work. Other studies confirm that family and friends are more likely to offer emotional support than practical support on work, and that many encouraged survivors to return to work (Dakof & Taylor, 1990; Main et al., 2005; Tiedtke et al., 2009). When being encouraged to return to work, participants explained how being appreciated and treated normally helped family and friends understand their limitations. While this support further enhanced their ability to feel confident and capable going back to work, for some participants, it was lacking. Without this
understanding of their new identities and abilities, it was difficult for cancer survivors to feel like their family and friends provided them with a supportive environment that encouraged returning to work. These consequences, as described in this study and in the literature, include being pressured to go back to normal and to meet unrealistic expectations at home by taking on their previous roles (Jefford et al., 2008). Therefore, this emotional support from family and friends is needed by cancer survivors when returning to work to improve their wellbeing and thus their ability to go back to work. In particular, it is recommended that a better understanding of cancer survivors’ limitations is developed through the encouragement of open and supportive conversations. This suggestion can lead to more successful and holistic return to work outcomes for survivors as they would also be receiving support outside of the workplace.

Interestingly, some participants noted that family members were more likely to maintain ongoing support than friends. However, the literature actually suggests that both family and friends provided less support after treatment was completed because they assumed that it was no longer needed (Jefford et al., 2008). Clearly, family and friends must be knowledgeable on the importance of support to meet their loved ones’ needs even after treatment. This ongoing support could be achieved by having cancer survivors themselves or healthcare providers inform family and friends that the effects of cancer are long-term and do not necessarily end when treatment is finished. Supporting cancer survivors in this ongoing way can help to ease them into a successful transition back to work especially if they decide to return after completing their treatment.

Family support plays a unique role for cancer survivors with regards to their day to day lives outside of work as well as inside. Many female participants discussed how important it was for their partners to take on new roles around the home that they were usually responsible for. This shift allowed them the opportunity to improve their health and their ability to return to work. It
was especially important for participants with children to swap duties as it was difficult for them to maintain the desired normalcy for their children and to focus on work-related needs at the same time. However, sometimes these roles were switched back after survivors were able to take them on, or in some cases survivors decided to keep these responsibilities throughout their journey to maintain their own sense of normality. Similarly, studies also confirm that role functioning is commonly altered between family members of cancer survivors as a form of support (Jefford et al., 2008; Short et al., 2005). These experiences can be explained by the concept of ‘gendered care work’ which illustrates how women take on more of the burden of unpaid work within the family and home (Craig & Powell, 2011). Furthermore, one of the male participants in this study also noticed how his gender role impacted the support he needed at home. He was struggling with the pressure of trying to remain the breadwinner for the family, but also being required to temporarily step down from that role along his journey. This need for males to be the provider is cultural and widespread. In fact, a qualitative study on masculinity and prostate cancer survivors found that a primary concern for participants was how they would be able to provide financially for their families (Chapple & Ziebland, 2002). Therefore, it is important for family members to understand how they can facilitate the ability of cancer survivors to return to work while appreciating their needs and these gender roles. The implications of this are that cancer survivors will be more prepared to return to work successfully if they are able to receive this targeted support at home.

Local community-based centers for cancer survivors were also a valued support for study participants because it met their need for targeted peer support. This social and emotional support has previously been found to be essential for healing and overcoming the negative psychological effects of the cancer journey (English, Wilson, & Keller-Olaman, 2008). Thus, these centres have the potential to support cancer survivors in a unique way, as many participants also passionately
discussed how the variety of cancer-targeted programs available, such as exercise classes, and symptom management and return to work seminars, improved their wellbeing and their ability to return to work. For instance, study participants found the wide variety of community-based resources specific to cancer survivors to be very helpful meeting their needs. A qualitative study on work readiness found the same community-based centres to be an excellent resource in facilitating the acquisition of work-related information (Stergiou-Kita, Pritlove, Holness, et al., 2016). These community-based centres should be actively advertised to cancer survivors along their journey in the healthcare system to make sure they can benefit from this support in a timely manner. This advertising could be achieved through the comprehensive checklist of targeted resources for cancer survivors returning to work that was discussed earlier.

Individuals with lived experience of cancer were described to be especially skilled at providing the support that cancer survivors need throughout these community-based centres and other sources discussed below. Exposure to peers with a shared lived experience of cancer can help to improve health outcomes and facilitate successful return to work. Peer support groups have been shown to provide a significant benefit to cancer survivors, particularly because of this mutual support (Cella, Sarafian, Snider, Yellen, & Winicour, 1993). In fact, interacting with individuals who have been through a similar experience can reduce the negative impacts of cancer (Campbell, Phaneuf, & Deane, 2004). Peer support can be provided through community-based centres, through family and friends who have experienced cancer, and also in other environments such as the workplace. Some participants pointed out that emotional support was best when received from individuals at work who had lived experience of cancer themselves. In this way, participants felt that their situations were truly understood and appreciated. The benefit of receiving emotional support from someone who has first-hand experience of the disease has been well documented. A
systematic review of peer-support for people with cancer found that survivors have a high level of satisfaction when receiving help from their peers, and the most effective way to offer peer support is through one-on-one face-to-face and group internet programs (Hoey, Ieropoli, White, & Jefford, 2008). The implementation of these supports might be difficult, especially in the workforce for smaller companies. Nonetheless, healthcare providers and community supports should advocate for the accessibility of peer support for cancer survivors in any way possible. Therefore, in order to improve the ability of cancer survivors to return to work, this kind of support from peers is suggested to be put into place, not just in the community, but also in the workplace and beyond.

**Study Limitations**

There are some limitations to this study that should be addressed. Firstly, the study sample had more female (n=13) than male (n=2) participants. This distribution made it more difficult to thoroughly compare and contrast sex and gender differences when returning to work, as per the second study objective. Despite this limitation, participants still offered valuable insight into how differences like gender roles, hair loss, and having children impacted the return to work journey. Further, this study only had four participants in each focus group due to scheduling issues, instead of the suggested 6-8 (Carlsen et al., 2011). This limitation may have impacted results as fewer perspectives were present at the focus group and maybe not all needs were thoroughly elucidated. Despite this potential limitation the discussion and associated results proved to be in-depth and meaningful.

Another limitation to consider is that the study sample was objectively well-off socio-economically (Table 1). They were generally well educated with at least a bachelor’s degree and almost all had a household income above Canadian low-income cut-offs (Statistics Canada, 2018).
A majority of participants were also either married or living with family members, which could have improved their access to support networks. These characteristics are important to keep in mind since it is possible that these factors could have had a disproportionately positive impact on their ability to go back to work.

Also, as mentioned, there was an educational component that was included in the focus group as a resource and an incentive to recruit participants. This component was a short presentation organized and led by an occupational therapist on the study team and discussed information on legislation relevant to returning to work, how to prepare to return to work, and where to get more information and support. Although the educational component did not contribute to this study, it is possible that some participants who attended a focus group and received this information before their interview had their answers influenced by these resources and social desirability bias. Nonetheless, these differences across participants were not apparent, and the data collected likely represents the views of the participants regardless of the educational component.

**Future Research Directions**

There are several possible future research directions to consider. First, it is important to continue exploring sex and gender differences in returning to work so as to improve the development of individualized work strategies (Stergiou-Kita et al., 2014). Although this study makes an important contribution to this body of literature, insight from a future study focused on this topic and with a more equal distribution of female and male participants is warranted. Further, given the relatively high socio-economic status of study participants, learning more about how this factor can impact return to work, especially in a Canadian context, is called for.
In this study, there was a wide range of ages from about 25 to 64, and a wide range in time off work from around 2 weeks to 6 years. This observation raises the question of whether there is a relationship between these factors when returning to work in Canada. A possible qualitative research question is, what are Canadian cancer survivors’ perspectives on how personal factors like age or time off work impacted their ability to return to work successfully? It is recommended that future studies attempt to narrow in on these personal factors to better understand how these can impact the needs of cancer survivors returning to work. Another finding discussed above was that systemic issues interacting with insurance companies seemed to be unique to participants in this study compared to the literature. Thus, an exploration of how insurance companies deal with cancer survivors in a Canadian-specific context can shed a light on how to improve these barriers when returning to work. These systemic factors could be explored by studying the perspectives of cancer survivors and insurance personnel.

Finally, although this study begins to fill the gap on comprehending the experiences of diverse Canadian cancer survivors (Stergiou-Kita et al., 2014), it should be noted that this study and its participants are located within one Canadian city. In order to truly appreciate the perspectives of Canadian cancer survivors, it will be important to branch out on both a provincial and national level.

**Conclusion**

This study sought to broadly explore the needs of cancer survivors returning to work, in order to better understand their perspectives on supports and how personal and employment factors can impact these needs. This exploration enhances existing literature as it contributes to filling gaps by exploring perspectives in diverse Canadian cancer survivors before and after returning to work.
work, the impact of accommodations and ongoing supports, and begins to uncover sex and gender differences (Mehnert, 2011; Stergiou-Kita et al., 2014). These sex and gender differences were integrated throughout the discussion and included how gender roles, changing perspectives on identity due to hair loss, and having children influenced cancer survivors’ ability to return to work. The key themes identified in this investigation were: changing perspectives on self and work; managing work and social systems; determining disclosure and accommodation; and the importance of supports for return to work and daily life. To reiterate, the main findings in these themes and subthemes were that cancer survivors may need: time and opportunity to come to terms with changing work capacity, work identity and centrality of work; help dealing with the dilemma of disclosure and determining workplace accommodations; professional assistance navigating the system to streamline access to resources and ensure effective communication across different sectors; and ongoing, targeted support from many different stakeholders to meet their unique needs with a focus on peer-support. These elaborated on how negative self-perceptions, systemic barriers, and a lack of accommodations and intercommunication can negatively impact cancer survivors when going back to work. In order to further improve the return to work experience for cancer survivors, it is recommended that more holistic, comprehensive services are put into place, and that existing ones are made more accessible, to ease their navigation throughout the system. This recommendation includes educating and training stakeholders to better support cancer survivors returning to work, and to make supports, resources, and accommodations more accessible to cancer survivors. Overall, this study informs Canadian cancer rehabilitation research by developing an understanding of the supports and strategies that should be implemented to help cancer survivors return to work successfully and improve their overall quality of life.
References


https://doi.org/10.1016/j.pec.2003.10.001


notion of saturated sample sizes in qualitative research. *Qualitative Research, 13*(2), 190–197. https://doi.org/10.1177/1468794112446106


Rasmussen, D. M., & Elverdam, B. (2008). The meaning of work and working life after cancer:


StatisticsCanada. (2018). Table 206-0094 - Low income cut-offs (LICOs) before and after tax by community and family size in current dollars. Retrieved from


https://doi.org/10.1177/0008417417701229


https://doi.org/10.1007/s10926-011-9312-6


https://doi.org/10.4278/0890-1171-10.4.282


https://doi.org/10.5271/sjweh.3199


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<th>Gender</th>
<th>Highest Level of Education</th>
<th>Marital Status</th>
<th>Household Income</th>
<th>Date of Cancer Diagnosis</th>
<th>Type of Cancer(s)</th>
<th>Stage of Cancer at Diagnosis</th>
<th>Type of Treatment(s)</th>
<th>Still receiving treatment?</th>
<th>Still experiencing symptoms?</th>
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<td>45-54</td>
<td>Female</td>
<td>Degree above Bachelor’s Degree</td>
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<td>$150,000-199,999</td>
<td>Nov 2013</td>
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<td>Chemotherapy</td>
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<td>Female</td>
<td>Bachelor’s Degree</td>
<td>Married</td>
<td>$200,000 or more</td>
<td>Mar 2016</td>
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<td>IV</td>
<td>C, Radiation</td>
<td>N</td>
<td>N</td>
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<td>Y</td>
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<td>Apr 2014</td>
<td>Ovarian</td>
<td>III</td>
<td>C, S</td>
<td>Y</td>
<td>Y</td>
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<td>Thyroid</td>
<td>I</td>
<td>R, S</td>
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<td>N</td>
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<td>Female</td>
<td>Bachelor’s Degree</td>
<td>Married</td>
<td>$150,000-199,999</td>
<td>Apr 2016</td>
<td>Head and Neck</td>
<td>II</td>
<td>R, S</td>
<td>N</td>
<td>Y</td>
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<td>7</td>
<td>55-64</td>
<td>Male</td>
<td>Bachelor’s Degree</td>
<td>Living common-law</td>
<td>Rather not say/not sure</td>
<td>Jan 2016</td>
<td>Leukemia</td>
<td>Not sure</td>
<td>C, R, Medication, S</td>
<td>N</td>
<td>N</td>
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<td>8</td>
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<td>Bachelor’s Degree</td>
<td>Married</td>
<td>$75,000-99,999</td>
<td>Dec 2015</td>
<td>Multiple Myeloma/Bone Marrow</td>
<td>II</td>
<td>Other: Complementary Alternative</td>
<td>Y</td>
<td>Y</td>
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<tr>
<td>9</td>
<td>25-34</td>
<td>Female</td>
<td>Degree above Bachelor’s Degree</td>
<td>Single/Never Married</td>
<td>$50,000-74,999</td>
<td>Aug 2016</td>
<td>Ovarian</td>
<td>III</td>
<td>C, M, S</td>
<td>Y</td>
<td>Y</td>
</tr>
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<td>10</td>
<td>35-44</td>
<td>Male</td>
<td>Bachelor’s Degree</td>
<td>Married</td>
<td>$100,000-149,999</td>
<td>Oct 2014</td>
<td>Leukemia</td>
<td>Not sure</td>
<td>C, R, M</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>11</td>
<td>45-54</td>
<td>Female</td>
<td>Degree above Bachelor’s Degree</td>
<td>Married</td>
<td>$100,000-149,999</td>
<td>Feb 2016</td>
<td>Head and Neck</td>
<td>II</td>
<td>R, S</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>12</td>
<td>45-54</td>
<td>Female</td>
<td>Degree above Bachelor’s Degree</td>
<td>Married</td>
<td>$75,000-99,999</td>
<td>Nov 2010</td>
<td>Breast</td>
<td>II</td>
<td>C, R, M, S</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>13</td>
<td>45-54</td>
<td>Female</td>
<td>Completed High School</td>
<td>Single/Never Married</td>
<td>Rather not say/not sure</td>
<td>Mar 2016</td>
<td>Uterine and Ovarian</td>
<td>I</td>
<td>C, R, S</td>
<td>N</td>
<td>Y</td>
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<tr>
<td>14</td>
<td>35-44</td>
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<td>Bachelor’s Degree</td>
<td>Married</td>
<td>$150,000-199,999</td>
<td>Aug 2016</td>
<td>Breast</td>
<td>II</td>
<td>C, R, S</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>15</td>
<td>45-54</td>
<td>Female</td>
<td>Bachelor’s Degree</td>
<td>Single/Never Married</td>
<td>Rather not say/not sure</td>
<td>Sep 2013</td>
<td>Breast</td>
<td>II</td>
<td>C, R, M</td>
<td>Y</td>
<td>Y</td>
</tr>
</tbody>
</table>
Table 2: Participant Employment Information

<table>
<thead>
<tr>
<th>ID #</th>
<th>Job Description</th>
<th>Time off Work*</th>
<th>Returned to work?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Quality Assurance Analyst</td>
<td>5 months</td>
<td>Yes</td>
</tr>
<tr>
<td>2</td>
<td>Human Resources</td>
<td>2.5 years</td>
<td>No</td>
</tr>
<tr>
<td>3</td>
<td>Senior Manager for Non-Profit</td>
<td>1 year</td>
<td>No</td>
</tr>
<tr>
<td>4</td>
<td>Personal Support Worker</td>
<td>6 months</td>
<td>No</td>
</tr>
<tr>
<td>5</td>
<td>Medical Resident</td>
<td>2 weeks</td>
<td>Yes</td>
</tr>
<tr>
<td>6</td>
<td>Nurse</td>
<td>9 months</td>
<td>Yes</td>
</tr>
<tr>
<td>7</td>
<td>Retired (looking for new part-time job)</td>
<td>2 years</td>
<td>No</td>
</tr>
<tr>
<td>8</td>
<td>Nurse</td>
<td>9 months</td>
<td>Yes</td>
</tr>
<tr>
<td>9</td>
<td>Physiotherapist</td>
<td>5 months</td>
<td>Yes</td>
</tr>
<tr>
<td>10</td>
<td>Quality Assurance Analyst</td>
<td>3 years</td>
<td>No</td>
</tr>
<tr>
<td>11</td>
<td>Associate Director of Lab Quality Control</td>
<td>1.5 years</td>
<td>No</td>
</tr>
<tr>
<td>12</td>
<td>Physiotherapist</td>
<td>6 years</td>
<td>No</td>
</tr>
<tr>
<td>13</td>
<td>Clerical Worker at a Bank</td>
<td>1.5 years</td>
<td>No</td>
</tr>
<tr>
<td>14</td>
<td>Human Resources</td>
<td>1 year</td>
<td>No</td>
</tr>
<tr>
<td>15</td>
<td>Project Manager for Government</td>
<td>4 years</td>
<td>No</td>
</tr>
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</table>

*Time off work* refers to the initial time taken off, and does not necessarily include any days off (i.e. sick days, for appointments, etc.) once the participant returned to work.
<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
<th>Brief Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changing Perspectives of Self and Work</td>
<td>Perceptions and Meanings of Work</td>
<td>Outlook changes and the importance of work to cancer survivors</td>
</tr>
<tr>
<td></td>
<td>Personal Motivators to RTW</td>
<td>How personal factors, such as desires, personality, age, and family or financial situations can motivate return to work</td>
</tr>
<tr>
<td></td>
<td>Reflecting on RTW: Feeling Ready</td>
<td>Feelings of readiness, defining successful RTW, psychosocial symptoms (e.g. anxiety) impacting RTW</td>
</tr>
<tr>
<td></td>
<td>Stigma Influencing Self-Perception</td>
<td>Feeling like a burden, and how stigma influences self-esteem</td>
</tr>
<tr>
<td>Managing Work and Social Systems</td>
<td>Quality and Accessibility of Resources</td>
<td>Types of resources required and/or provided to meet unique needs (SES, sex/gender); gaps in resources</td>
</tr>
<tr>
<td></td>
<td>Navigating the Systems</td>
<td>Navigating the RTW process, experiences and barriers, the need for professional help with navigation</td>
</tr>
<tr>
<td></td>
<td>Communication within the System</td>
<td>Experience with communicating amongst stakeholders trying to RTW</td>
</tr>
<tr>
<td>Determining Disclosure and Accommodation</td>
<td>Requesting Symptom-related Accommodations</td>
<td>How symptoms impact accommodations at work and the stigma associating with disclosing to receive these</td>
</tr>
<tr>
<td>Importance of Supports for RTW and Daily Life</td>
<td>Supportive Work Environment</td>
<td>Presence or absence of ongoing, emotional support and understanding from employers and coworkers</td>
</tr>
<tr>
<td></td>
<td>Interacting with Insurance Companies</td>
<td>Support or lack of from insurance companies</td>
</tr>
<tr>
<td></td>
<td>Family and Friend Support</td>
<td>Emotional support, role of family and social life, and help within the home</td>
</tr>
<tr>
<td></td>
<td>Experience with Healthcare Providers and Community Supports</td>
<td>Impact of HCPs and related community groups addressing survivors’ RTW needs; understanding and supporting the survivors’ goals</td>
</tr>
</tbody>
</table>
Figure 1: Thematic Analysis – Themes and Sub-themes

*RTW – Return to work; HCP – Healthcare professional
Appendix I – Demographic Information for Return to Work Study

Study ID: _________________________ Date: _________________

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
   - Trans

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 is your current marital status (check one)?
   - Married
   - Living common-law
   - Widowed
   - Separated
   - Divorced
   - Single/never married

5. What is your total household income (check one)?
   - Less than $20,000
   - $20,000-$34,999
   - $35,000-$49,999
   - $50,000-$74,999
   - $75,000-$99,999
   - $100,000-$149,999
   - $150,000-$199,999
   - $200,000 or more
   - Rather not say/Not sure
6. What was the date of your cancer diagnosis? Month _______ Year __________

7. 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) __________________________

8. What stage was your cancer when it was diagnosed (check one)?
   - Stage I
   - Stage II
   - Stage III
   - Stage IV
   - Don’t know/not sure

9. 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)
   - No treatment
   - Other (please specify)

10. Are you still receiving treatment for your cancer diagnosis?
    - Yes
    - No

11. Are you still experiencing any cancer or treatment-related symptoms?
    - Yes
    - No
    If yes, please specify: _____________________________________________________
Contact Information

For more information about the study, or if you are interested in participating, please contact:

Ivona Berger
(University of Toronto Rehabilitation Science Institute MSc Candidate, Graduate Research Student)

tel: 416-XXX-XXXX xXXXX
email: XXXXX@XXXXXX.ca

Please note that communication via e-mail is not absolutely secure. Thus, please do not communicate personal sensitive information via e-mail.
About the Back to Work Study

Many people have problems with returning to work after cancer treatment. These unique challenges can arise due to emotional stress, persistent fatigue, or ongoing cognitive and psychosocial impairments.

This study will explore what the needs of cancer survivors are when returning to or staying in the workforce after treatment.

We will be identifying what processes and accommodations are most relevant to successful return to work and how various factors can affect the need for these supports.

We hope this study will help us develop new and better-targeted supports that are unique for people who are returning to work or staying in the workforce after cancer diagnosis.

You may be interested in participating in this study if you:

- have been treated for cancer
- are an adult, and speak English
- were working for pay when you were diagnosed with cancer
- wish to return to work or have returned to work

If you participate in this study, you will be asked to do one or both of the following:

- Join a focus group of 6-8 cancer survivors to discuss return to work experiences. There will be an educational component at the end of the discussion to provide information on supported return to work. (1.5 hrs)

- Participate in a 1-on-1 interview in which you will be asked about your return to work needs. (1 hr)

All transportation (transit, parking, etc.) costs to get to and from the study location will be reimbursed.

Taking part in the study may make you feel uncomfortable. If you are upset, stressed, or uncomfortable at any time during the interview you can choose to opt out of answering questions, leave the room to take a break, or completely stop at any time. If you need any additional help, we can direct you to a clinician or support service on hand. We will also have some time at the end of the interview to discuss your experiences in participating in the interviews and any questions you may have for us.

You may benefit from this study through the return to work information that will be provided in the focus group session. Through participating in our study, you will be helping with the development of best practices for workplace supports following cancer to ensure successful reintegration.
Appendix III – Contact Consent Form

CANCER SURVIVORS

Study Title: Exploring the needs of cancer survivors when returning to or staying in the workforce

Principal Investigator: Ms. Lydia Beck

Co-Investigators: Dr. Bonnie Kirsh and Ms. Ivona Berger

Contact Information: XXXXXXXXXXX

Name of Sponsors: • XXXXXXXXXXX

CONSENT

I agree to be contacted by the ‘Back to work needs of cancer survivors’ study at the phone number below in order to discuss the study, including scheduling and follow-up regarding my participation in the study’s focus group and interviews, and ask any questions I may have. I know that I may decide not to participate in the study at any time.

Telephone number: ___________________

_______________________
Study Participant’s Name

Signature

Date

You will be given a signed copy of this consent form.

My signature means that I have recommended the participant above to the study or I have provided them with information on the study based on their interest.

_______________________
Person Obtaining Consent

Signature

Date
Appendix IV – Study Poster

Back to Work Needs of Cancer Survivors

This study will explore the needs of cancer survivors when returning to or staying in the workforce after treatment.

You may be interested in participating in this study if you:
1. have been treated for cancer
2. are an adult, and speak English
3. were working for pay when you were diagnosed with cancer
4. wish to return to work or have returned to work

To participate, you would:
1. Join a focus group of 6-8 cancer survivors to discuss return to work experiences. There will be an educational component to provide information on return to work. (1.5 hrs)
2. Be invited to a 1-on-1 follow-up interview. This will provide an opportunity for more in-depth discussions on your return to work needs. (1 hr)

Transportation costs are covered by the study. For more information about the study, or if you are interested in participating, please contact:

Ivona Berger
(University of Toronto Rehabilitation Science Institute MSc Candidate, Graduate Student)
tel: 416-XXX-XXXX xXXXX  email: XXXXX@XXXXXX.ca

Please note that communication via e-mail is not absolutely secure. Thus, please do not communicate personal sensitive information via e-mail.
Appendix V – Phone Script for Recruitment

Hi [Participant Name], I am [Insert Name] and I’m a [graduate student/clinician] with the return to work study at the XXXXXXXX. Thank you for your interest in our ‘Back to work needs of cancer survivors’ study. Is this a good time to talk?

[If yes…]

Great! I’d like to start off with some basic study details that you may have seen in our pamphlet or on our posters. This study hopes to explore the needs of cancer survivors when returning to or staying in the workforce after treatment. You are eligible for this study if you have been treated for cancer, are an adult and speak English, were working for pay when you were diagnosed with cancer, and wish to return to work or have returned to work. Do you think you meet these criteria?

[If yes…]

Excellent! The first part of this study will consist of a 2-hour facilitated focus group session to discuss your return to work experience and will include an educational component. You will also have the option of participating in a 1-on-1 interview. I just want to let you know that all transportation getting to and from the study will be covered, so please keep a receipt of your parking or taxi expenses if that’s how you’re getting to the study. Transit tokens will be provided if you took transit. In addition, if you are upset, stressed, or uncomfortable at any time during the interview you can choose to opt out of answering questions, leave the room to take a break, or completely stop at any time. If you need any additional help, we can direct you to a clinician or support service on hand. You can leave the study at any time, and your interview data will only be used if it has already been de-identified. Personal information connecting you to this study will be kept private and confidential. Your name, telephone number and any personal health information will be kept in the XXXXXXXX office in locked filing cabinets. Does this still sound like something you’re interested in or would you like some time to think about it?

[If yes…]

Thank you, through participating in our study, you will be helping with the development and understanding of what supports help cancer survivors, how to address return to work needs, and best practices for workplace supports that should be implemented to ensure successful reintegration. I’d like to ask, do you have any questions for me? […] At this point, can I get an email address from you so that I can send you a detailed consent form for you to review prior to your focus group or interview? [If you already have email – After our phone call, I will send you a detailed consent form to the email address you provided for you to review prior to the focus group.] We will go over the consent form and sign it in person prior to beginning the focus group or interview. In the meantime, can I get your verbal consent to participate in the study? [If yes…] Thanks again for your willingness to participate in this study! Please let me know if you have any additional questions or concerns. You can reach me at [email and phone number]. Thank you for your time today and for your interest in our study.
Appendix VI – Study Consent Form

CANCER SURVIVORS

Study Title: Exploring the needs of cancer survivors when returning to or staying in the workforce

Principal Investigator: Ms. Lydia Beck

Co-Investigators: Dr. Bonnie Kirsh and Ms. Ivona Berger

Contact Information: XXXXXXXXXXX

Please note that communication via e-mail is not absolutely secure. Thus, please do not communicate personal sensitive information via e-mail.

Name of Sponsors: • XXXXXXXXXXX

INTRODUCTION
You are being asked to take part in research study entitled, “Exploring the needs of cancer survivors when returning to or staying in the workforce.” This study is being funded by a grant provided by XXXXXXX. Please read this form and the information about the study and its risks and benefits before you decide if you would like to participate. Please take as much time as you need to make your decision and feel free to talk about the study with anyone you wish including friends, family and your health care team. You should ask the investigator or co-investigators to explain anything that you do not understand and to make sure that all your questions have been answered before signing this consent form.

BACKGROUND/PURPOSE
You are being asked to consider participating in this study because you have been identified as an individual who has been diagnosed with cancer and who wishes to return to work or has stayed at work since your diagnosis. You have also expressed a desire to be part of this study to your clinician, the XXXXXXX clinic receptionist, or you have contacted the study directly. We recognize that your experience trying to return to work or staying in the workforce since your diagnosis and during treatment may have been challenging. We want to better understand your unique experience and how we can shape the delivery of better supports for cancer survivors trying to return to work or staying in the workforce after their diagnosis. About 15 participants will be recruited in total, with 6-8 in each focus group.

Your participation in this study will help us to understand:

1) The needs of cancer survivors when returning to work or staying in the workforce
2) Sex and gender differences when returning to work or staying in the workforce
3) Factors that influence the need for return to work supports

If you meet the following criteria, you will be eligible to participate in this study:

1) You are older than 18 years of age and are fluent in English
2) You have been diagnosed with cancer
3) You were working part or full time for pay when you were diagnosed cancer
4) You either remained at work during your treatment or are planning to return to work after your treatment and are interested in discussing your needs when returning to work with us.

PROCEDURES
Once you have provided your consent to participate in this study, you will be asked to do the following:

1) Participate in a 1.5-hour long focus group session at the XXXX clinic. There will be an educational component at the end of the discussion to provide information on supported return to work. During the focus group component at the beginning, yourself and others will be asked questions about your experiences returning to or staying in the workforce after your diagnosis. The focus group will share their stories with each other in an open discussion that will be led by both the investigator and one co-investigator. If you are feeling uncomfortable, you can skip any questions during the focus group. Each focus group will be digitally recorded and transcribed. Transcription is taking the audio recording of the focus group and typing it word for word. The educational component of the focus group will not be recorded or transcribed.

2) Following the focus group, you will be asked to participate in a 1-hour long one-on-one interview. You may also be asked to participate in this interview even if you were unable to attend a focus group session. Again, you will be asked questions about your experience returning to or staying in the workforce after your diagnosis. This will help us get a more in-depth understanding of your experiences. You do not have to answer questions that you do not feel comfortable answering during the interview. Each interview will be digitally recorded and transcribed. Again, transcription is taking the audio recording of the focus group and typing it word for word.

Identifiable information will be collected using a demographic information form in order to characterize our study participants. The information will be obtained from you and will include your age (not date of birth), and cancer diagnosis.

POSSIBLE RISKS
We do not anticipate that you will experience any risks as a result of participating in this study. However, it is possible that you may feel uncomfortable, sad, embarrassed, or anxious during the focus group or interviews while discussing your experience. You might also see someone that you know during the focus group that might make you feel uncomfortable. If you experience any of this discomfort during the focus group or interview, you can choose not to answer any questions, leave the room to take a break, or completely stop at any time. If you need any additional help, we can direct you to a clinician or support service on hand. We will have some time at the end of the focus group or interview to discuss your experiences in participating in the study and answer any questions you may have for us.

POSSIBLE BENEFITS
Through participating in our study, you will be helping with the development of best practices for workplace supports following cancer to ensure successful return to work for cancer survivors.
You may also benefit from this study through the return to work information that we will provide in the focus group session.

CONFIDENTIALITY

If you consent to participating in this study, personal information such as your name, age (not date of birth), cancer type and date of diagnosis will be collected. Personal information is any information that could identify you. This study will keep any of your identifiable personal information private and confidential and will only be available to the investigator and co-investigators. Your name, telephone number, email, and any other personal information on consent forms and demographic forms will be kept in the XXXX office in a locked filing cabinet. A co-investigator will remove all identifying information from your transcripts and will only use pseudonyms (an alternative name) or numbers to identify you and any other services providers, employers, supervisors, co-workers or family members/significant others that you may have mentioned in the focus group or interview. This will also ensure that any quotes used from your focus group or interview will not contain any identifying information. If it is not possible for us to get rid of all identifying information in part of your transcript, or if there is any doubt, then we will not use that quote when reporting our study results. These transcripts and other de-identified (with an alternative name or number) data will be kept encrypted, password protected, and stored electronically on a secure server. Again, this will only accessible by the investigator and co-investigators. After being transcribed and analyzed, the recorded version of your focus group and interview will be destroyed in order to further protect your identity. The principal investigator will keep de-identified study data in a secure and confidential location for 5 years.

The following people may come to the hospital to look at the study records and at your personal health information to check that the information collected for the study is correct and to make sure the study is following proper laws and guidelines:

- Representatives of the XXXX including the [Hospital Name] Research Ethics Board

Your name and any contact information (telephone numbers and e-mail addresses) will be kept for one year after the study is over to make sure we can still contact you if we have any additional questions that may come up during the data collection. Again, all personal information that you provide us during the course of this study will be kept private and confidential, and will not be shared with anyone outside the study unless required by law. You will not be named in any reports, publications, or presentations that may come from this study.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary (your choice). You have the right not to participate in this study, or to stop participating at any time. We will give you new information that is learning during the study that might affect your decision to stay in the study.

WITHDRAWAL FROM THE STUDY

You will be reminded at the start of the focus group and interviews that you may choose not to answer any questions, and leave at any point if you feel uncomfortable. If you do withdraw from the study, the data will be immediately destroyed. You can withdraw from participating in the study up until the point that the student research has de-identified your transcript and begun data.
analysis. This is because at this point your transcript will already be being used to analyze the data.

COSTS AND REIMBURSEMENT
Participating in this study will not cost you anything, except for your time getting to and from the study and during the focus group and interview. Any transportation costs paid by you to get to and from the study will be covered by the study. We will do our best to schedule the focus group at a time that works for you and all the other focus group participants. The interview will also be scheduled at a time that works for you and that does not conflict with your other responsibilities.

CONFLICT OF INTEREST
As researchers, we have an interest in making sure we can complete this study. Our interests should not influence your decision to participate in this study. The investigator and co-investigators will only receive financial payment to cover the study costs.

RIGHTS AS A PARTICIPANT
You have the right to receive all information that could help you make a decision about participating in this study. You have the right to ask questions about this study and about your rights as a participant, and to have them answered to your satisfaction, before you making a decision to participate in this study. By signing this form you do not give up any of your legal rights against the investigators or involved institutions, nor does this form relieve the investigators or involved institutions of their legal and professional responsibilities.

QUESTIONS ABOUT THE STUDY
If you have any questions about this study you may contact:

Ms. Ivona Berger
University of Toronto Rehabilitation Science Institute MSc Candidate, Graduate Research Student
Tel: 416-XXX-XXXX xXXXX Email: XXXX@XXXXX.ca

If you have any questions about your rights as a research participant or if you have concerns about this study, call the Chair of the [Hospital Name] Research Ethics Board (REB) or the Research Ethics office number at 416-XXX-XXXX. The REB is a group of people who oversee the ethical conduct of research studies. The [Hospital Name] REB is not part of the study team. Everything that you discuss will be kept confidential.
CONSENT
This study has been explained to me and my questions have been answered. I know that I may leave the study at any time. I agree to take part in this study.

_______________________  ____________________  ____________________
Study Participant’s Name  Signature  Date

You will be given a signed copy of this consent form.

My signature means that I have explained the study to the participant named above. I have answered all questions.

_______________________  ____________________  ____________________
Person Obtaining Consent  Signature  Date

CONSENT – STUDY COPY
I agree to be contacted at the following email and/or telephone number for further scheduling and follow-up.

Email: ____________________  Telephone number: ____________________

This study has been explained to me and my questions have been answered. I know that I may leave the study at any time. I agree to take part in this study.

_______________________  ____________________  ____________________
Study Participant’s Name  Signature  Date
You will be given a signed copy of this consent form.

My signature means that I have explained the study to the participant named above. I have answered all questions.

_______________________  ____________________  ____________________
Person Obtaining Consent  Signature  Date
Appendix VII – Focus Group Semi-Structured Interview Guide

Return to Work Study Focus Group Interview Guide

Facilitators: ____________________________________________

Date: ____________________________________________

Total # of participants: _______________________________

General characteristics of participants
(gender, employed etc.): _______________________________________________________

Introduction:

Welcome and thank you all for coming to our focus group. This ‘Back to work needs of cancer survivors’ study hopes to explore the needs of cancer survivors when returning to or staying in the workforce after treatment. This session will run for about 2 hours in total. The first part will be a facilitated discussion where you are all encouraged to speak freely about return to work issues. You do not have to answer questions that you do not feel comfortable answering. If you are upset, stressed, or uncomfortable at any time during the group discussion you can choose to opt out of answering questions, leave the room to take a break, or completely stop at any time. If you need any additional help, we can direct you to a clinician or support service on hand. This part of the session will be digitally recorded and transcribed, and everything you say will be kept strictly confidential. The second part of the session will be an educational component to provide you with information about legislation relevant to returning to work, how to prepare for your return to work, and where you can get more information and support. We will also have some time at the end of the interview to discuss your experiences in participating in the interviews and any questions you may have for us.

Questions and Probes:

1. What has your experience been like when returning to work or staying at work following your cancer diagnosis?
   a. What did you do about work when you were diagnosed (i.e., stay, leave, new job)?

2. What challenges have you been faced with when returning to work or staying at work?
   a. What supports have been offered, if any, that you feel were particularly helpful?
   b. What supports were not offered that could have helped you face these challenges?

3. Can we talk about your relationships with your employers and any accommodations they’ve provided to you?
   a. Have they helped you? Who is deciding on them?
4. What kinds of symptoms have made it difficult to return to work or try returning to work?  
   a. How have these changed over time and how has this impacted your work ability?

5. Has there been anyone along the way that’s helped you (i.e. healthcare practitioners)?  
   a. What sort of advice did they or did they not provide that helped with returning to work or staying at work?

6. What do you think impacts your needs when returning to work or staying at work the most?  
   a. What are the gaps between what is offered and what you need to return to work or stay at work successfully following diagnosis?

7. Let’s talk about whether your attitudes toward work have changed since your diagnosis?  
   a. Do you feel like you’ve been supported in these new attitudes and how?  
   b. Do others in your life support this?

8. Do you have any further comments or questions for us?

Thank you once again.
Appendix VIII – One-on-one Semi-Structured Interview Guide

Return to Work Study One-on-one Interview Guide

Facilitator: ____________________________________________

Date: ____________________________________________

Participant ID: ____________________________________________

General characteristics of participant (gender, employed etc.):

Introduction:

Welcome and thank you for choosing to be a part of our one-on-one interview. This ‘Back to work needs of cancer survivors’ study hopes to explore the needs of cancer survivors when returning to or staying in the workforce. This session will run for about 1 hour. This interview will allow for in-depth discussion on return to work needs. If you are upset, stressed, or uncomfortable at any time during the interview you can choose to opt out of answering questions, leave the room to take a break, or completely stop at any time. If you need any additional help, we can direct you to a clinician or support service on hand. This session will be digitally recorded and transcribed, and kept confidential. [If participant did not attend a focus group and/or did not fill out a demographic survey: “To begin, I would like to ask you all to complete a short demographic survey that will ask questions including your age, family status, date of diagnosis, education and some questions about your work. All responses are strictly confidential.”] We will have some time at the end of the interview to discuss your experiences in participating in the interviews and any questions you may have for us.

Questions and Probes:

1. What has your experience been returning to work or staying at work following your diagnosis?
   a. What describes the position you held at diagnosis (i.e., manager, self-employed)?
   b. How would you describe your employment since then (i.e., stay, leave, new job etc.)?
   c. If you left work, for how long? If you stayed at work or worked at a different job, what arrangements were made, if any, (i.e., different roles, gradual return and flexibility)?

2. How has your perspective about work and your outlook changed since your diagnosis?
   a. What has influenced or supported you to make or not make (work) changes (sense of normalcy, supportive employer, etc.)?

3. What is/was your overall work environment like?
a. What is/was your comfort level with your employers and coworkers, particularly with regards to communication?
b. What sort of emotional supports, if any, have you been offered and by whom?
c. Have these emotional supports impacted your ability to return to work or to stay at work either positively or negatively?

4. What do you think impacts your needs when returning to work or staying at work the most?
   a. What are the gaps between what is offered and what you need to return to work or stay at work successfully following diagnosis?

5. What has your experience been with the resources that you have been provided?
   a. What did these resources try to address (financial issues, symptoms etc.)?
   b. Have these resources been able to address your unique needs?
   c. If not, what was missing from these resources?

6. What symptoms have you experienced and in what ways have they impacted your performance and/or ability to return to work or stay at work?
   a. How have these changed over time?
   b. How often do you experience these symptoms?

7. What has your experience been like trying to navigate back into the workforce?
   a. In what ways have your experiences been influenced by personal factors?
   b. What has the role of your family life been throughout this process?
   c. If you are living with a partner and/or family members, in what ways have they or have they not accommodated or supported your needs?

8. What has your experience been like navigating the system as a whole?
   a. What supports have been offered by other agencies such as insurance companies?

9. What has your experience with healthcare practitioners been like?
   a. What sort of advice did they or did they not provide that helped with returning to work or staying in the workforce?

10. Do you have any further comments or questions for us?

Thank you once again.
## Appendix IV – Codebook

### Employment Factors

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Short Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accommodations</td>
<td>General and individualized accommodations provided in the workplace and ability to receive these. Including a gradual return, modified hours, working from home, etc.</td>
<td>E-Acc</td>
</tr>
<tr>
<td>Work Environment</td>
<td>Including the physical environment, demands of work, job description, culture, and structure. In addition, how this influences the survivor’s experience.</td>
<td>E-Env</td>
</tr>
<tr>
<td>Work Status</td>
<td>Current work status for the survivor, including off work, back full-time, etc.</td>
<td>E-Stat</td>
</tr>
</tbody>
</table>

### Meaning of Work

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Short Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaning of Work</td>
<td>The meaning of work to the survivor. Including work as an identity, financial security, social relationships, health, etc.</td>
<td>M-Wrk</td>
</tr>
<tr>
<td>Perspective &amp; Changes on Work</td>
<td>How the perspectives and outlooks of the survivor towards work have changed throughout their journey. For instance, making work-life balance a priority. Workplace attitude towards the cancer survivor and the survivor’s attitude about returning to the workplace.</td>
<td>M-Chge</td>
</tr>
</tbody>
</table>

### Needs and Gaps Navigating into the Workforce

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Short Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>Ability and experiences communicating needs at work and throughout the system; comfort level with communicating; communication with and between stakeholders.</td>
<td>N-Com</td>
</tr>
<tr>
<td>Disclosure</td>
<td>Factors influencing the need to disclose such as the emotional impact of choosing to disclose or not and being in control of disclosure.</td>
<td>N-Dis</td>
</tr>
<tr>
<td>Resources</td>
<td>Description of resources accessed or desired (ex. Community, financial, healthcare); accessibility, availability, and quality of resources (ex. Individualized, gaps, etc.)</td>
<td>N-Res</td>
</tr>
<tr>
<td>RTW Process</td>
<td>Includes barriers, and challenges about the RTW process; logistics behind RTW and readiness to RTW; factors affecting successful RTW.</td>
<td>N-RTW</td>
</tr>
</tbody>
</table>
### Societal Challenges
Dealing with the burden, stigma, and shame in society associated with cancer when trying to return to work. Ageism in the workplace belongs here.

### Personal Factors

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Short Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advocacy</td>
<td>Desire to advocate for self and other survivors to ensure successful RTW. Includes participating in research, educating stakeholders, etc.</td>
<td>P-Adv</td>
</tr>
<tr>
<td>Age</td>
<td>The impact of age on the RTW process and supports (ex. Resources provided), age influencing quality of life, etc.</td>
<td>P-Age</td>
</tr>
<tr>
<td>Family and Social Life</td>
<td>Impact of cancer on participation in family and social life, demands of F &amp; S outside of cancer (ex. Household chores, children), how F &amp; S influences RTW, etc.</td>
<td>P-FAS</td>
</tr>
<tr>
<td>Other Health Factors</td>
<td>Other health related factors including diet changes, radiation, other surgical interventions etc.</td>
<td>P-Oth</td>
</tr>
<tr>
<td>Personality and Emotions</td>
<td>How the survivor’s personality affects their ability to cope and RTW, and psychosocial perceptions about RTW (fear, anxiety, concern, control, self-esteem, etc.)</td>
<td>P-PAE</td>
</tr>
<tr>
<td>Socioeconomic Status</td>
<td>SES factors that played a role when returning to work. For instance, whether or not financial issues or level of education were a concern.</td>
<td>P-SES</td>
</tr>
<tr>
<td>Sex and Gender</td>
<td>Any sex and gender differences in the RTW process. For instance, gender-specific resources, having children, visibility of hair loss, household roles, etc.</td>
<td>P-Sex</td>
</tr>
<tr>
<td>Symptoms</td>
<td>Includes physical, cognitive, and psychosocial symptoms. Also, the impact of this on RTW and how these are being alleviated.</td>
<td>P-Sym</td>
</tr>
</tbody>
</table>

### Support from Stakeholders

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Short Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Support</td>
<td>The quality and availability of support provided by community groups, strangers, church groups etc. for RTW.</td>
<td>S-Com</td>
</tr>
<tr>
<td>Family, Friend Support</td>
<td>Support (emotional, informal, etc.) provided by family and friends. Satisfaction with the support provided (ex. Wants more emotional support, proximity to family, etc.)</td>
<td>S-FAF</td>
</tr>
<tr>
<td>Healthcare Support</td>
<td>Experience with support from healthcare providers. Includes barriers &amp; gaps, RTW advice provided, levels of satisfaction, types of supports, holistic care, etc.</td>
<td>S-Heal</td>
</tr>
<tr>
<td>Impact of Support</td>
<td>The impact of support on RTW. Includes feeling grateful, undeserving, overwhelmed, and appreciating the potential benefits, etc.</td>
<td>S-Imp</td>
</tr>
<tr>
<td>Insurance Support</td>
<td>The support that insurance companies provided and how this influenced RTW (ex. Feeling stressed, pressure, supported, etc.). Includes barriers and individual needs.</td>
<td>S-Ins</td>
</tr>
<tr>
<td>Other Descriptions of Supports</td>
<td>Other descriptions of support, including the lack of certain types of support, the responsibility of the individual to seek support, and the desire to receive supports, etc.</td>
<td>S-Oth</td>
</tr>
<tr>
<td>Work Support</td>
<td>Work-specific support, including presence of a supportive employer, support from coworkers, and the impact of these supports and potential gaps on RTW, etc.</td>
<td>S-Wrk</td>
</tr>
</tbody>
</table>

**Quotes (Short Form: Q)**